

EDINBURGH NAPIER UNIVERSITY

**A phenomenological exploration of the  
biographical impact of newly diagnosed  
MS on the individual and their support  
person.**

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Thesis submitted in partial fulfilment of the award of Doctor of  
Philosophy (Ph.D.)

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## **Declaration**

I hereby declare that the work presented in this thesis has been conducted  
by myself.  
This thesis has not been presented for any other academic award.

Karen Strickland

## Acknowledgments

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## **Abstract**

**Aim:** The aim of this study was to provide an understanding of the biographical impact of newly diagnosed Multiple Sclerosis (MS) on the individual and their support person(s) and how this impacts on how the person manages the transition to living with MS.

**Background:** Being diagnosed with a chronic illness is a significant life event which may result in stress for the individual and their family. Previous studies in chronic illness have identified how previously held ideas of the self and identity, which are strongly linked to social roles, are challenged as a consequence of being diagnosed.

**Methods:** The research was underpinned by a hermeneutic phenomenological approach. A focus group with seven MS specialist nurses was conducted to identify the support needs of people newly diagnosed with MS, and their role in providing support and intervention during the period following diagnosis. The data from this focus group then informed the development of the interview guide for the interviews with the people with MS and their support person. Semi-structured interviews with ten people with MS and nine support persons were conducted. The data were analysed using interpretative phenomenological analysis.

**Findings:** The diagnosis of MS created an acute disruption to the taken-for-granted sense of self, both among people with MS and their support persons. The lived experience involved a number of disruptions to daily life which impacted on the identities associated with the many roles individuals had. Key themes were identified which add to existing knowledge by developing the meaning of being diagnosed with MS for the self, and identifying the processes that individuals go through on their journey to living with MS as part of a new biography. The three superordinate themes: '*Road to diagnosis*', '*The liminal self*' and '*Learning to live with MS: an uncertain future*' emerged from the interview data with a cross cutting theme of '*The impact on the self*' for both the person with MS and their support person.

The findings captured the lived experience of being diagnosed with MS as close to the time of diagnosis as was possible within the constraints of the study. This has led to a nuanced description of the lived experience which has highlighted the concept of a liminal self in MS. The liminal self describes the experience where the individual's conceptualisation of their taken-for-granted self has become invalid, as they are faced with new knowledge of their diagnosis of MS which needs to be incorporated into the new self. The uncertainty relating to this condition makes this a difficult and liminal transition.

To articulate this new knowledge, I have developed a conceptual framework which builds on previous theoretical positions of chronic illness and biographical theory to further illuminate the understanding of living with MS in the initial stages following diagnosis. This thesis argues for understanding the lived experience of biographical disruption following a diagnosis of MS to be understood in the proposed conceptual framework of '*Threshold concepts and the liminal self in MS*'. The framework has four main components: the '*preliminal self*' which conceptualises the lived experience prior to diagnosis where symptoms of MS are experienced but the cause is not yet known; the '*threshold concept: being diagnosed*' conceptualises the experience of being diagnosed as a pivotal moment in the transition from person with symptoms to person with MS, or partner to potential carer; the '*Liminal self in MS*': conceptualises the lived experience of biographical disruption where the person's sense of self is in transition; the '*Post-liminal self in MS*' conceptualises the reincorporation of the sense of self transforming the self as a person with MS or support person of someone with MS. This experience is subject to on-going uncertainty and as such is never quite stable.

**Conclusion:** The findings from this study highlight the need for health care professionals to recognise the liminal self and consider this in the support of the person with MS and their support person. The conceptual framework, grounded in the data from this study, provides a new way of understanding the lived experience of those affected by a new diagnosis of MS. As such, this framework offers an original contribution to knowledge.

## Table of Contents

<b>Declaration</b> .....	<b>i</b>
<b>Acknowledgments</b> .....	<b>ii</b>
<b>Abstract</b> .....	<b>iv</b>
<b>List of tables</b> .....	<b>xi</b>
<b>List of figures</b> .....	<b>xi</b>
<b>Chapter One: Introduction</b> .....	<b>1</b>
<b>1.1 Introduction</b> .....	<b>1</b>
<b>1.2 Overview of MS</b> .....	<b>1</b>
1.2.1 Diagnosis of MS.....	2
1.2.2 Types of MS and treatment.....	3
1.2.3 MS within the context of chronic illness .....	4
1.2.4 MS specialist support.....	5
1.2.5 Context of the study .....	7
<b>1.3 Position of the Researcher</b> .....	<b>8</b>
<b>1.4 Structure of the thesis</b> .....	<b>10</b>
<b>Chapter Two: Literature Review</b> .....	<b>13</b>
<b>2.1 Introduction</b> .....	<b>13</b>
<b>2.2 Review of the MS literature</b> .....	<b>14</b>
2.2.1 Search strategy .....	15
2.2.2 Analysis of the literature .....	17
<b>2.3 The need for information and support</b> .....	<b>18</b>
<b>2.4 The meaning of being diagnosed with MS</b> .....	<b>22</b>
2.4.1 Initial reactions .....	23
2.4.2 Psychological impact .....	24
2.4.3 Social and occupational impact .....	25
2.4.4 Impact on identity.....	27
2.4.5 Impact on couple relationships .....	30
<b>2.5 The experience of the support person</b> .....	<b>32</b>
2.5.1 Psychological impact of MS on the support person .....	33
2.5.2 Support person identity.....	34
<b>2.6 Discussion and summary of the findings of the literature review</b> ...	<b>36</b>
2.6.1 Methods of inquiry .....	37
2.6.2 Origins of the studies.....	38
2.6.2 Theoretical perspectives.....	39
<b>2.7 Theoretical perspectives on chronic illness</b> .....	<b>39</b>

2.7.1 Transition theory.....	40
2.7.2 Identity theory.....	42
2.7.3 Uncertainty theory .....	49
2.7.4 Coping theory.....	53
2.7.5 Summary of theoretical perspectives on chronic illness.....	55
<b>2.8 Summary and conclusions .....</b>	<b>56</b>
2.8.1 Rationale for the study.....	57
<b>Chapter Three: Methodology .....</b>	<b>59</b>
<b>3.1 Introduction .....</b>	<b>59</b>
<b>3.2 Rationale for the choice of research approach .....</b>	<b>60</b>
<b>3.3 Qualitative research approaches.....</b>	<b>61</b>
3.3.1 Symbolic Interactionism.....	63
3.3.2 Ethnography .....	63
3.3.3 Grounded Theory.....	65
3.3.4 Phenomenology.....	66
3.3.5 The Hermeneutic Circle .....	72
3.3.6 Background to Interpretative Phenomenological Analysis .....	75
<b>3.4 Chapter summary .....</b>	<b>78</b>
<b>Chapter Four: Research Design and Methods .....</b>	<b>80</b>
<b>4.1 Introduction .....</b>	<b>80</b>
<b>4.2 Ethical Approval.....</b>	<b>80</b>
<b>4.3 Selection of the research participants .....</b>	<b>82</b>
4.3.1 Sampling.....	83
<b>4.4 Access to participants.....</b>	<b>85</b>
4.4.1 Inclusion criteria for MS Nurses .....	85
4.4.2 Access to MS Nurse participants .....	85
4.4.3 Recruitment of MS Nurses.....	86
4.4.4 Inclusion criteria for people with Multiple Sclerosis.....	86
4.4.5 Exclusion criteria for people with Multiple Sclerosis.....	86
4.4.6 Access to persons with MS and their support person .....	86
4.4.7 Recruitment of people with MS and their support person(s) .....	87
4.4.8 Reflections on participant recruitment.....	88
<b>4.5 Informed consent.....</b>	<b>90</b>
4.5.1 Consent of Specialist MS Nurses .....	91
4.5.2 Consent of people with MS and their support person .....	92
<b>4.6 Risk to participants.....</b>	<b>92</b>

<b>4.7 Confidentiality and data handling .....</b>	<b>94</b>
<b>4.8 Methods of data collection.....</b>	<b>95</b>
4.8.1 Focus Groups with MS Nurses .....	97
4.8.2 Interviews with PWMS and the support persons.....	101
4.8.3 Practical issues related to field interviews.....	106
<b>4.9 Recording of interviews .....</b>	<b>107</b>
<b>4.10 Role of the researcher in the interviews .....</b>	<b>108</b>
<b>4.11 Data analysis .....</b>	<b>109</b>
4.11.1 Theoretical approaches to analysis.....	109
4.11.2 The analytic process of IPA .....	114
<b>4.12 Credibility .....</b>	<b>119</b>
4.12.1 Owning one's own perspective .....	120
4.12.2 Situating the sample .....	120
4.12.3 Grounding in examples.....	120
4.12.4 Providing credibility checks .....	120
4.12.5 Coherence .....	121
4.12.6 Accomplishing general vs specific research tasks.....	121
4.12.7 Resonating with readers.....	122
<b>4.13 Chapter summary .....</b>	<b>122</b>
<b>Chapter Five: Findings .....</b>	<b>124</b>
<b>5.1 Introduction .....</b>	<b>124</b>
<b>5.2 Key findings from MS nurse focus group.....</b>	<b>125</b>
5.2.1 The diagnostic event .....	125
5.2.2 The role of the nurse .....	127
5.2.3 Readiness of the individual.....	128
5.2.4 Lack of resources .....	129
5.2.5 Summary of findings from the MS nurse focus group.....	130
<b>5.3 Key findings from the PWMS and the support persons .....</b>	<b>131</b>
<b>5.4 Road to diagnosis.....</b>	<b>133</b>
5.4.1 Knowing one's body: knowing one's self .....	134
5.4.1. i A shared journey .....	141
5.4.2 Being diagnosed: crossing a threshold.....	143
<b>5.5 The Liminal Self .....</b>	<b>149</b>
5.5.1 A self disrupted.....	150
5.5.2 Disruption to roles and relationships .....	153
5.5.2. i The self as mother .....	153

5.5.2. ii The self as partner .....	157
5.5.2. iii The self at work .....	161
5.5.2. iv The anticipatory carer.....	163
5.5.3 Self and others with MS.....	166
<b>5.6 Learning to live with MS: an uncertain future .....</b>	<b>168</b>
5.6.1 Impact of MS on daily life .....	170
5.6.2 Living with uncertainty .....	176
5.6.3 Negotiating health care.....	181
<b>5.7 Chapter summary .....</b>	<b>185</b>
<b>Chapter Six: Discussion.....</b>	<b>187</b>
<b>6.1 Introduction .....</b>	<b>187</b>
<b>6.2 Threshold concepts and the liminal self in MS .....</b>	<b>189</b>
<b>6.3 Road to diagnosis: the preliminal journey.....</b>	<b>191</b>
6.3.1 The preliminal self in MS .....	191
6.3.2 Embodied experience.....	192
6.3.2 Being discredited: undermining the self.....	194
6.3.3 A Shared Journey.....	196
<b>6.4 Being diagnosed as a threshold concept .....</b>	<b>198</b>
<b>6.5 The Liminal Self in MS.....</b>	<b>203</b>
6.5.1 A Self Disrupted .....	205
6.5.2 Stigma and the new self .....	208
6.5.3 Impact on the family .....	212
6.5.3.i Impact on the self as mother.....	212
6.5.3.ii Impact on couple relationships.....	215
6.5.4 The Anticipatory Carer.....	220
<b>6.7 The Post-Liminal Self in MS.....</b>	<b>223</b>
6.7.1 Living with MS .....	224
6.7.2 Living with uncertainty .....	224
6.7.3 Negotiating health care.....	226
<b>6.8 A Conceptual Framework for MS.....</b>	<b>228</b>
<b>6.9 Reflection on the research design .....</b>	<b>230</b>
6.9.1 Reflective account .....	231
6.9.2 Limitations and considerations .....	232
6.9.3 Strengths.....	236
<b>6.10 Chapter summary .....</b>	<b>238</b>
<b>Chapter Seven: Conclusions and recommendations .....</b>	<b>240</b>

<b>7.1 Introduction .....</b>	<b>240</b>
<b>7.2 Main arguments of the thesis .....</b>	<b>240</b>
<b>7.3 Recommendations .....</b>	<b>242</b>
7.3.1 Clinical practice .....	242
7.3.2 Further research .....	243
<b>7.4 Dissemination strategy.....</b>	<b>244</b>
<b>7.5 Final summary.....</b>	<b>245</b>
<b>References.....</b>	<b>246</b>
<b>Appendices.....</b>	<b>267</b>
<b>Appendix 1: Table of literature reviewed .....</b>	<b>267</b>
<b>Appendix 2: Participant information leaflets (nurses).....</b>	<b>281</b>
<b>Appendix 3: PowerPoint from neurology unit.....</b>	<b>285</b>
<b>Appendix 4: Poster for recruitment.....</b>	<b>287</b>
<b>Appendix 5: Participant information sheet (PWMS) .....</b>	<b>288</b>
<b>Appendix 6: Consent form (nurses).....</b>	<b>291</b>
<b>Appendix 7: Consent form PWMS .....</b>	<b>292</b>
<b>Appendix 8: Topic guide for focus group with MS nurses.....</b>	<b>293</b>
<b>Appendix 9: Interview guide for people with MS.....</b>	<b>294</b>
<b>Appendix 10: Annotated transcript .....</b>	<b>295</b>
<b>Appendix 11: Table of themes .....</b>	<b>298</b>
<b>Appendix 12: Relationship of focus group themes to interview guide</b>	<b>299</b>
<b>Appendix 13: List of presentations .....</b>	<b>301</b>

## List of tables

Table 1: Search terms.....	17
Table 2: Search results.....	18
Table 3: Focus group themes and interview guide for PWMS.....	96
Table 4: Key steps in IPA process .....	112
Table 5: Guidelines for Qualitative Research .....	117
Table 6: Participant details.....	129
Table 7: Timing of interviews from diagnosis.....	129
Table 8: Table of themes for “Road to diagnosis” .....	131
Table 9: Table of themes for “The Liminal Self ”.....	146
Table 10: Table of themes for “Learning to live with MS” .....	166

## List of figures

Figure 1: The hermeneutic process.....	73
Figure 2: The hermeneutic circle.....	73
Figure 3: Relationship of key theories to conceptual framework.....	228
Figure 4: Threshold concepts and the liminal self in MS.....	229

# **Chapter One: Introduction**

## **1.1 Introduction**

This study is concerned with the impact of the diagnosis of multiple sclerosis (MS) on the person newly diagnosed and their support person. The purpose was to develop an understanding of the lived experience and in particular the impact on the individual's sense of self in order to enable healthcare professionals to provide better support for people affected by MS. The qualitative approach taken, hermeneutic phenomenology and in particular, interpretative phenomenological analysis, allowed for the study participants to reflect upon their lived experience. These narratives helped to communicate the meaning of their experience for the individual's sense of self.

This chapter will provide an introduction to the focus of the study, providing the background to the problem of MS, outlining why it is important within the Scottish and United Kingdom (UK) health care context and a critique of the services offered to people who are newly diagnosed with this condition. The chapter therefore sets the scene for the development of the research focus and informs the literature review in Chapter Two.

In keeping with the qualitative research tradition, I also provide an overview of my own position within the study and highlight my prior assumptions so that these may be taken into consideration within the context of the study.

## **1.2 Overview of MS**

Multiple sclerosis is a chronic neurological condition with an unpredictable trajectory. Chronic illness is defined as 'any physical or mental condition that requires long term care (over six months), monitoring, and / or management to control symptoms and shape the course of the illness' (Corbin, 2001, p1). There are many conditions which fall under this definition, all with different trajectories. The term trajectory originally emanates from the physical

sciences however it has increasingly been used to describe the journey an individual goes through in relation to their physical, psychological, social and emotional struggle when confronted with a chronic illness (Corbin, 2001). MS has no clear cause but a number of factors, including environmental factors, are thought to contribute to an increased prevalence of the illness as it is more common in populations further away from the equator.

It is estimated that MS affects more than 100,000 people in the UK, with Scotland having the highest incidence of MS worldwide (MS Trust, 2005). This identifies MS as a significant health care problem in Scotland. MS is a degenerative neurological condition which usually affects young adults in their 20s and 30s and is more common in women than in men. Although MS can appear in people who are older than this, it is rare in teenagers and children (MS Trust, 2005).

### **1.2.1 Diagnosis of MS**

Being diagnosed with a chronic illness is widely acknowledged as a significant life event which may result in stress for the individual and their family (Bury, 1982; Newby, 1996). The time of diagnosis has been widely acknowledged as a time when individuals have a heightened desire to seek accurate information and support (Heesen, Kolbeck, Gold, Schulz, & Schulz, 2003; Hepworth, Harrison, & James, 2002; Johnson, 2003; Koopman & Schweitzer, 1999; Kralik, Brown, & Koch, 2001). MS may present as a series of small and often seemingly mild and insignificant symptoms. However, it may also present as a dramatic loss of function such as paralysis of the legs. Depending on the nature of onset of the disease, diagnosis may be a slow process involving a culmination of linking together signs and symptoms or it may be relatively quick in the case of dramatic loss of function. Confirming the diagnosis of MS involves a combination of clinical tests including magnetic resonance imaging (MRI) which would demonstrate damage to the myelin sheath in affected areas and clinical history of symptoms. Given the fluctuating nature of symptom presentation this makes MS a very difficult disease to diagnose. Clinical diagnosis is usually not confirmed after one isolated incident of demyelination, but after subsequent episodes diagnosis

may be confirmed. This may involve the patient in a prolonged and uncertain pre-diagnostic period.

Whilst having confirmation of a diagnosis may be helpful, it is often accompanied by frustration and disappointment as individuals are faced with ambivalence from health care professionals who are unable to offer solutions to some of the problems incurred (Thorne, 1993). Furthermore, a confirmed diagnosis of MS does not immediately bring with it solutions, as it is not a curable illness, nor does it have a predictable course, thus creating a degree of uncertainty (Crigger, 1996).

As MS usually affects young adults in their 20s and 30s, it has the potential to have a considerable impact on the individual and their family with the gradual realisation that this condition is for life, and that taken-for-granted activities may be affected by the diagnosis. Thus, the time of diagnosis of MS may be viewed as the beginning of a 'transition period', where the individual and those close to them are engaged in making sense of the situation and coming to terms with any limitations this poses to the way they conduct their everyday life. Being diagnosed with a chronic illness is widely acknowledged as a significant life event which may result in stress for the individual and their family (Bury, 1982; Newby, 1996). Previous studies in chronic illness have identified biographical disruption as following the period of diagnosis (Bury, 1982; Charmaz, 1983; Corbin, 2003). Biographical disruption may be defined as the impact of a disruptive event which affects the individual's sense of identity. Bury (1982) argues that being diagnosed with a chronic illness often leads to strains on interpersonal relationships, as previously held ideas of the self and identity, which are strongly linked to social roles, are challenged.

### **1.2.2 Types of MS and treatment**

There are four types of MS: benign, relapsing–remitting, primary progressive or secondary progressive MS, with relapsing-remitting and primary progressive being the two most common forms of the condition. At the time of diagnosis it may not be known which type of MS the person has, thus

creating a degree of uncertainty, as MS is a complex and unpredictable condition which has a variable illness trajectory (Crigger, 1996). The symptoms of MS include: muscular spasticity, fatigue, cognitive dysfunction, depression, visual disturbances, vertigo, bladder dysfunction, bowel dysfunction, sexual dysfunction, and neuropathic pain. Symptoms may appear and disappear from day to day, but there can also be relapses or exacerbations, followed by periods of remission. Most commonly people are left with a degree of residual disability (Barnes, 1997). This presents difficulties in explaining the effects of having MS to patients, as one cannot predict the nature and course of the disease. Adaptation to living with MS is influenced both by the diagnosis experience, the symptoms and outward signs and course of the condition.

Treatments for MS focus on symptom management as there is currently no cure for the condition. However, more recently the availability of disease modifying therapy (DMT) in the UK, has offered hope to those with relapsing-remitting MS as the medications slow the progress of the condition. Advising and supporting individuals with MS about treatments for their symptoms with DMT is a key role of the specialist services which provide information on the medication regime, with monitoring being part of the role of the MS nurse specialist. However, the role extends far beyond this in providing support for the person with MS and their families during the immediate post-diagnostic phase of the illness and during any subsequent relapses.

### **1.2.3 MS within the context of chronic illness**

The prevalence of chronic illness is increasing worldwide (Corbin, 2001; Department of Health, 2004). Socioeconomic factors have largely contributed to people living longer through better housing, sanitation and the availability of food and clean drinking water. In the UK, developments in health care provision, through the formation of the National Health Service in 1948 have led to better access to health care for all. Additionally, advances in medical technology, such as a wider range of available medicines, and improved diagnostic and treatment procedures, have led to people living longer. In Scotland, life expectancy has improved over the last 20 years,

increasing from 69.1 years for males and 75.4 years for females born around 1981, to 74.3 years and 79.4 years respectively for those born around 2004 (General Register Office for Scotland, 2005). One of the downsides to people living longer is that individuals often have one or more chronic illnesses. Within Scotland 20% of the population have one or more chronic conditions (General Register Office for Scotland, 2007).

Within the UK, people with chronic conditions place considerable demands upon the health service, with 80% of all GP consultations, and 60% of hospital bed days being due to chronic conditions (Department of Health, 2004). Over the past decade one of the key challenges facing health care professionals in the UK is configuring services to provide care that is responsive to the changing needs of people with complex long term conditions including MS, to enable them to be able to self-manage their condition and stay at home (Department of Health, 2005; Scottish Executive, 2005; Scottish Government, 2009).

One criticism of health care provision is that it has mainly been suited to the needs of people with acute conditions and as such does not adequately address the needs of people with chronic conditions such as MS (Thorne, 1993). Currently much of the guidance for services providing care for people with chronic conditions is focussed on an aging population as chronic illness is often associated with getting older (Scottish Government, 2009). MS affects a significantly younger population it is therefore imperative that we understand the lived experiences of those with MS in order to consider how to better meet their health care needs.

#### **1.2.4 MS specialist support**

The need for professional support from a team of MS specialists for people newly diagnosed is widely acknowledged as good practice (Koopman & Schweitzer, 1999). This support includes emotional, psychological and informational support to help the patient and their families adjust to living with MS. Current clinical guidance for the care of people with neurological conditions highlights the need for specialist health care services from

diagnosis and with each new symptom (National Collaborating Centre for Chronic Conditions, 2003; NHS Quality Improvement Scotland, 2009). The guidance specifies that all services and health care professionals involved in the care of patients with MS must be responsive to the unique and changing needs of each patient. Both guidance documents focus on the presence of physical symptoms as being the instigating factor for specialist support whilst acknowledging the significant psycho-social impact of the condition.

One of the professionals in the MS team designated to provide specialist intervention and support to patients who are newly diagnosed with MS is the specialist MS nurse. At 2013 there are approximately 20 of these nurses in Scotland, with patients in some geographical areas not having access to this type of specialist nursing support, raising issues of equity in health care provision.

Specialist MS nursing has developed in the UK largely due to support and investment from MS charities such as the MS Society which pump primes specialist MS posts for three years, and the MS Trust, which provides support and training for MS specialists. The support role of the MS nurse is a common theme amongst the published literature, with a number of descriptive papers addressing the role of the MS nurse alluding to the need for the MS nurse to provide psychological support for the patient and family as well as practical advice and information (Coleman, Rath, & Carey, 2001; Porter & Keenan, 2003; Taggart, Park, Banner, & Hart, 2000). The evidence base in support of these assertions is however lacking in these papers. Such recommendations are therefore unlikely to provide support for the MS nurse role in practice but may provide a source of guidance.

A study by McGuinness and Peters (1999) argued that the nurse has a crucial role in supporting the patient following a diagnosis of MS. The support role of the nurse was based on Peplau's model of Interpersonal Relations (1952). This theoretical model focusses on the development of a therapeutic relationship between the patient and nurse with the goal of that relationship being the creative, constructive and productive community and personal

living for the patient (McGuinness and Peters 1999). In a Finnish study, Leino-Kilpi & Luoto (2001) explored the role of the nurse in supporting patient education about MS. They used a questionnaire with structured closed questioning relating to methods of teaching and assessing learning and open ended questions asking MS nurses to describe best and worst teaching scenarios. From a relatively small sample of 35 responses, they reported that the focus of teaching was on disease and treatment and practical issues such as self catheterisation. Less attention was given to psychosocial issues such as social security, sexuality and family relationships, indicating that psychosocial care was not the primary focus.

These findings from the studies described in this section, along with the emphasis in the clinical guidelines, suggest that, while the specialist nurse is seen as the health care professional who is ideally placed to provide emotional and psychological support, this may still be lacking. For people who are faced with a new diagnosis this may pose a significant problem. I argue that this reflects a dominance of the biomedical model in the service provision which perhaps does not equally address the support needs for those individuals who may be experiencing emotional and/or psychological distress, a potential consequence of being diagnosed with MS in addition to physical symptoms. Health care professionals can offer limited support, so many of the needs are addressed by individuals and family members. Chapter Two will consider this in more detail and in the context of chronic illness.

### **1.2.5 Context of the study**

It is against this backdrop of an environment where the incidence of chronic illness continues to rise, where questions arise about service provision and whether the patient's needs are met, that this study is set. This study seeks to provide an insight into the experiences of the transition to living with MS for individuals, and their support person in the current health care system in Scotland.

### **1.3 Position of the Researcher**

My professional background is that of a nurse, lecturer and researcher, and my interest in MS arose from my clinical experience in palliative care where I experienced caring for a number of patients with advanced MS. My own experience as a nurse in the acute hospital setting and the hospice environment meant that my reference point for someone with MS was of individuals with significant physical symptoms and disability; in this study, however, I chose to focus on the experience of being diagnosed as I was interested to see how this early experience affected those with MS.

My early assumptions about being diagnosed with MS were that this would be a catastrophic event. On reading the literature there is significant support for this view, particularly in the terms used by theorists such as Charmaz (1983) and Bury (1982). Charmaz refers to the 'loss of self' as a result of chronic illness and Bury describes a theory of 'biographical disruption'. Both terms communicate the negative impact of the illness and led me to assume that this would lead to a negative psychological impact with an expressed need for support.

In addition to this, on speaking to people about my research I met with further confirmation for my assumptions. An instance I recall which particularly confirmed this was when I met with a former colleague whose brother had had neurological symptoms for the previous year and was waiting and expecting a diagnosis of MS. She described him as 'beside himself with worry' and like 'a cat on a hot tin roof' when outside the neurologist's office. This led me to become further entrenched in my own assumptions.

Throughout the thesis, I will chart how these assumptions were explored, challenged and revised through reflexive engagement with the literature and during supervision as new understandings emerged. The challenge to look at how some people do get on with lives as normal and learn to live with and adapt to having MS offered another possible alternative which my supervisors kept on encouraging me to consider. Whilst I acknowledged this

as a possibility and stated that I would be open to this possibility throughout the research I still held firm to my beliefs that a diagnosis of MS would be life changing.

A few years ago I attended the MS Society conference where I listened to a woman with MS give a talk about her experiences of living with the illness and how it had changed her life. This I believe was the turning point for me in seeing a more positive projection of the impact of MS. She then described how being diagnosed with the condition made her re-evaluate her life and 'take stock'. The woman described how lucky she felt to have been given this opportunity which she put down to having MS changing her as a person. On hearing this woman speak I was transfixed. I thought to myself how fantastic it would be if some of my participants could describe so profoundly how MS has affected them. The main value of this experience for me was having my own previously entrenched assumptions exposed and challenged. This experience and looking back on my reflexive notes helped me become more aware of my assumptions and how entrenched they were.

It is clear then that I saw health care through the lens of a nurse and this has the potential to bring an element of bias to the study, however through engaging with the literature which focusses on the patient's perspective, discussions with my supervisors and the use of a reflexive diary I hope I have brought my assumptions to the fore and have allowed the participants' voices to be heard. I am not a specialist nurse in MS and I believe this to be an advantage, as it allowed me to have an element of naïve curiosity as a researcher in this study. Nevertheless the study required me to engage in reflexive activity throughout the study.

I considered very early in the study that a qualitative approach would be most suitable to meet the aim of the study as my study sought to explore the experience of transition to living with MS. The biographical impact of the illness on the self became an important theme throughout the literature discussed in Chapter Two, with much of the previous research suggesting a qualitative approach was suitable for this type of biographical study

supporting my choice. Consequently the study developed a strong sociological focus to it and the notion of studying the experiences of individuals in their natural setting also supported a qualitative approach.

My previous research experience at masters level (Lockhart-Wood, 2000) where I conducted a phenomenological study informed by critical theory, and supervising masters dissertations (Minto & Strickland, 2011) gave me a good foundation for doing qualitative research within the phenomenological paradigm.

I set out to describe each step of the research process through the process of hermeneutic reflection which aims to co-construct meaning from the data as both participant and researcher interact. My position as researcher and how I interpreted the data that were generated must be viewed as subjective and integral to the interpretative process in interpretative phenomenological research (Finlay, 2009; Smith, Flowers, & Larkin, 2009). Pezalla, Pettigrew, & Miller-Day, (2012) describe the phenomenological researcher's position as an "instrument of the research" (p167), with the research interview being viewed as a social interaction. With this in mind, I have adopted a "meta-reflexive voice" throughout this thesis highlighting areas where my position has been particularly important (Finlay, 2002) thus providing an audit trail to enhance the trustworthiness and rigour of the study.

## **1.4 Structure of the thesis**

This thesis presents the results of a phenomenological investigation into the lived experiences of individuals newly diagnosed with Multiple Sclerosis (MS), from diagnosis through the transition period of learning to live with the condition in their social setting. The following chapter presents a review of the literature on biographical disruption in chronic illness and provides an overview of the current state of knowledge of the topic within the population of people affected by multiple sclerosis. The strategies used to inform the search of the literature are outlined. The literature review concludes with a rationale for this study, based on the gaps in current understanding. The

research aim and specific research questions were developed from the literature review and are detailed at the start of Chapter Three

The research methodology and methods of investigation are then discussed in Chapters Three and Four, along with the ethical considerations of the research. In these chapters I critically discuss the theoretical basis for the research approach and design and I justify the choices made in this study. Here I consider the relationship between the Gadamerian-informed hermeneutic approach and interpretative phenomenological analysis (IPA) and justify their application to researching the lived experience of biographical disruption in people affected by MS.

The findings from the study are presented in Chapter Five under the superordinate themes with extracts from relevant interviews to support the findings and to demonstrate trustworthiness of the analytic process. The three superordinate themes include; *“Road to diagnosis”*, *“The liminal self”* and *“Learning to live with MS: an uncertain future”*. This thesis argues for understanding the lived experience of biographical disruption following a diagnosis of MS to be understood in the proposed conceptual framework of *“Threshold concepts and the liminal self in MS”*.

The data from the findings in this study informed the development of a conceptualisation of the shared experience of being diagnosed with MS. This articulates a phased approach to understanding the experience of biographical disruption, from the onset of early symptoms, to the moment of diagnosis and beyond. I argue that this conceptual framework contributes to our existing understanding of the lived experience of being diagnosed with MS, and as such may inform health care professionals engaged in providing support for people affected by MS.

Chapter Six presents the discussion of the findings, structured around the components of the conceptual framework proposed in this thesis within the context of the wider literature on chronic illness and biographical theory. The chapter then focusses on a reflexive analysis of the research methodology,

identifying the strengths in the approach used and highlighting the study limitations for the reader to consider. Chapter Seven provides a summary of the main arguments of the thesis highlighting recommendations for practice and research before concluding with some personal reflections on my development throughout the research process.

## **Chapter Two: Literature Review**

### **2.1 Introduction**

Chapter One outlined the context of the study, and positioned MS as a chronic neurological condition with an uncertain trajectory. The chapter also indicated that being diagnosed with a chronic condition may result in biographical disruption in the period following diagnosis (Bury, 1982; Charmaz, 1983; Corbin, 2003). The purpose of this chapter is to report the findings of the literature review, to frame the current study within the body of existing theoretical knowledge and research, and to clearly identify the contribution this study will make to advance the current state of understanding. The place of the literature review in qualitative research has been widely debated with some authors suggesting that literature should be reviewed after data collection in phenomenological research (Munhall, 2001). The rationale behind this thinking is that an in depth knowledge of the literature may limit the researcher's openness and subsequently bias the study. On the other hand, a review of the literature offers the researcher the opportunity to explore what is already known about the topic, identifying gaps in knowledge or understanding by reviewing previous research, thus providing a rationale for the study (Parahoo, 2006). Additionally, the literature review helps to contextualise and define the theoretical basis of the study (Parahoo, 2006). For these reasons, a literature review was undertaken prior to data collection and has been updated throughout the study.

This review seeks primarily to clarify what is known about the impact of MS on those closely affected by a new diagnosis of MS. For the purpose of this research study, I have referred to this period of the illness trajectory as the 'transition to living with MS'. I began reviewing the literature in 2005 and this was updated in 2013. In order to address the multidimensional nature of the topic, the literature has been drawn from healthcare, sociological and psychological fields.

This chapter has been organised into three main sections. The first section of this chapter provides a review of the literature specific to MS. This section begins by outlining the search strategy and justifies the inclusion of each database. A critical review of the state of knowledge is presented with gaps in understanding clearly identified. The literature review will also identify the main theoretical perspectives that have informed the study of chronic illness. Section 2.5 provides a critical overview of these theories which include theories relating to illness trajectories, uncertainty and coping, as well as biographical theory. The influence of the illness trajectory on the transition to chronic illness in relation to the sense of self will be considered in relation to previous studies. The chapter concludes by summarising the key points from the literature and identifying the focus of this study.

## **2.2 Review of the MS literature**

This section of the thesis presents the focussed narrative review of literature relevant to MS (Coughlan, Cronin, & Ryan, 2013). The literature was identified through systematic searches of electronic databases. It should be emphasised that although this review is not a systematic review as defined by The Cochrane Collaboration (Higgins & Green, 2006), I adopted a systematic approach to the searches, which has been influenced by my background and experience of undertaking Cochrane Systematic Reviews (Cruickshank, Kennedy, Lockhart, Dosser, & Dallas, 2008; Lockhart, Dosser, Cruickshank, & Kennedy, 2008). The search in this thesis is therefore more inclusive than a Cochrane Systematic Review as it contains a wider range of sources of information considered relevant to the study but it is also more subjective, as only literature that was deemed relevant to the study was included.

Coughlan, Cronin and Ryan (2013) suggest a focussed narrative review is a useful approach to providing a comprehensive overview of the literature whilst retaining some of the features of the systematic review approach which allows the review to be focussed by outlining the parameters used to select

the papers for inclusion. The review presented in this chapter has followed a focussed narrative review style and includes original research studies, systematic reviews, reviews of literature, case studies, and commentaries. In doing so this review provides an overview of the current status of knowledge on the area of interest for this study and identifies areas for further study which subsequently informed the development of the aim of the study and research questions which have guided the study. Where relevant I have also drawn from the wider chronic illness literature to compare and contrast or support the discussion further. The rationale for including chronic illness sources was to help contextualise the subject within the content of the wider health care setting. The theoretical concepts from this wider literature are influential and informative for considering the lived experience for those affected by MS.

### **2.2.1 Search strategy**

Literature was drawn from detailed searches of health and sociological databases hosted on both the EBSCO and ProQuest platforms. EBSCO hosted databases include: MEDLINE, CINAHL, PsycINFO, PBSC and the Cochrane Library; ProQuest hosted databases include: ASSIA, BNI and CSA (Sociological Abstracts). The rationale for selecting each of the databases was as follows:

- MEDLINE (1966 – 2013): provides a comprehensive source of biomedical literature which encompasses literature from medicine, nursing and allied health care. The database covers more than 9.5 million records from more than 3,900 indexed journals.
- The Cumulative Index to Nursing & Allied Health (CINAHL) (1982 – 2013): database provides coverage of more than 1200 international journals related to nursing and allied health. The database also provides access to healthcare books, nursing dissertations and conference proceedings. Approximately 70% of CINAHL headings are also indexed in MEDLINE therefore there is some duplication,

nevertheless with an additional 30% of material not indexed in MEDLINE it is a valuable database to include in the search.

- The British Nursing Index (BNI) (1984 – 2013): the primary bibliographical database for nurses in the UK as it covers over 220 UK and other English language nursing, midwifery and health care journals. Whilst it is not as large as MEDLINE and CINAHL, its UK focus makes it an important database to include in the search.
- PsycINFO (1967 – 2013): database of American Psychological Association and includes international literature selected from more than 1,700 journals and periodicals. In addition to journals, the database also contains listings of book chapters, books and dissertations in psychology. It was included in my search strategy as it covers psychology related to medicine, nursing, and sociology. Given the multidimensional impact of chronic illness, I considered this to be an important database to include.
- CSA Sociological Abstracts (1962 – 2013): Database has an international selection of over 2,600 journals and other serials publications, plus conference papers, books, and dissertations. It is considered to be the premier database for access to the latest sociological research and also covers health related sociology, making it a valuable resource.
- The Applied Social Sciences Index and Abstracts (ASSIA) (1987 – 2013) database has over 600 social science journals indexed. This database provided a complementary source of sociological literature for my search.

Key search terms were identified with assistance from the subject specialist librarian. Search term groupings were then used together in each database. Searches were undertaken to cover the areas of MS and adaptation and also included papers relating to both people with MS and carers.

The following table represents the typical approach to searching the EBSCO hosted databases:

EBSCO database search terms	
1	multiple sclerosis.mp. [mp=title, subject heading word, abstract, instrumentation]
2	demyelinating disease.mp. [mp=title, subject heading word, abstract, instrumentation]
3	neurologic\$ disease.mp. [mp=title, subject heading word, abstract, instrumentation]
4	1 or 2 or 3
5	adaptation.mp. [mp=title, subject heading word, abstract, instrumentation]
6	4 and 5

**Table 1: Search terms**

### 2.2.2 Analysis of the literature

During the initial searches a total of 367 citations were identified. Titles and abstracts were then screened for their relevance to the study topic. That is, that they pertained to MS from the perspective of patient, carer or health care professional. A total of 109 citations appeared relevant; however there was a large number of duplicates, and following their removal this left 31 articles for further review. Following the review of the full text articles, 18 papers were selected for inclusion. Table two summarises the search results from the database searches.

I identified a number of additional sources from the reference lists of the articles which included book chapters and conference proceedings. Key authors were identified through familiarisation of book and journal articles and scrutiny of reference lists of relevant studies. Author searches were then conducted on the relevant database to obtain key sources by influential authors in the area. This added to the comprehensiveness of the overall search and yielded a further 23 sources for inclusion. Each article was summarised using a standardised data extraction sheet which is presented in a table in Appendix One. The following sections will now provide a critical review of the literature.

Database	No. of hits	No. excluded (not relevant)	No. of titles and abstracts reviewed	No. when duplicates removed	Excluded studies (not relevant)	No. included
<b>EBSCO</b>						
MEDLINE (1966-2013)	138	111	27	17	4	13
CINAHL (1982-2013)	50	21	29			
PsycINFO (1967-2013)	80	53	27			
Cochrane database of systematic reviews	63	62	1			
PBSC	19	11	8			
<b>ProQuest</b>						
ASSIA (1987-2013) BNI (1984-2013) CSA Sociology abstracts (1962-2013)	17		17	14	9	5
<b>Totals</b>	<b>367</b>	<b>258</b>	<b>109</b>	<b>31</b>	<b>14</b>	<b>18</b>

**Table 2: Search results**

## **2.3 The need for information and support**

The need for information and support leading up to and following a diagnosis of MS has been highlighted as an important issue for those affected. Johnson's (2003) qualitative study involving 12 participants, which was part of a wider mixed methods study funded by the MS Trust, discovered that even prior to the confirmation of diagnosis, people begin to raise suspicions and worry over what might be the cause of their symptoms, with some considering MS as a possible diagnosis. The data in this study highlight the fact that many people engage in active information seeking and arrive at a self-diagnosis of MS before it is confirmed by a physician. This stage is described by Corbin & Strauss (1988) as pre-diagnostic limbo and is a stage which is common in other chronic conditions with symptoms which may be described as "non-specific" (Dickson, Knussen, & Flowers, 2008).

There are few previous studies examining the pre-diagnosis phase of MS, however Koopman and Schwiezer's (1999) phenomenological study explored the experience of five people with relapsing and remitting MS who were newly diagnosed and found they experienced a "labyrinth which connected them to multiple voices and led them on various paths" (p17) often with significant delays between being seen by specialists. For the participants in this study, the time from symptom onset to diagnosis spanned a range of six months to 22 years, and the findings revealed anxiety and uncertainty as to the cause of the symptoms, with many worrying that the diagnosis might be cancer.

Previous studies which have explored the experience of being diagnosed with MS have highlighted being given a name for the condition as contributing to a reconstruction of identity (Finlay, 2003; Mozo-Dutton, Boot, & Simpson, 2012; Toombs, 1995). The need for a confirmed diagnosis can be linked to the sense of self, as a number of studies have highlighted that people with chronic conditions are often discredited in their quest to seek medical help (Bury, 1982; Dickson et al., 2008; Grytten & Måseide, 2005). Charmaz (1983) identified being discredited as a factor which contributed to the loss of self. Thus the reactions of health care professionals can be understood to have an influence over how this period in the road to diagnosis is experienced by the individual.

Information provision and support have been identified as important measures which may help to reduce levels of uncertainty. Some studies have also alluded to the potential impact of the diagnosis on the sense of self, which suggests that the need for a diagnosis is somehow linked to identity, and that the experience of uncertainty surrounding the diagnosis may be unsettling for the individual and their sense of self.

Several studies support the need or desire for information to help reduce uncertainty at the time of diagnosis (Crigger, 1996; Heesen et al., 2003; Johnson, 2003; Koopman & Schweitzer, 1999). A survey involving 434 people with MS and 80 neurologists, conducted by Heesen et al. (2003) in

Germany highlighted the debate amongst physicians regarding the best time to deliver information about MS. With the diagnostic process often being prolonged in MS, the degree of uncertainty experienced by individuals is often protracted. This is of particular significance, as highlighted in a study of people with chronic fatigue syndrome and fibromyalgia (Asbring, 2001), which linked the length of time from the onset of illness to confirmed diagnosis as impacting negatively on psychological adjustment to the illness. Despite the reservations of the physicians in Heesen et al.'s (2003) study, the patients' desire for early receipt of information about MS, even prior to a confirmed diagnosis, would appear to support the provision for information as a means to supporting individual's appraisal of their situation which helps them through the transition.

A study funded by the MS Trust (Hepworth et al., 2002) identified the period following diagnosis of MS as being a significant time period where individuals require support in the form of information about the illness. This study involved sending questionnaires to 2030 people with MS throughout the UK and conducting focus groups to gather qualitative data with 103 people with MS. The study reported that whilst information provision at the time of diagnosis has improved since the 1980s, the consistency of information provision still needed to be improved. At the time of diagnosis 50% of the individuals who participated in the study reported a 'lack of support', 'little information' or 'poor attitude' by professionals. Over half of the participants wanted information on managing symptoms, drug treatments, disease course, physical symptoms, exercise, diet and information for the family at this time.

Crigger (1996) used the 'Mishel Uncertainty in Illness Scale' (MUIS) (Mishel & Epstein, 1990) to quantify levels of uncertainty in people with MS in a mixed methods study. This study involved interviewing 93 women with MS who had been diagnosed with the illness for a minimum of two years (mean 10.7 years). The women are described as having middle to late stage MS, with 72.2 % having moderate to severe impairment with walking. Results of levels of uncertainty are not clearly presented within the findings of this study,

but are implicit in the discussion relating to mastery. Factors which impact on the levels of uncertainty in this group of women with MS include the influence of family and social relationships, spiritual well-being, and other life stressors not related to MS.

Crigger (1996) argues that uncertainty is a challenge to successful adaptation to living with MS throughout the course of the illness due to the unpredictable nature of the illness trajectory. This concurs with Mishel & Braden's (1988) study of 61 women with gynaecological cancers which found that where the illness trajectory was unpredictable, this correlated with a high level of uncertainty in their participants. Furthermore, where the illness was characterised by periods of remissions and relapses, the unpredictability gave rise to greater levels of ambiguity and uncertainty. Whilst this study focussed on American women with gynaecological cancer, the theory is of particular significance to the individual with MS, as the illness trajectory does not follow a set pattern, thus giving further credence the findings of Crigger's (1996) study.

A more recent study also using the MUIS in the study of MS, focussed the spiritual well-being of individuals with MS and its impact on perceived uncertainty and psychosocial adaptation (McNulty, Livneh, & Wilson, 2004). Spiritual well-being was measured by the Spiritual Well-being Scale (Ellison, 1983; McNulty et al., 2004) and psychosocial adjustment was measured by the Psychosocial adjustment to Illness Scale (Derogatis & Lopez, 1983, in McNulty et al., 2004). This study involved 50 participants (40 women, 10 men) with MS aged between 22 to 76 years (mean 45.5). The length of time since diagnosis varied from one to 34 years (mean 10.9 years). The study recruited potential participants through advertisement in the local MS Society publication asking them to call the researcher. This method of recruitment may immediately bias the sample as readers of the local branch of the MS society publication may not be typical of the wider population of people with MS and certainly not of those newly diagnosed. This limitation was not acknowledged by the researchers but they do acknowledge the relatively small sample size, ethnic homogeneity and Christian beliefs as possible

sources of bias. Participants were mailed the questionnaires for completion and postal return. It would appear that all those who agreed to take part returned the completed forms but three forms were unable to be included in the analysis due to missing data or co-existing chronic illnesses. The findings of this study suggest that higher levels of uncertainty, when compounded with lower levels of spiritual well-being, impact negatively on psychosocial adjustment to the illness. Given that participants in this study had medium to late stage MS, this would indicate that uncertainty pervades the illness trajectory beyond the immediate post-diagnostic phase. It is difficult to generalise the findings of this study to the wider population of people with MS due to the bias in participants, and more specifically, since the study did not focus on the period immediately following diagnosis, the findings do not illuminate the experience of uncertainty or its influence on adaptation to living with MS at this critical time period.

In summary, this section highlighted the findings of previous studies which have identified the immediate phase surrounding diagnosis of chronic illness as a time when uncertainty and anxiety levels may be high. The following section will explore the impact of the diagnosis on the person and those close to them.

## **2.4 The meaning of being diagnosed with MS**

The impact of a diagnosis on the person with MS and those close to them has been widely researched and has highlighted the impact as being multidimensional. The following section will explore the literature in relation to the initial reaction to being diagnosed with MS, as well as providing a critical overview of the literature relating to the psychosocial impact of being diagnosed with MS before turning to the implications for identity. As being diagnosed with MS is not a solitary experience, the impact of MS on family will also be examined.

### **2.4.1 Initial reactions**

The reactions to a diagnosis of a chronic illness may result in a number of emotional responses including fear or relief (Bury, 1982; Corbin, 2003). Similarly, individuals' reactions to being diagnosed with MS vary. For many this may provoke feelings of fear, anxiety, despair and depression (Koopman & Schweitzer, 1999) or uncertainty (Mishel & Braden, 1988). This may be due to common misunderstandings and stereotypical representations of people with MS which includes the perception of the wheelchair bound, dependent person. Whilst this may become the reality for some individuals with MS, it affects only around 10% of people with the condition (MS Trust, 2005). The image of MS in the media is often portrayed as an illness with profound physical impairment which results in being wheelchair bound (Koopman & Schweitzer, 1999). It is reasonable then to assume that this time is a critical time of need for accurate information about the illness, treatment and its effects in order to be able to cope with the illness and bring a sense of perspective to living with the condition.

Koopman & Schweitzer (1999) found that for some individuals diagnosed with MS, the confirmation of a diagnosis came as a relief as they had suspected other diseases such as cancer, or during their attempts to receive medical care they had been branded as malingerers. A confirmed diagnosis brought about validation to the symptoms individuals had been experiencing, often over a prolonged period of time overshadowed by uncertainty and stress (Bury, 1982; Charmaz, 1983). However such relief is often short-lived as the unpredictable prognosis and trajectory of MS in particular means that the pervading uncertainty may not be alleviated even when a diagnosis is given (Healy, 2003).

Previous studies which have explored the impact of a diagnosis of MS have tended to involve participants with a wide ranging length of time since being given the diagnosis (Crigger, 1996; Johnston, 2003; Mozo-Dutton, Simpson

& Boot, 2012) or not been focussed exclusively on the experience of people with MS (Bury, 1982; Charmaz, 1983; Pollock, Christian, & Sands, 1990). This poses limitations on the findings of such studies as participants have to rely on their memory of being diagnosed with MS, and with the passage of time, diagnostic procedures and attitudes to giving patients information may have significantly changed. In addition to this, the participants would have been reflecting after a period of adjustment, so the accounts presented may be edited and reconstructed versions of how they actually felt at the time.

The impact of chronic illness on the sense of self is relevant to the person newly diagnosed with MS as they may face many losses on a multidimensional scale. In a mixed methods study focussing on seven women with MS, Cahill, Connolly, & Stapleton (2010) report loss of role as one of the major losses which impact on many dimensions of the self. Psychologically, people find it hard to adapt and ask 'why me', 'why now' (Russell, White, & White, 2006). Socially, people may become withdrawn and are more likely to face relationship problems resulting in separation or divorce (Cheung & Hocking, 2004).

#### **2.4.2 Psychological impact**

A number of studies highlight the prevalence of psychological distress in relation to dealing with the diagnosis of MS (Barrett, 1995; Dilorenzo, 2008; Lexell, Iwarsson, & Lund, 2011; McCabe, McKern, & McDonald, 2004; Pakenham, Stewart, & Rogers, 1997; Pollock et al., 1990; Wineman, 1990). A qualitative study by Pollock and Sands (1997) involving semi-structured interviews with twenty people with MS explored the concept of suffering, and concluded that the psychological processes follow a hierarchical progression from shock and denial, through to acceptance and understanding, as well as finding meaning in their suffering. The findings of Pakenham's (2007) quantitative study of over 500 people with MS appear to support these qualitative findings data suggested that where people with MS could find benefit in their situation they were more able to adjust psychologically to living with the condition. A similar process was found to influence the coping

strategies of people with MS in an earlier quantitative study by Matson & Brooks (1977).

In an earlier quantitative study involving 134 patients with MS and their carers, Pakenham, Stewart and Rogers (1997) used a number of quantitative questionnaires to measure levels of disability (Expanded Disability Status Scale (EDSS), (Kurtzke, 1983), perceived threat and controllability using a 7 point Likert scale, levels of psychosocial adjustment (Psychosocial Adjustment to Illness Scale, Derogatis & Lopez, 1983) and physical and psychological symptoms. Statistical analysis was then used to correlate the variables. Psychological adjustment to MS appeared to be influenced more by the perceived threat of the illness, and the coping strategies employed by the individual, than the actual illness related symptoms. These findings would appear to suggest that the presence of symptoms does not always correlate with a poorer level of psychological adaptation, which is in contrast to the findings in Pakenham's (1999) later study which indicated that lower levels of physical disability were related to better psychological adaptation.

McCabe, McKern & McDonald (2003) also explored psychological adaptation to living with MS, but this study also compared the population of people with MS to a healthy population, thus giving a control group to allow comparisons to be made. The significant findings of this study indicated that there may be gendered differences in relation to psychological adaptation and coping styles. The authors concluded that women were more likely to use emotion focussed coping strategies than men and that women were more willing to seek social support to help them cope. These findings suggest the need for practice to include helping women to develop more problem focussed coping strategies, and men to develop effective support networks in order to balance good emotion and problem focussed coping strategies towards adaptation.

### **2.4.3 Social and occupational impact**

Social and occupational roles are roles which often define the person. As MS predominantly affects young adults, it has the potential to have a significant

impact on the social, occupational and leisure activities of the person with the condition (Cahill et al., 2010). As suggested by Kralik et al. (2001), this may have implications for the self-identity of the person as uncertainty can permeate into the individual's self-concept and challenge previous constructs of the self as these are closely linked with the social and occupational roles that individuals assume in society.

Lexell et al.'s (2011) qualitative study with ten participants used the constant comparative method of analysis to gain an enhanced understanding of how people with multiple sclerosis experience their occupational adaptation. Findings suggest participants' occupational adaptation was experienced as a constant struggle and unpredictable, and served as the means of achieving either a desired self or a desired family life. While people with newly diagnosed MS may not always experience debilitating physical symptoms, the experience of fatigue often prevents participating fully in social and occupational roles as before (Smith & Arnett, 2005). This has implications for the financial status of people with MS; previous studies have found that people with MS may be financially worse off since having the illness as it interferes with their ability to function at work (Cahill et al., 2010). For health and social care professionals, advising people with MS how to adapt to living with the condition and providing information on financial aspects may help to ease their adaptation to this potential change.

The perceived stigma of MS has also been highlighted as a factor which influences how people engage in social and occupational roles following diagnosis. Grytten & Måseide's (2005) qualitative study of 14 participants with middle and later stages of MS drew on Goffman's (1963) concept of stigma and Charmaz's (1983) "loss of self" to explore the experience of stigma within the context of social relationships. This sociological study, informed by symbolic interaction, focussed on how participants constructed their identity through interaction with others by interpreting the meaning and reality being negotiated in communication with others. The authors found that there was a strong desire by participants to maintain their pre-MS identity, such as being the 'breadwinner', through purposefully concealing their

diagnosis of MS which acted as a protective buffer to the disruption of the self. They go on to suggest these active coping strategies created a 'protective capsule' around the person with MS and shielded them from feeling stigmatised in their social and occupational contexts.

This section has highlighted the findings of previous research which has outlined the impact of MS on social and occupational roles. The literature reviewed also suggests that these roles are linked to the individual's sense of self. The following section will now consider the impact of MS on the sense of self in more depth.

#### **2.4.4 Impact on identity**

A changing conceptualisation of the self is a theme which has been identified across a number of chronic conditions (Koch, Jenkin, & Kralik, 2004; Osborn & Smith, 2006; Sanderson, Calnan, Morris, Richards, & Hewlett, 2011; Werner, Isaksen, & Malterud, 2004). Section 2.2.2 provided an overview of the influential theoretical perspectives relating to identity with Bury (1982) and Charmaz (1983) being the two influential theorists whose work has gone on to influence the study and interpretation of biographical research. Within the context of the study of the experience of living with MS, a number of studies have highlighted the implications of the diagnosis for the person's sense of self (Barrett, 1995; Finlay, 2003, 2006; Gagliardi, 2003; Mozo-Dutton et al., 2012; Toombs, 1995).

Both Toombs (1995) and Barrett (1995) presented autobiographical accounts of living with MS which articulate the impact of the condition on their own sense of self. Toombs (1995) presents her accounts as a chronological narrative of her own experience with reflections on the experiences of those close to her, whereas Barrett (1995) conducted what could be termed autobiographical research. Barrett's (1995) paper presents the findings from qualitative interviews with her friends and relatives on their experience of seeing her live with MS. There are obvious risks to the integrity of the data through the interviewer being known to the participants, and interviewing

them about their perceptions of her condition, and one may consider that the participants may not fully disclose how they feel for fear of offending. With this limitation in mind however, her study drew on van Gennep's (1960, cited in Bigger, 1962) "Rites of passage" theory and drew attention to the liminality of the experience of being a person with MS.

Toombs (1995) on the other hand presented a powerful account of her experiences of living with MS from being diagnosed with the condition, to sitting in the support groups and subsequent experiences of her worsening physical condition and its impact on her sense of self. In her narrative Toombs (1995) described her experience of her changing physical ability as influencing the transformation in her sense of self. Toombs (1995) also described her reaction to watching a video of a person with MS who became wheelchair bound, and forced to sell his house. She described this experience as being "shown a detailed blueprint of the future" (p5) for herself and what she would become; her identity being consumed by MS. When considering Toombs' (1995) perspective in the context of Bury's (1982) theory of biographical disruption, it supports a relationship between the embodied experience and the sense of self, as taken-for-granted assumptions of physical and cognitive ability are challenged by MS, instigating a re-thinking of self-concept as a person with MS.

A later study by Finlay (2003) also highlighted the relationship between the embodied experience and the sense of self. Finlay (2003) explored the dynamic relations between body-self-world in her idiographic phenomenological study of "Ann", a woman with advanced MS. The embodied experience of the symptoms of MS were inextricably intertwined with the sense of self and being-in-the-world and the findings are relevant to understanding identity theory within the context of the experience of MS.

Self-concept was also highlighted as being closely linked to the experience of sexuality among people with MS in Gagliardi's (2003) qualitative study of five women and three men. Gagliardi (2003) highlighted how self-concept was closely linked to the participants' experience of living with MS and

subsequent feelings about their sexuality. Gagliardi (2003) drew comparisons with Roy's adaptation model (Roy, 1980), however the focus on self-concept also links to identity theory specifically in relation to the work of Price, (1990) presented in section 2.2.2. Although Gagliardi's (2003) study had a larger sample than the others reviewed in this section, the sample size remains small and as the study was conducted in the United States, there may be social and cultural differences pertinent to understanding the experience of sexuality and MS within the Scottish context.

A more recent UK based study by Mozo-Dutton, Boot & Simpson (2012) explored the experiences of biographical disruption in eight female and four male participants with MS. The study employed an Interpretative Phenomenological Analysis (IPA) approach, which considers the lived experience from an idiographic perspective. The authors found that whilst all participants spoke of changes to their perceptions of self, these were not exclusively described as negative. Some participants spoke of holding on to their sense of self in spite of MS, suggesting an unwillingness to be defined by MS, whereas others believed that they had grown as a person because of their experience of MS. Mozo-Dutton, Boot & Simpson (2012) conclude that MS should not be perceived to result in an inevitable loss of self, challenging the relevance of Charmaz's (1983) theory of "Loss of Self" to understanding the experience of biographical disruption in people with MS.

The participants in Mozo-Dutton, Boot & Simpson's (2012) study had been living with the symptoms of MS from six to 28 years, with the time preceding diagnosis ranging between four and 14 years and the study only included the perspectives of the person with MS. It is not clear if any of the participants in this study were newly diagnosed, however the authors do conclude that time spent living with MS did not appear to influence the findings as the themes were similar across all participants.

To date, the studies of the biographical impact of MS have adopted the qualitative paradigm and have used very small samples. As such the studies have presented an idiographic approach to understanding the experience. At

the time of writing none of the studies focussing on this aspect of the experience of living with MS have been conducted within the Scottish context. With the exception of Barrett's (1995) study, the studies discussed in this section have also mainly focussed on the experience from the person with MS's perspective. Gagliardi's (2003) study highlighted a possible connection between self-concept and sexuality in people with MS. The following section will now consider the impact of MS on couple relationships.

#### **2.4.5 Impact on couple relationships**

The experience of chronic illness within the coupled relationship has been researched within the context of a number of conditions, with the experience of couples affected by stroke (Burton, 2000; Eriksson & Svedlund, 2006; Pringle, 2011) and cancer (Badr & Taylor, 2008; Belcher et al., 2011; Fergus, 2011; Navon & Amira, 2004; Zunkel, 2002) being among those most commonly researched. Themes from this body of literature suggest that the coupled relationship may significantly affect the experience of psychological adjustment to living with MS for both partners (Burton, 2000; Belcher, et al., 2011; Fergus, 2011; Navon & Armina, 2004). A number of the studies refer to transition theory as the theoretical underpinning (Belcher, et al., 2011; Burton, 2000; Pringle, 2011). Likewise, previous studies in MS have identified couple relationships as an important social context within which the psychological process of learning to live with MS is managed (Esmail, Huang, Lee, & Maruska, 2010; Harrison, Stuijbergen, Adachi, & Becker, 2004; O'Connor, McCabe, & Firth, 2008; Pakenham, 2008; Starks, Morris, Yorkston, Gray, & Johnson, 2010).

The impact of MS related symptoms and disability have been found to cause a degree of disruption within the couple relationship in people with MS (Gagliardi, 2003; Harrison et al., 2004). In a longitudinal quantitative study Harrison et al. (2004) explored the impact of MS-related disability on marital relationships. Their findings imply that the quality and stability of the marital relationship influences the person with MS's ability to accept their disability, suggesting that being in a stable relationship may have therapeutic effects for

some people with MS. The study also highlighted gender differences, with men with MS showing a greater acceptance of MS-related disability over time when compared to women. Harrison's et al.'s (2004) findings support Gagliardi's (2003) earlier findings which emphasised the relationship status as a factor which influences the self-concept of those with MS. One of the themes in Gagliardi's (2003) qualitative study drew attention to the impact of MS on the sexual relationships of couples, with some participants having a positive outlook despite their symptoms of MS and others experiencing psychological distress when they could no longer participate in sexual intercourse due to the impact of their MS on the relationship.

The importance of self-concept was also highlighted in Esmail et al.'s (2010) qualitative study which explored the biographical impact of impaired sexual relationships in people with MS. The findings from their study support the findings of Gagliardi (2003) and Harrison et al. (2004) and go on to suggest that individuals construct their own definition of sexuality, influenced by various social and cultural factors as well as personal experience.

The participants in both Gagliardi's (2003) and Esmail et al.'s (2010) studies described feeling less attractive and therefore less inclined to engage in sexual activity, however the desire for intimacy was still there. These findings indicate a degree of insecurity within the self which infiltrates the relationship. Esmail et al. (2010) found the problem of insecurity within the self and the relationship led to a re-evaluation of the relationship, with men being more likely to re-evaluate the relationship negatively. Thus the impact of MS on the couple relationship may be seen to pose a threat to the stability of the relationship.

Starks et al.'s (2010) study highlighted responses to the demands and stressors of MS which they identified as being "in-sync" and "out-of-synch" (p 196) with each other. The authors identified the characteristics which indicated which category a couple would fall into, with "in-sync" couples having a relapsing-remitting type of MS, which was relatively stable, allowing both partners to maintain their social roles and identity, and a collaborative

problem solving style. The characteristics of out-of-sync couples include rapid progression of MS, having to give up work early, oppositional styles of responding to the increased demands and stress of MS, and struggles with parenting adolescent children. The authors suggest that health care professionals may use these criteria to assess possible relationship problems in couples with MS and identify families who might benefit additional support; however they did not address the influence of the nature of the relationship prior to MS.

Much of the literature to date has focussed on the experiences of people with middle to advanced MS (Harrison et al., 2004; Esmail et al., 2010; O'Connor, McCabe & Firth, 2008) and originates from the USA (Gagliardi, 2003; Harrison et al., 2004; Starks et al., 2010), Canada (Esmail et al., 2010) and Australia (O'Connor, McCabe & Firth, 2008; Pakenham, 1998). The literature reviewed in this section indicates that the experience of MS poses challenges for both partners in the couple relationship, which suggests the experience of MS is a shared experience. The following section will explore the experience of MS from the partner or close relative's perspective.

## **2.5 The experience of the support person**

The literature reviewed so far has focussed mainly on studies which have focussed the experience of MS from the person with MS's perspective. However the literature has indicated the experience of living with MS extends beyond the individual with MS and this was particularly highlighted in section 2.4.5 which considered the impact of MS on coupled relationships. The previous section discussed the support person within the context of the couple relationship, whereas this section will explore the literature which addresses the impact of MS on the support person experience. In reviewing the literature for the support person of those with MS I came across a number of terms which were used in the literature therefore it is helpful to clarify the terms used from the outset of this section of the review.

The term 'carer' has been defined almost exclusively in terms of physical activities required to help an individual with a particular handicap or condition, with much of the literature relating to carer roles referring to those with physical caring duties, such as providing personal care, and administration and monitoring of medications (Eriksson & Svedlund, 2006; Ferrell, Taylor, Grant, Fowler, & Corbisiero, 1993; Murray et al., 2002; Nolan & Grant, 1989; Persson, Rasmusson, & Hallberg, 1998) and is related to older individuals where chronic illness is often interpreted as an inevitable consequence of the aging process (Adamson & Donovan, 2005; Ray, 2006). This term 'carer' does not fit well with the support person of the newly diagnosed person with MS, as the support person may not be actively engaged in traditional caring duties, nor may they identify themselves as 'carers'. To avoid confusion, in relation to the possibility of people not identifying themselves as 'carers', the term 'support person' has been used to refer to carers within my research study, however, when reviewing the literature it is acknowledged that a variety of terms have been used including carer, relative, and partner.

### **2.5.1 Psychological impact of MS on the support person**

Despite the fact that physical care may not be required for the person in the early stages of living with MS, the need for support within close relationships has been highlighted as an important factor in influencing a positive transition to living with MS (Harrison et al., 2004; Gagliardi, 2003). The provision of such support has been associated with significant impact on psychological wellbeing, and has been referred to as emotional labour (Ray & Street, 2007). Emotional labour is defined as "the labour involved in dealing with people's feelings, a core component of which is the regulation of emotions" (James, 1989, p15).

Several studies have highlighted the need for psychological support for the support person as well as people with MS (O'Connor et al., 2008; Pakenham, 2001; Pakenham, 1998). The quantitative study by Pakenham (1998), which explored the coping experiences of couples with MS, indicated that support

persons experienced problems with psychological adjustment and distress levels similar to those of the person with MS.

Cheung and Hocking's (2004) qualitative study from an interpretative phenomenological perspective highlighted the psychological impact of caring for a person with MS by conceptualising the experience as "caring as worrying", with worries about their own health, their relationship, and requesting support, indicating an internalisation of the process which may cause psychological distress. It should be acknowledged that the participants in this study all provided at least one hour of hands-on care per day to the person with MS, therefore the findings may not be so relevant to the support person of the person in the early stages of living with MS.

Similarly, Pakenham's (2001) quantitative study of 51 carers of people with MS found that almost one third reported clinically significant levels of psychological distress and that this was related to less disability in the person with MS. Pakenham (2001) also found a correlation between a lack of social support and psychological distress. Social support was also found to be significant to marital relationship satisfaction in a study of the experience of patients and carers of people affected by Parkinson's disease, Motor Neurone Disease and MS (O'Connor, et al., 2008).

### **2.5.2 Support person identity**

The experience of being diagnosed with MS has been linked to biographical disruption in those with the condition. This section of the thesis will consider the effect on the identity of the support person. The literature relating to the impact of MS on the individual, discussed in section 2.4.3, bears many similarities to that of the support person. Where the individual was faced with biographical disruption (Bury, 1982) and was described in terms of "loss of self" (Charmaz, 1983), literature examining the impact of chronic illness on carers has also highlighted such themes (Adamson & Donovan, 2005). Similarly, a number of studies have highlighted the significance of biographical disruption in people closely affected by a diagnosis of MS,

suggesting their identity may be permanently changed as a result of the experience (Cheung & Hocking, 2004; Toombs, 1995).

An ethnographic study of carers' experiences of living with motor neurone disease (MND) used semi-structured interviews with carers and observation (Ray & Street, 2007). This methodology has the potential to overcome some of the limitations related to carers not reporting the burden of the caring role due to incorporating observation, however observation is interpreted through the eyes of the researcher and the perception of burden may still be different from the carer. The findings of this study presented the experiences in terms of losses, which often related to the physical deterioration of the individual with MND. For example, the worsening of the patient's condition triggered threats to the carers' expectations of life goals, personal relationships and identity.

A qualitative study involving a focus group with twelve spousal carers of people with MS found that the spouses of people with MS struggled to maintain their identity in the face of changes to their role from partner to caregiver within the relationship (Courts, Newton & McNeal, 2005). The length of time since the person with MS had been diagnosed with MS varied from two to 13 years.

In a qualitative study of ten spousal carers of people with MS, Cheung and Hocking (2004) identified that they often have to face long term caring for their partner and this may involve giving up their own employment and income, lifestyle, independence and future goals. Similarly, Toombs (1995) intimated that her diagnosis of MS made her question if her husband may also have to abandon his goals. Having to give up such roles and take on new roles is often associated with a reconstruction of the biographical narrative (Bury, 1982). However, the role of the support person in the early stages of living with MS cannot be clearly considered from Cheung and Hocking's (2004) study as the participants were spousal carers who provided at least one hour of hands-on care each day for people with MS who had been diagnosed for at least five years.

The availability of support for the support person is something that may be questioned, as the findings from Pakenham's (2001) study suggest that social support for the support person is a key factor in maintaining identity. Starks et al.'s (2010) study suggests a slower pace of change of role for the support person facilitates easier adjustment to a new identity.

The impact of MS on the support person has been emphasised in this section with psychological distress and biographical disruption being most apparent in the literature. It has been suggested that there may be a link between the perceived levels of carer burden and satisfaction with caring, and perceived quality of life (Bogosian, Moss-Morris, Yardley, & Dennison, 2009). The consequences of this are of relevance for health care professionals who are involved in supporting individuals who may face being in a caring role. The studies discussed in this section have highlighted the significance of biographical disruption in people closely affected by a diagnosis of MS, suggesting their identity may be permanently changed as a result of the experience. Most of the studies have been conducted with participants who have a clearly defined carer role therefore little is known about the impact of MS on the support person in the early months of learning to live with the condition. At the time of this study the issues relating to biographical disruption following the diagnosis of MS have not been fully explored. The ontological nature of my study is suited to exploring such issues to elicit the lived experience of the support person throughout the transition to living with MS.

## **2.6 Discussion and summary of the findings of the literature review**

This literature review has provided an overview of the current body of literature which relates to MS and, where relevant compares and contrasts this with included literature from other conditions. Key themes have emerged from the literature in relation to both the individual with MS and the

support person. These have included the impact of MS on the individual and their identity, the reactions to learning to live with MS, and coping with a chronic condition in everyday life. Uncertainty has also been identified as a concept which may influence the experience of MS. The findings from the review frame MS within the context of chronic illness, thus highlighting the relevance of chronic illness theory to the study of people with MS. The following section will provide a summary critique of the body of literature reviewed.

### **2.6.1 Methods of inquiry**

Of the 41 papers which were related to MS, there were 18 qualitative studies, making this the most common methodology of choice, which would suggest that it is an appropriate methodology for researching the subject area. The majority of papers were described as qualitative, with five of those being described as phenomenological studies (Cheung & Hocking, 2004; Esmail et al., 2010; Finlay, 2003, 2006; Koopman & Schweitzer, 1999; Mozo-Dutton et al., 2012) and two were autobiographical accounts (Barrett, 1995; Toombs, 1995). Qualitative studies are common in health care and sociological studies seeking to explore experiences of those directly affected as they allow participants to tell their stories of health and illness, which gives the opportunity to explore the meaning and understanding that is associated with the situation (Corbin, 2003).

Of the 11 quantitative papers reviewed, the vast majority (ten) used a survey methodology with validated quality of life assessment tools. Only one quantitative study was an intervention study which explored the benefits of mindfulness technique to help promote psychological adjustment to living with MS (Pakenham & Samios, 2012). Seven studies were referred to as mixed methods. A criticism related to some of these studies was that they predominantly focussed on the quantitative elements of the study (Cahill et al., 2010; Pollock et al., 1990; Wineman, 1988, 1990) with only the studies by Hepworth, Harrison and James (2002), Pakenham (1998) and Pakenham

(1999), who employed the use of focus groups or individual interviews, having any meaningful engagement with qualitative methods.

The literature relating to chronic illness and identity has established a clear link between illness and self-identity, however several areas are as yet unclear. It remains to be seen how the knowledge of a confirmed diagnosis of MS is appraised by the individual and whether this results in biographical disruption regardless of the level of physical or social impairment. The literature has described the experience of chronic illness both in terms of loss (Charmaz, 1983) and transcendence (Asbring, 2001). What is unclear is how this relates to the individual who is newly diagnosed with MS. Thus the emotional reaction to the diagnosis is also an important aspect which requires further investigation.

In summary, reactions to a diagnosis of MS are varied and are influenced by a number of factors. The length of time a person has suffered with symptoms has been shown to impact on their reactions, as the diagnosis may come as a relief or serve as validation of their suffering (Asbring, 2001; Bury, 1982; Charmaz, 1983; Corbin, 2003; Koopman & Schweitzer, 1999). The predictability of the illness trajectory also appears to be significant in how people cope with coming to terms with the illness. MS is characterised by unpredictable illness trajectory which leads to uncertainty (Crigger, 1996; Mishel & Braden, 1988). The experience of uncertainty has been shown to be particularly high in the first six months following diagnosis in women with breast cancer (Ritz et al., 2000). Whilst studies in people with MS have demonstrated that uncertainty is an on-going feature of the illness, to date no studies have explored this experience in the six months following diagnosis.

### **2.6.2 Origins of the studies**

The majority of studies originate in the USA and Canada, with the UK being the second most common source. Australia has contributed a significant number of studies also, but is well represented in the wider chronic illness

literature in comparison to the literature focussed on MS. Europe contributes the fewest number of studies. To date there have been no studies conducted on the experience of biographical disruption in people affected by a new diagnosis of MS within an exclusively Scottish context.

### **2.6.2 Theoretical perspectives**

The review of the literature has revealed four key theoretical perspectives which have been relevant to the study of MS. These include: transition theory (Meleis, Sawyer, Im, Messias, & Schumacher, 2000); theories of biographical disruption (Bury, 1982; Charmaz, 1983); uncertainty theory (Mishel, 1988); and stress and coping (Lazarus & Folkman, 1984). The following section of this chapter will provide an overview of each of these theories with reference to relevant studies in chronic illness.

## **2.7 Theoretical perspectives on chronic illness**

The purpose of this section is to provide an overview of the theoretical perspectives which have informed the study of chronic illness. The previous section identified four key theoretical perspectives and these will now be considered in relation to their relevance to the current study. As a chronic degenerative neurological condition, MS is one of many different conditions which come under the umbrella term of chronic illness or, as they are more commonly referred to in health care now, long term conditions. A general search of the literature relating to chronic illness was conducted with the resulting literature being analysed to identify the theoretical frameworks which have informed the research to date. The literature search included searches of the following databases; MEDLINE (1966-2013), CINAHL (1982-2013), and PsycINFO (1967-2013). Search terms included: chronic disease, long term ill health, long term condition, combined with adjustment, adaptation, psychological, coping, stress. This search was more limited than the main search for the literature on MS as the purpose of this search was to inform the theoretical perspectives as opposed to identifying a gap in literature.

### **2.7.1 Transition theory**

Transition theory is a nursing theory developed by Meleis et al. (2000) to provide a theoretical construct to explain the experience of transition. This theory has developed from earlier work on transition theory where Schumacher & Meleis (1994) identified four types of transitions including: developmental, which involves a natural transition from adolescence to adulthood, parenthood and old age; situational, which refers to changes in professional roles such as the move from education into employment; organisational, such as new staffing patterns, or management systems; and finally health to illness transitions which includes the impact of health conditions on the individual and those close to them.

The main feature of transition is that it begins with a change in status whether that is a normal lifespan change or disruptive change like being diagnosed with a chronic condition. Within the context of chronic illness, Kralik, Visentin, & Van Loon (2006, p321) define transition as “a process of convoluted passage during which people redefine their sense of self and redevelop self-agency in response to disruptive life events”. Meleis et al. (2000) suggest that transition may make those affected feel vulnerable as their reality is disrupted and a new reality dawns. This theoretical perspective is supported by the findings of Kralik's (2002) qualitative study involving women with chronic illness. In this study Kralik (2002) explored the participants' sense of meaning making in relation to living with chronic illness. The findings suggest that being diagnosed with a chronic illness is a distressing experience which initiates a quest for regaining a sense of “ordinariness”.

A diagnosis of chronic illness represents a permanent change to one's health status. In his study of women with rheumatoid arthritis (RA), Bury (1982) pinpointed the time of diagnosis as marking the end of one stage of the lifespan and the beginning of the illness trajectory. This transition period involves a process of evaluating the new information about the diagnosis with existing ideas and assumptions. Bury (1982) found that the diagnosis of RA

was often viewed as a relief for the women in his study as it was felt that with diagnosis came the offer of treatment and new hope emerged. The point of diagnosis therefore appears to be the starting point for a transition period where people learn to live and cope with chronic illness, and manage the symptoms with the appropriate level of support, information and advice from health care professionals (Johnson, 2003).

The severity of chronic illnesses varies, as does the impact on the individual's lifestyle. Chronic illness has however, been conceptualised as a disruptive life event which highlights the taken-for-granted abilities and liberties enjoyed by the individual in the pre-illness state, as either limited, or no longer available (Bury, 1982). Social and familial relationships are also tested at this time as normal interaction and dependency states may become inverted, thus forcing re-evaluation of accepted roles by the family members and others close to the individual (Cheung & Hocking, 2004; Pringle, Hendry, & McLafferty, 2008). This disruption results in a re-evaluation of the self through comparison of the pre- and post-illness state involving a re-evaluation of one's role and place in society. It is argued that such evaluation results in a transition involving a reconceptualisation and redefinition of the self (Bury, 1982; Meleis, et al., 2000).

A disruption to the individual's sense of self has been identified in a number of qualitative studies which have explored transition to living with a chronic condition (Cheung & Hocking, 2004; Dickson et al., 2008; Tina Koch et al., 2004; McCann, Illingworth, Wengström, Hubbard, & Kearney, 2010; Navon & Amira, 2004), suggesting a link between being diagnosed with a chronic condition and a change in the person's sense of self. Meleis et al. (2000) highlight the flexible sense of self as characteristic of the individual in the midst of the transition. The study by Kralik, Koch, Price, & Howard (2004), involving nine people with arthritis used participant journals to document autobiographical accounts along with two telephone interviews. The data presented in Kralik, Visentin and van Loon's (2006) review of the literature suggest longitudinal studies are required to capture the full biographical transition experience.

Previous studies of chronic illness have tended to present trajectory interpretations to transitions to living with a chronic condition as a linear process (Corbin & Strauss, 1988; Shaw, 1999) with Corbin's (2001) trajectory acknowledging a varied trajectory including acute exacerbations similar to MS relapses. Kralik, Visentin and Van Loon, (2006) challenge such notions of linear transitions, suggesting instead that learning to live with a chronic condition requires a fluid interpretation with movement in a number of directions. This suggests a much more chaotic approach to transition which needs to be understood within the context of being diagnosed with a chronic condition.

In summary, transition theory has been an influential theory informing the study of chronic illness, particularly from a qualitative perspective. The findings from the studies informed by transition theory appear to suggest a link between transition theory and biographical disruption as a result of the impact of chronic illness on the individual and their family. Recognising chronic illness as a disruptive life event alters how people view themselves and their relationships. This further development of the theory takes into cognisance the biographical theory developed by Bury (1982) and Charmaz (1983) which is discussed in the following section of this chapter.

### **2.7.2 Identity theory**

The previous section on transition theory highlighted a link between transitioning to living with chronic illness and a threat to the perceived identity of the individual. This section will explore the relationship between chronic illness and identity in greater depth by examining some of the key theoretical perspectives and research contributions in this area.

Bury (1982) is credited as being among the first to research the biographical impact of chronic illness. He based his theory on a qualitative study using semi-structured interviews with 30 people who had been referred to the rheumatology clinic. All but one of the participants subsequently had a

diagnosis of rheumatoid arthritis (RA) confirmed. The study focussed on the participant's experience of the emerging illness and its effect on how the individuals made changes to their life and relationships to accommodate this new illness. Bury (1982) argues that the conduct of everyday life, such as social and work roles, are disrupted by chronic illness and often this leads to strains on interpersonal relationships, as previously held ideas of the self and identity which are strongly linked to social roles are challenged. Due to this impact, he suggests the development of a chronic illness is a critical life event which results in "biographical disruption" (p169).

Bury (1982) defines biographical disruption as having three aspects to it; "taken-for-granted assumptions and behaviours", "fundamental re-thinking of self-concept" and "response to disruption and mobilisation of resources". To illustrate his concept of biographical disruption Bury highlighted the profound impact a diagnosis of RA had for individuals, particularly those who were younger. The new diagnosis was conceptualised as 'premature aging' by many of the younger participants (p171) and as such had a negative effect on their self-concept. The personal significance and meaning the illness had for participants challenged their self-concept.

Self-concept is closely linked with body image; a dynamic personal image which changes in response to aging, health, illness or injury (Price, 1990). Price (1990) suggests body image is comprised of three main components: body reality, body ideal and body presentation (Price, 1990). Body reality is how the body actually is, whereas body ideal is how the individual would wish the body reality to be and body presentation refers to how we present our bodies to the external world, for example in the way we choose to dress. Alteration in body image occurs when there is a significant mismatch in the perception of body reality and body ideal causing distress or upset to the individual. Wilde (2003) explains that body image is not only affected by physical alterations in the body, but the knowledge of illness which may not be physically apparent may also cause alteration in body image or disruption to mind-body harmony, this she calls "embodied knowledge in chronic illness and injury" (Wilde, 2003, p170). Thus the link between self-concept and how

the person views themselves may be affected by perceived alterations of body image as a result of chronic illness and subsequently contribute to biographical disruption.

An early qualitative study using grounded theory by Charmaz (1983) involved people with various chronic illnesses, at a stage where they experienced severe disability. Charmaz (1983) identified four main themes in her study: living restricted lives, social isolation, being discredited and burdening others. Similar to Bury (1982), Charmaz (1983) viewed the impact of chronic illness as a challenge to the individual's identity. From the findings of this study, Charmaz (1983) suggested, people with chronic illness experienced a "crumbling away of their former self-images without simultaneous development of equally valued new ones" (p168) thus causing disharmony and emotional distress. Charmaz's participants talked almost exclusively in a language of loss when discussing their illness. The chronic illness experience therefore results in a sense of loss for the former self, the person they used to be. Indeed, Charmaz (1983) uses the term "loss of self" to conceptualise her theory of suffering in chronic illness. What is clear from the findings in Charmaz's (1983) paper is that the construction of the self is closely inter-related with the functions and activities, such as work and relationships normally carried out by the individual. When chronic illness impedes to the extent that such activities are restricted or no longer able to be carried out, this poses challenges to how the individual has viewed the self (Corbin, 2003). Bury's (1982) work on biographical disruption and Charmaz's (1983) loss of self contributed significantly to current understanding of the impact of chronic illness on the sense of self.

There have been a plethora of previous studies of chronic illness that have drawn on either Bury's (1982) or Charmaz's (1983) theories of the self in chronic illness as the theoretical framework or perspective (Asbring & Närvänen, 2004; Dickson, Allan, & O'Carroll, 2008; Osborn & Smith, 2006; Sanderson et al., 2011). Whilst both theoretical perspectives address identity in chronic illness, they can be seen as having distinct differences. Where Bury refers to disruption of the self requiring a reconceptualisation of a new

self, it does not assume a loss of self like Charmaz. The differences between the theories may be subtle, yet they may also be significant in helping to understand the lived experience of the person with a chronic illness. It may be considered that the differences in perspectives may be down to the participant groups that have informed the theories. Bury's (1982) participants had rheumatoid arthritis which is a condition characterised by relapses and remission, similar to that of MS, whereas Charmaz's (1983) participants all had advanced chronic conditions, which may have resulted in a greater degree of disability.

The qualitative study by Kralik et al. (2004) explored how people learned to live with chronic illness through interviews and focus groups with 24 individuals with arthritis. Readjusting to the limitations set by the condition required recognition of such limitations, managing the shift in identity this caused through balancing activities, pacing daily life, and prioritising. The findings imply that there may be a close link between the levels of physical limitation imposed by the condition and ensuing biographical disruption and a reconceptualisation of self-identity.

A changing conceptualisation of the self is a theme which has been identified across a number of chronic conditions including: arthritis (Kralik et al., 2004; Sanderson, Calnan & Morris, 2011); chronic pain (Lillrank, 2003; Osborn & Smith, 2006; Werner et al., 2004) and cancer (Blows, Bird, Seymour, & Cox, 2012; Hubbard, Kidd, & Kearney, 2010; McCann et al., 2010; Navon & Amira, 2004) as well as MS (Barrett, 1995; Dyck, 1995; Thorne, Con, McGuinness, McPherson, & Harris, 2004; Toombs, 1995). In addition to the person with a chronic condition, several studies have also identified the relevance of identity theory for relatives of those with a chronic condition (Adamson & Donovan, 2005; Cheung & Hocking, 2004; Pakenham, 1998; Payne & Ellis-Hill, 2001; Pringle et al., 2008; Pringle, 2011).

Corbin (2003), who has led the field in development of chronic illness trajectory theory, in a keynote speech to the 8th Annual Qualitative Health Research Conference in Canada, explained that in health, self-concept and

identity is built around what people can do rather than what they can't do, and the self becomes what is through the body (p257). Corbin's (2003) explanations of self-concept and self-identity echo Wilde's (2003) description of embodied knowledge, where limitations on physical and social activity caused by the illness cause disharmony in previous ideas of the individual's identity. Thus new conceptualisations of the self are not congruent with what has been formed and taken-for-granted prior to the illness state.

Embodiment of the self and illness was highlighted in studies by McCann et al. (2010) and Osborn and Smith (2006). These qualitative studies explored the lived experiences of people from two distinct illness groups. McCann et al. (2010) explored the lived experience of twelve women with breast cancer during the first year since diagnosis, whereas Osborn and Smith focussed on the experience of people with chronic benign lower back pain. While it may be argued that the study in women with breast cancer focussed on a condition where the women were undergoing an active treatment phase and may have been optimistic about the outcome, there is evidence to suggest that living as a "cancer survivor" has an impact on the self of self. Osborn and Smith on the other hand, focus on a chronic enduring condition. The authors of this study considered the experience of back pain sufferers in relation to the participant's body and sense of self. While the studies discussed above linked the embodiment of the illness to the self, Osborn and Smith (2006) suggest that people with chronic back pain consciously try to detach the body and the self. The authors suggest there is a "complex and paradoxical relationship between the body, chronic pain and the self" (p216).

Whilst the above studies have largely focussed on the negative effects chronic illness has on the individual's self-concept, a study by Asbring (2001) on women with chronic fatigue syndrome (CFS) and fibromyalgia (FM), provides some mixed and perhaps more positive results. Asbring (2001) concluded that the biographical disruption experienced in chronic illness had both losses and gains for the individuals. Following a confirmed diagnosis of either CFS or FM, a number of women in the study continued living as before and did not accept the consequences of the illness. The level of biographical

disruption experienced by this group was less pronounced. Since this study adopted a qualitative approach, the difference of biographical disruption was not quantified. Nevertheless, the majority of the participants experienced the kind of biographical disruption described by Bury (1982), Charmaz (1983) and Corbin (2003). Asbring (2001) did however add to previous concepts of biographical disruption in her description of transcendence. Transcendence was illustrated where participants viewed the illness as a positive feature in their lives. Some of the participants spoke of ignoring the less trivial matters in life, such as material gains, and valuing leisure time and time with family more than they had done prior to their illness.

The findings of Asbring's study are of particular significance to my study and the concept of transcendence is worthy of further exploration within the context of learning to live with a diagnosis of MS. This concept contrasts with Charmaz's (1983) earlier findings, where the participants described their illness in terms of loss. Perhaps the timing of the research is significant to both studies; Charmaz's study was conducted in the late 1970s to early 1980s with individuals who were severely disabled by their condition, whereas Asbring's study was conducted in the late 1990s with women who had varying degrees of disability, including those who were still able to work and those who were not. Equally, cultural factors may have influenced the results of both studies; Charmaz's study was set in America, whereas Asbring's study was set in Sweden. The health care system in Sweden is largely free as in the UK, whereas in the USA health care costs are a common cause of personal bankruptcy. A similar exploration of such issues relating to the initial impact of a diagnosis on the sense of self in the UK setting will add to the current state of knowledge and understanding which at present lacks a contemporary perspective.

A clear theme is beginning to emerge in the literature so far: when faced with living with chronic illness, the person's previous sense of self is subject to challenge and change. Dickson, Knussen and Flowers (2008) refer to this changing self as "the old self" and "new self" as the participants in their study of people with chronic fatigue syndrome referred to an "old life" which was

“like a past life” (p459). Similar themes have been found in studies which have referred to van Gennep’s (1960) concept of the liminal self to explore the rites of passage through transition to living with a chronic condition (Barrett, 1995; Glenton, 2003; Navon & Amira, 2004; Werner et al., 2004). In most studies, however, liminality has mainly been used as a framework to explore and describe the processes of transitioning, rather than deep exploration on the conceptualisation of the self in illness.

The concept of liminality has its roots in the anthropological work of van Gennep (1960, cited in Bigger, 1962), who suggested the lifespan was made up of a series of passages through life events and is also closely linked to transition theory (Kralik, Vesentin & van Loon, 2006). Within the context of identity theory, liminality refers to a stage where participants "stand at the threshold" between their previous way of structuring their identity, which has become invalid as the individual is faced with new characteristics to be incorporated into the self (Turner, 1964). This stage of liminality is often referred to as “betwixt and between”, where the sense of self has become unbalanced and is ambiguous (Barrett, 1995; Turner, 1964). Turner (1964) suggests this phase is a transitional phase where the person is in a “state of progressive movement” to “becoming” a new self (Turner, 1964, p46). In terms of biographical disruption the threshold may be the moment of diagnosis where the individual moves from being a person with symptoms to a person with an identified condition.

It is suggested that liminality may be an “adaptive, enduring phase” characterised by a search for meaning and challenges to identity (Blows et al., 2012, p5). This permits the fluidity of the participants’ biographical narratives to move between old and new self as described by Dickson, Knussen and Flowers (2008). The complicated transitions between the old self and new self and moving beyond can often be compounded by a compulsion to preserve the old self (Charmaz, 1983).

In summary, identity theory has proved to be a significant underpinning theoretical perspective, which has informed the study of the chronic illness

experience to date. Qualitative methodology is the predominant research approach in studies which focus on identity in chronic illness, suggesting the approach has proved useful in developing understanding of this phenomenon. The following section will now discuss the theory of uncertainty as it relates to the illness experience.

### **2.7.3 Uncertainty theory**

Mishel's (1988) theory of "Uncertainty in illness" proposed a four stage model which incorporated antecedents, appraisal, coping efforts and adaptation. Uncertainty surrounding the time of diagnosis and during the process of adapting to living with a chronic illness has been a recurring theme in the literature relating to both chronic illness and MS. Uncertainty is defined as "the inability to determine the meaning of events and occurs in a situation where the decision-maker is unable to assign definite values to objects and events and / or is unable to accurately predict outcomes." (Mishel & Braden, 1988, p98). Mishel postulated that uncertainty pervades all the steps of the process from diagnosis to adaptive adjustment of the new illness into the everyday life of the individual.

Mishel has subsequently developed a measurement tool called the "Mishel Uncertainty in Illness Scale" (MUIS) (Mishel & Epstein, 1990) to quantify levels of uncertainty. This tool has been used in a number of studies in cancer and other chronic illnesses including MS, to study how uncertainty affects the illness experience (Crigger, 1996; McNulty et al., 2004; Ritz et al., 2000).

Ritz et al. (2000) used the MUIS to explore how advanced practice nurse intervention impacted on levels of uncertainty in women, in the two years following diagnosis of breast cancer. This randomised controlled trial compared a group of women receiving the intervention of the advanced practice nurse, with a group receiving standard medical care. The findings suggest that high levels of uncertainty are experienced at the time of diagnosis until six months following diagnosis by both groups. This was

significantly less in the group receiving care from the nurse ( $p=0.043$  at baseline,  $0.043$  at one month,  $0.026$  at three months and  $0.017$  at six months). Levels of uncertainty at 12 months were similar for both groups. The findings suggest not only that the six month period following diagnosis is a time when individuals experience significant levels of uncertainty, but also that advanced practice nurse support may be beneficial in helping to reduce levels of uncertainty and thus improve quality of life (Ritz et al., 2000).

Considering the results of the study by Ritz et al. (2000), which demonstrated a reduction in levels of uncertainty in the short term for individuals receiving nursing support, over a twelve month period this reduced in both groups, suggesting the period of uncertainty subsides without such intervention. Part of the nursing intervention in Ritz et al.'s study was to provide information about the illness and treatment. Information is seen as an important factor in helping individuals improve their knowledge and understanding related to their illness. To date no studies in MS have demonstrated a clear link between support mechanisms such as specialist nurse support and an improvement in uncertainty. McNulty et al.'s (2004) study demonstrates the problem of uncertainty in MS as an on-going feature which is likely to be attributable to the unpredictable illness trajectory; however further research is required to explore the nature of uncertainty in the immediate period following diagnosis of MS. The findings of Ritz et al.'s (2000) study suggest that it is possible to reduce patient uncertainty with specialist nursing support in the period following diagnosis.

A variety of chronic illnesses have also been researched from a qualitative perspective and have highlighted the uncertainty of the illness experience (Asbring, 2001; Asbring & Naraven, 2004; Dickson, O'Brien & Ward, 2010; Eriksson & Svedlund, 2006; Kralik, Brown & Koch, 2001; Lillrank, 2003; Pringle, 2011). The uncertainty of the self was a common theme in a number of these studies which suggests a link between identity theory and the experience of uncertainty (Asbring & Naraven, 2004; Eriksson & Svedlund, 2006; Lillrank, 2003; Pringle, 2011). To return to Mishel and Braden's (1988) definition of uncertainty to consider why uncertainty is an issue of

importance, suggests that people with chronic illness may be struggling in their quest to make meaning of their situation. The unpredictability of the condition may also be a factor in influencing the experience of uncertainty in chronic illness (Kralik, Visten and Van Loon, 2006; McNulty et al., 2004). Uncertainty is an on-going feature of the lived experience of people with chronic conditions, and particularly in those with MS, as they face the constant threat of relapse (Grytten & Måseide, 2005; Johnson, 2003; McNulty et al., 2004).

Chronic illness trajectories have been the subject of continued discourse in the literature with Glaser & Strauss' (1968) "Dying Trajectory" being a seminal piece which has influenced the development of further theories more specific to chronic illness. Corbin & Strauss, (1988) revised Glaser and Strauss' (1968) "Dying Trajectory" theory within the context of chronic illness to contribute an understanding of how illness trajectories influence the illness experience. Corbin and Strauss (1988) propose their chronic illness trajectory both as a theoretical perspective, and as a theoretical framework, both of which have influenced the study of chronic illness to date. The embeddedness of the social context of the individual within the framework is one of its key strengths as the close relationship of the individual with chronic illness and their carer is highlighted as influential in shaping the illness trajectory. Lunney, Lynn, Foley, & Lipson (2003), identified different patterns of decline in an elderly American population, which illustrated condition-specific trajectories. Therefore the experience of chronic illness may be influenced by the condition itself as well as the social context in which the illness is experienced.

The framework has been used to research a number of other chronic conditions such as cardiac disease, cancer, and diabetes, as well as MS, where it has been used to explore the impact of the illness on an individual's social world (Burton, 2000; Miller, 1997; Morse & Fife, 1998; Wiener & Dodd, 1993) The process of adaptation to chronic illness is well described in Corbin & Strauss's (1988) theory, and it combines the both the psychological and physical impact of chronic illness on the individual and their social world.

This has allowed the model to be flexible enough to be applied to a number of chronic conditions as illustrated by the number of studies of different conditions which have used this theory as a framework. Earlier theories have tended to be unidimensional in character or lacking in one or more important aspect in comparison to the Corbin & Strauss (1988) framework.

Further development of trajectory theory has been contributed by Shaw (1999) who proposed a framework for the study of coping, illness behaviour and outcomes. This model links the appraisal of the illness situation with the coping behaviours of the individual. Central to this framework is the assumption that appraisal is closely bound to how the individual copes with an illness and affects their adaptation to living with the illness. Whilst useful in its attempt to expand on previous theoretical contributions, this framework is rather complicated in its attempt to address all of the theories which may be relevant to the study of chronic illness. As such, the framework is overly complex which casts doubt over the relative usefulness of such a framework by healthcare practitioners caring for individuals with chronic illness. Shaw's (1999) work appears to be based on a theoretical construction rather than being the result of empirical work, and it has a dichotomous endpoint of adaptation or maladaptation to chronic illness. Bearing in mind the longitudinal nature of many chronic illnesses which often have exacerbations and remissions, such an end point does not appear to be realistic as each exacerbation causes a new appraisal of the situation. Further development and research based on Shaw's (1999) framework could highlight a more cyclical nature to the experience.

The experience of uncertainty in relation to chronic illness has been well researched and has emerged as an important concept in the study of a number of chronic illnesses including MS. While a number of studies have adopted a quantitative approach, being influenced by the work of Mishel and Braden (1988), a significant number of qualitative studies have also explored this phenomenon which has provided a rich theoretical basis for how we understand the experience of uncertainty in chronic illness. Whilst it may be argued that a degree of uncertainty may be inevitable in people with chronic

conditions, particularly given the unpredictable illness trajectory, the experience of uncertainty has further implications for the psychosocial adaptation of the person to living with the illness. The literature on uncertainty has alluded to the influence on how individuals cope with their condition and the following section will now explore theory relating to coping with chronic illness in depth.

#### **2.7.4 Coping theory**

The majority of studies relating to coping in chronic illness draw on the seminal theory initially developed by Lazarus (1976) and later, Lazarus & Folkman (1984), who described two main ways of coping: emotion focussed coping, where the individual adopts an emotional response to the stress such as vigilance or avoidance; and problem focussed coping, where the individual engages in making changes to the situation to make it easier to manage. Neither is described by Lazarus and Folkman (1984) as inherently good or bad ways of coping, but the literature appears to have evolved to support problem focussed coping as a more adaptive and positive way of coping with chronic illness (De Ridder, 1997; McCabe et al., 2004; Pakenham et al., 1997; Wiener & Dodd, 1993). This may be due to the fact that it is easier to identify and quantify the practical steps individuals take to cope with their condition.

Learning to cope with a new chronic illness has been the focus of a number of studies which have provided understanding of the experience of transition to living with a chronic illness (Dysvik, Natvig, Eikeland, & Lindstrøm, 2005; Stanton & Snider, 1993; Tsay, Lee, & Lee, 2005). Lazarus and Folkman's theory has been used to define the concept of coping and measure the levels of coping in quantitative studies as they developed the "ways of coping" questionnaire which explores the indicators of coping including problem solving, cognitive appraisal, social support, emotional expression and problem avoidance. Each of the items indicates either problem or emotion focussed coping. This questionnaire has been widely used in a number of studies focussed on the experience of chronic illness including MS

(Dysvik et al., 2005; Stanton & Snider, 1993; Tsay et al., 2005). Factors which influence how people cope in times of stress include differences in their personality, knowledge of the situation, and the perception of meaning the situation has for the individual (Callahan, 2003).

In learning to cope with a new illness, the person requires to have the knowledge to be able to recognise symptoms and how to manage them. Symptoms which are distinguishable from other illnesses and recognisable as a threat to health are more likely to receive the attention of the individual and cause them to seek medical help (Mishel & Braden, 1988). Whilst most widely known for the theory relating to coping, Lazarus' works also relate this theory to adjustment, as the two are inextricably linked. Lazarus defines coping as consisting of "cognitive and behavioural effects to manage psychological stress" (Lazarus, 1999, p237). Managing the emotional reactions to chronic illness has been found to be of greater significance in relation to successful adaptation than the physical limitation posed by the illness (McCabe et al., 2004; Pakenham et al., 1997; Stanton & Snider, 1993).

Appraisal of the situation refers to a process whereby the individual absorbs the new information about the illness and its potential impact on their life and evaluates this. Part of the process of learning to cope involves appraising the threat of the illness to the lifestyle and activities previously enjoyed by the individual. The process of appraising the threat of the illness is largely dependent on the perception the individual has of the illness and their interpretation of the health threat posed by the illness (Shaw, 1999).

The role of spirituality has not been addressed in relation to its effect on coping in many studies. However, Brooks and Matson (1982) conducted a qualitative study of 103 people with middle to late stage MS and reported that religious beliefs and faith were beneficial in helping them cope with the illness (Brooks & Matson, 1982). In relation to Lazarus' theory, the use of spiritual approaches to coping may be both adaptive and maladaptive depending on whether the individual uses them as a source of strength and inspiration or is

waiting for miracles and is engaged in wishful thinking. Similarly, a body of literature has identified hope as a coping strategy which helps individuals adapt to life with a chronic illness (Dysvik et al., 2005; Felton, Revenson, & Hinrichsen, 1984; Grytten & Måseide, 2005; Stanton & Snider, 1993; Wiener & Dodd, 1993).

In summary, research related to coping behaviours in chronic illness has been largely influenced by the work of Lazarus and Folkman (1984) and has been researched mainly from a quantitative perspective with few qualitative studies addressing coping. The literature has highlighted links with transition theory, identity and uncertainty theories suggesting these concepts may be symbiotic.

### **2.7.5 Summary of theoretical perspectives on chronic illness**

This section of the thesis has considered the theoretical perspectives that have been of major influence to the study of the experience of chronic illness. From this review it appears that individuals affected by chronic illness may experience multiple challenges. The theoretical perspectives of chronic illness suggest that being diagnosed with a chronic condition signifies the beginning of a transition period to living with the condition. The transition to living with chronic illness is influenced by the uncertainty of the illness trajectory, as well as the individual's ways of coping. Identity theory suggests that the meaning-making related to the situation influences how well the individual adapts to living with the condition. The review of the literature has identified that there are few MS-specific studies, but the review of theoretical perspectives on chronic illness supports the relevance of the concept of biographical disruption to the study of people with MS and their support person whilst acknowledging the influences of transition, uncertainty and coping theories.

## **2.8 Summary and conclusions**

Chapter One provided an overview of MS as a medical condition and framed it within the context of chronic illness, thus highlighting the relevance of chronic illness theory to the study of people with MS. This literature review has provided an overview which includes original research studies, systematic reviews, reviews of literature, case studies, opinion pieces and commentaries which relate to the wider chronic illness literature. Key themes have emerged from the literature in relation to both the individual with chronic illness and the support person. These have included the impact of chronic illness on the individual and their identity, the reactions to living and coping with a chronic condition in everyday life, self-care of chronic conditions and carer burden.

The findings of Bury (1982) and Charmaz's (1983) studies have influenced the study of many other chronic illnesses, including MS, that have highlighted the sociological and psychological impact a chronic illness has on the individual and their support persons. Similar to Bury (1982), Charmaz (1983) viewed the impact of chronic illness as a challenge to the individual's identity. Similar themes have emerged from a number of studies in MS (Barrett, 1995; Finlay, 2003, 2006; Gagliardi, 2003; Mozo-Dutton, Boot & Simpson, 2012; Toombs, 1995). Even in individuals where there are little outward indications of illness, the knowledge of MS causes a degree of re-evaluation. Previous studies have mainly focussed on the perspectives of individuals with advanced MS with the exception of Bury (1982), who interviewed individuals awaiting diagnosis of their illness.

Uncertainty has emerged as an important concept in the study of chronic illness including MS. Uncertainty surrounding the time of diagnosis and during the process of adaptation has been a recurring theme in the literature relating to both chronic illness and MS. Many chronic illnesses are characterised by unpredictable illness trajectory which leads to uncertainty

(Crigger, 1996; Mishel & Braden, 1988). Whilst studies in people with MS have demonstrated that uncertainty is an on-going feature of the illness, to date no studies have explored this experience in the six months following diagnosis. Thus the study of the transition to living with MS in this period is a unique area of study and has the potential to contribute to knowledge and theory relating to how people affected by this condition manage the transition period.

The majority of studies relating to coping in chronic illness draw on the seminal theory developed by Lazarus (1976) (Dysvik et al., 2005; Felton et al., 1984; Stanton & Snider, 1993; Wiener & Dodd, 1993). Ways of coping are inextricably linked to how an individual adapts to life with a chronic illness.

The support person role in chronic illness has traditionally been defined by the physical caring duties required by the individual with the condition. Much of the literature on carers refers to carer burden, the effects of which are multidimensional with physical, social and emotional effects being most apparent (Esmail et al., 2010; O'Connor, McCabe & Firth, 2008). Attention has been drawn to the experience of biographical disruption in people closely affected by a diagnosis of MS, suggesting their identity may be permanently changed as a result of the experience. Most of the studies have been conducted with participants who have a clearly defined carer role, therefore little is known about the impact of MS on the support person in the early months of learning to live with the condition.

### **2.8.1 Rationale for the study**

The literature available suggested that chronic illness is an aspect of health which has a significant impact on health and wellbeing of those closely affected by it. The management of chronic conditions is an area of health care which is seen as a priority due to the demographic profile of the developed world. Previous studies and government policy have tended to focus on the on-going long term care needs of older individuals with

established chronic conditions, but it could be argued that the needs of those who are younger and may be coming to terms with a new diagnosis of chronic illness have largely been less well addressed.

Biographical disruption appears to be a concept which is of particular significance to the experience of being diagnosed with MS. The evidence of the experience of biographical disruption for people with MS is so far incomplete, as it would appear from the literature reviewed above that in undertaking the biographical work, the individual must appraise the impact of the illness on their life. Additionally, there is some ambiguity over whether it is the knowledge of the diagnosis or the level of physical and social limitations as a result of the condition which causes significant disharmony in the sense of self.

Further research is needed to inform the systems of health care provision and theories of caring for younger people and their support persons affected by a new diagnosis of MS, as this is an area of study which has not been adequately addressed to date. This study attempts to address the current gaps in the literature, and contribute to knowledge and understanding, by exploring the experiences of individuals newly diagnosed with MS and their support person during the transition to living with MS. The following chapter will outline the aims of the research and research questions before considering the research approach used in this study.

## **Chapter Three: Methodology**

### **3.1 Introduction**

This chapter provides a discussion of the theoretical underpinning to the methodological approach and methods used in my study. In choosing an appropriate methodology for the study, it was important to consider the aim of the study, the research questions, and how these would best be explored. Newell and Burnard (2006) warn that methodological choices are often based on the preference of the researcher, rather than being selected for the suitability in answering the research questions. Whilst recognising the obvious perils of basing the choice of approach on researcher preference, rather than methodological fit, Newell and Burnard (2006) suggest that this approach does promote completion of research projects which are the focus of student work by engaging the student in work that is of interest to them. This chapter will provide discussion of the chosen methodology and justify the choice in relation to its congruence with the aim of the research thus ensuring the approach chosen is “fit for purpose” (Newell & Burnard, 2006, p22).

It should be stated at the outset of this chapter, that from very early in the planning stages of this study, I considered that a qualitative approach would be most suitable to meet the aim of the study, which sought to explore the experience of transition to living with MS. The biographical impact of the illness on the self, became an important theme throughout the literature discussed in Chapter Two, with much of the previous research suggesting a qualitative approach was suitable for this type of biographical study. Consequently, the study developed a strong sociological focus to it, and the notion of studying the experiences of individuals in their natural setting also supported a qualitative approach.

The purpose of this study was to explore the biographical impact of newly diagnosed MS on the individual and their support person(s) and how this impacted on how the person managed the transition to living with MS.

The aim of this study was to provide an understanding of the biographical impact of newly diagnosed MS on the individual and their support person(s) and how this impacts on how the person manages the transition to living with MS.

1. What impact does a new diagnosis of MS have on how a person views the 'self'?
2. How has the onset of MS affected how the person goes about their daily life?
3. How has MS affected close relationships?
4. How have those affected by MS managed the physical and emotional changes during the transition to living with a confirmed diagnosis?
5. What support have people found helpful / lacking?
6. What are the experiences of MS nursing support and intervention from people with MS and their support person during the initial stages of being diagnosed?

To give background to the choice of research approach, this chapter will begin by outlining the nature of qualitative research and will explore different qualitative approaches with regard to their fitness for purpose for this study. Bearing in mind Newell and Burnard's (2006) suggestion that my choice may be a biased decision based on my preferences, I explored the fitness for purpose of the various qualitative approaches to ensure that the choice I made was based on sound methodological reasons. The chosen approach will then be explored in greater depth and contemporary debates around this approach will be acknowledged.

### **3.2 Rationale for the choice of research approach**

In Chapter Two I considered the main theoretical underpinnings which have informed the study of chronic illness to date. This review highlighted a significant number of quantitative studies which explored concepts related to the illness experience. Quantitative research is influenced by the traditional

sciences and seeks to objectively examine the relationships between variables through measurement and statistical analysis (Parahoo, 2006). Of the quantitative studies reviewed in Chapter Two, survey methods were mainly used to quantify the experience of coping (Fournier, De Ridder, & Bensing, 2002; McCabe & O'Connor, 2012) or uncertainty (Crigger, 1996; McNulty et al., 2004; Ritz et al., 2000; Sullivan, 2001). I reflected that these tools did not embrace the experience of biographical disruption in chronic illness and thus were not suited to this study. I could have considered developing a questionnaire to explore the concept of biographical disruption, but I considered that the development of the questions may introduce bias, as structured questionnaires would not allow for the participant's experience to be communicated in their own words.

Whilst there are a number of validated questionnaires available for the study of chronic illness, I considered their focus too narrow to fully address the research questions outlined above. I therefore concluded that quantitative methods were not particularly suited as the primary method of data collection as I wanted to engage in dialogue with the participants about their lived experience in a way which was truly participant-centred. In addition, the literature review highlighted that for studies exploring the biographical impact of the illness, the predominant approach used was informed by the qualitative paradigm. I came to the conclusion that a qualitative approach would be more suited to the research questions outlined above. The following sections will explore qualitative research methods in depth.

### **3.3 Qualitative research approaches**

Qualitative research approaches have been described as post-modern or constructivist paradigms which have evolved in contrast to the natural scientific or positivist paradigm; paradigms, being a set of beliefs, values and understandings which may be held by a particular discipline (Denzin & Lincoln, 2011). Denzin and Lincoln (2011, p3) describe qualitative research as a "set of interpretive material practices that make the world visible" which use a variety of data collection methods such as narratives, personal

accounts, life histories, and ethnographic methods of observation. Thus, qualitative research predominantly focusses on the experiences of individuals or groups, and takes into account the social, cultural, and situational nature of that experience (Parahoo, 2006). It follows that the human experience and therefore the research data in qualitative research are socially constructed, highlighting the importance of contextual influences in the qualitative research paradigm (Thorne, 2000). Such influences include past experiences, personal and moral values, and religious and cultural beliefs. As human beings who have lived and experienced many things, we are products of our historical journey through life. Qualitative researchers are thus concerned with the thoughts and feelings people have about a particular situation or phenomenon, and the meaning they attribute to this, all the time recognising the contextual influences and subjective nature of the attributed or constructed meaning.

Bearing this in mind, the social history of the researcher is also embedded within qualitative research, although some theories try to impose a reductionist approach to give the illusion of objectivity. My journey as a researcher throughout this study was chronicled in my reflexive diary and where appropriate, is referred to in the thesis so that the role and influence of myself as a researcher is explicit and may be judged by the reader. I believe this also enhances the trustworthiness of my conduct as a researcher throughout this study and consequently adds to the credibility of the thesis.

Qualitative research is a paradigm or worldview which may be understood as an umbrella term to encompass a variety of different qualitative approaches, each with its own epistemological underpinning, leading to a defined philosophical or sociological perspective. The qualitative movement is largely attributed to two main schools; the “Chicago School” which has sociology as the underpinning theory and the “Frankfurt School” which is deeply embedded in philosophy out of which the phenomenological approaches have developed (Denzin & Lincoln, 2011).

The main qualitative approaches include ethnography, grounded theory and phenomenology. Although these approaches all acknowledge the subjective nature of human experience as integral to the theoretical approach, there are a number of assumptions or traditions which relate to each approach which make them distinct. Such distinctions influence the research design and methods of investigation, thus the selection of an appropriate methodological approach is crucial to meeting the research aim. Qualitative ethnography and grounded theory are particularly influenced by the theoretical influences of the “Chicago School”, specifically the theory of symbolic interactionism (Haralambos & Holborn, 2008).

### **3.3.1 Symbolic Interactionism**

Symbolic interactionism is an American branch of interactionism which was founded by George Herbert Mead (1863-1931) in the “Chicago School” (Haralambos & Holborn, 2008). The basis of symbolic interactionism suggests that human thoughts and experiences are socially constructed; that is in relation to self-concept, an individual has an image of themselves which is built up through their experiences, and reinforced or modified by subsequent experiences and social exposure (Haralambos & Holborn, 2008).

### **3.3.2 Ethnography**

Ethnography is a qualitative approach which has its roots in social anthropology, and as such, involves an in-depth study of a particular group of people in their own cultural setting (Newell & Burnard, 2006). The ethnographer seeks to understand the experiences and culture of the “subject” and thus gain understanding of the self. The influence of symbolic interactionism as an underpinning theoretical perspective to this approach is apparent (Denzin & Lincoln, 2011).

Qualitative ethnography therefore requires significant time spent in the social world of the subject, allowing detailed observation to gain understanding (Denzin & Lincoln, 2011). Typically, the ethnographer will use observation and field notes as primary data collection methods (Parahoo, 2006).

Interviews may also be used to gather more in depth data about certain phenomena as they occur. Observation is perhaps the key method which distinguishes the ethnographer, as observing the participants in their natural setting to uncover the social and cultural influences of the group of people is the goal.

Whilst this qualitative approach has been used to research many health and social care issues, the phenomena of interest must be of an observable nature for this to be a viable approach. For example, when considering this approach for my own study, it was hard to envisage how I could apply observation to reveal the essence of the experience of transition to living with MS. I also considered that to spend time with the individual in their social setting would be quite intrusive, additionally the time required to be spent in the field would be considerable, making this a less viable option. I did consider that I could have incorporated observation to the consultations with the health care professionals such as the neurologist, the MS specialist nurse, General Practitioner or district nurse; however this would only provide a snapshot of the interactions during the consultation which would not fully address the research questions of the study. It is also difficult to know how my presence may have influenced this environment.

An ethnographic approach may have been useful if I had been investigating the nature of support from health care professionals (HCP) for people who have been newly diagnosed with MS or the interactions with HCPs around the time of diagnosis. I concluded however that this approach would not meet the aim of my research into the biographical impact of MS during the transition to living with the condition, as the experience is, to a certain extent, an internal experience, not readily observable in the way suggested above. To achieve the aims of the study by using ethnography, I considered that I would have had to manipulate the consultations with health care professionals, which is neither acceptable nor desirable. Indeed many people who have been newly diagnosed with the condition may not avail themselves of any further health care advice or support until the time of their first relapse, therefore this group would immediately be discounted from my

study. Whilst it was still possible that some people in this category may not have wished to participate in my study, my chosen approach did not immediately discount them from participation. Ethnography was subsequently rejected as a possible approach for this study.

### **3.3.3 Grounded Theory**

Grounded theory is an inductive qualitative approach also influenced by the Chicago School. Glaser and Strauss (1967), who developed the grounded theory approach, used symbolic interactionism to inform the theoretical basis of their study from which “Grounded Theory” emerged. The grounded theory approach is used with the aim of generating theory where little is known about a particular topic or phenomenon. A fundamental principle of grounded theory is that the theory is generated from or is “grounded” in the data from the participants. Some differences exist in whether the emergent theory is claimed to be discovered, generated or constructed (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998) but essentially all must be grounded in the data. This approach has been widely used in the study of chronic illness, with Charmaz (2006) being one of the most influential contemporary grounded theorists. She has developed the tradition towards a more constructivist approach, where the experience of the participant is shaped by their social world, therefore it has an ontological stance. This approach therefore would perhaps have been suitable for my study, however I discounted it based on the practicalities of the PhD process which required me to produce a substantial review of the literature prior to data collection. This key step in the research process in grounded theory is traditionally conducted after the data collection to allow the researcher to develop the theory from the data.

Many significant grounded theory studies have become seminal works as they have produced new understandings through theoretical explanations in the area of chronic and terminal illness. Examples of such works include, Corbin and Strauss (1998) Glaser & Strauss, (1968), Kubler-Ross (1972). It is evident that grounded theory has value in researching the experience of transition to living with MS and could potentially have contributed to further

development of the biographical and transitional theories; however a pragmatic analysis of the undertaking must also be undertaken in order to examine if the approach is viable.

The grounded theory approach is characterised by theoretical sampling whereby participants are selected for their likelihood of being able to provide data on a particular topic (Glaser & Strauss, 1967). This sampling approach is used until no new data emerge – a point reached called “data saturation” (Charmaz, 2006). The methods of data collection used in grounded theory, like ethnography, may include; observation, field notes and interviews. The approach can be seen to be quite exhaustive, necessitating a considerable amount of data collection to achieve the desired data saturation. One may question whether this can be achieved in a relatively small and time constrained study such as a doctoral thesis. Indeed, Charmaz (2006) criticises the indiscriminate use of the approach, with inadequate samples which she states results in inadequate data. This, she warns, may lead to incomplete or premature theory generation. To avoid falling into this category I considered that grounded theory may not be an appropriate approach to use even though the theoretical underpinning appears to concur with the aims of the study. Pragmatically it was not justified.

### **3.3.4 Phenomenology**

The word phenomenology comes from the Greek word ‘phainomenon’ which means ‘that which appears or is seen’. Phenomenology is thus concerned with exposing meaning from experiences or situations to make them known. Phenomenology was originally developed as a philosophical approach which has been applied as a model for scientific investigation (Giorgi, 2000). As a research paradigm, it emerged from the naturalistic paradigm which seeks to understand the social reality of the individual and their experiences in the natural setting (Bryman, 2004). Phenomenology is thus concerned with questions of an existential nature, where the contextual world of the individual is important when interpreting the meaning of the data.

Phenomenological research has been particularly popular amongst nurse researchers adopting a qualitative approach, which is perhaps due to the espoused holistic nature of nursing. The use of Husserlian phenomenology by nurse researchers has been heavily criticised by Crotty (1996) and Paley (1997), who believe that many authors have misconstrued the original intentions of Husserl. However in the absence of a theoretical underpinning of its own, nursing has traditionally drawn from other 'borrowed' theories such as positivism, sociological theory and psychology. The basis of Crotty's (1996) & Paley's (1997) critique of nurse researchers' use of the phenomenological approach is that few have bothered to reference the primary writings of Husserl. This may in part be explained as the original writings were published in German and some translations have not been easy to understand or access.

One of the major problems for phenomenological researchers is that in undergoing translation the original meanings may have been interpreted, thus the true meaning of the original text may have been distorted in this process. Whilst this is a legitimate criticism, it is not one which may be easily overcome. In an attempt to address such shortcomings, some authors have referred to the original German texts to provide further discussion and debate on the topic (Fleming, Gaidys, & Robb, 2003). Conversely Koch (1995, p174) suggests that "wrestling with obscure German texts" is not the objective of nursing research, rather an understanding of the arguments surrounding the philosophical underpinnings of the methodology and its traditions, is more appropriate. The emerging body of literature on the topic of phenomenological research provides researchers who do not speak German with a basis for understanding their research approach. It is therefore acknowledged that my understanding of phenomenology has been gained from interpreted texts.

Also of significance is that the original writings of Husserl date back to 1913. It has to be borne in mind that, just as significant advances and developments have been made in technology and sociology which have shaped the world we live in today, the philosophical debate around

phenomenology has also developed in the past century. One could argue that development of the philosophy is both desirable and necessary to meet the changing needs of society and the research environment. Paley (1997) however, does not recognise the value of this and criticises the “tiers” of phenomenology as being problematic to the way phenomenology has been applied in nursing research (p187). Giorgi (1985) has made significant contributions to the development of phenomenology and states clearly that it is a research approach that is no longer applied in exactly the way it was originally presented. Giorgi (2000) suggests that there should be a distinction made between philosophical and scientific phenomenology and offers some suggestions for trying to apply what is essentially a complex philosophy to enable scientific inquiry. Giorgi (2000) dismisses Paley’s critique as ill-informed and in the main unsupported. Similarly Crotty’s (1996) criticisms of Nurse Researchers’ use of phenomenology have also been challenged as being based on a narrow and misinformed view (Darbyshire, Diekelmann, & Diekelmann, 1999).

Nevertheless, the works of Husserl, Heidegger and Gadamer have been particularly influential, with many Nurse Researchers attributing the basis of their approach to one of these authors (Fleming et al., 2003; Lowes & Prowse, 2001). Consideration of the philosophical stances of the works of Husserl, Heidegger & Gadamer will therefore be discussed along with the contemporary debates around the relevance and contribution of phenomenology to nursing research.

The German philosopher Edmund Husserl is widely acknowledged as the founding father of phenomenology (Jasper, 1994; Koch, 1995b; Pascoe, 1996; Schultz & Cobb-Stevens, 2004; Walters, 1995). The underpinning ideology of phenomenology is that in experiencing a phenomenon the person attaches meaning and understanding to it, thus the term ‘lived experience’ is used to describe this (Jasper, 1994). Husserl introduced the concept of ‘life-world’ or *lebenswelt* to describe the lived experience of the individual experiencing it (Koch, 1995).

Husserl's philosophical approach was based on the purity of the research participant's experiences being untouched by the researcher which is achieved through phenomenological *epoche* or bracketing (Walter, 1995). This leads to an epistemological stance where the researcher obtains knowledge from the participants and provides a description of the phenomena from the participant's perspective, thus it is often referred to as descriptive phenomenology. The notion of bracketing has perhaps received the most attention, and as such has become the most significant criticism of Husserl's philosophy as it is interpreted as being steeped in the positivistic tradition, with the notion of objectivity having Cartesian influences (Crotty, 1996).

What must be borne in mind is that Husserl developed early phenomenological theory in a time when the traditional scientific approach was dominant, and as such he pioneered the development of qualitative research in a culture where positivism was the dominant paradigm. Husserl's attempts to apply reductionism and objectivity to his phenomenological philosophy may therefore be understood in this context. Additionally, some researchers who have attempted to use this methodology have criticised Husserl for not providing a clear description of a research method, leaving them to consult further authors such as Heidegger and Gadamer for direction (Sadala & Adorno, 2002). It must be remembered that Husserl's original theory has its grounding in philosophy, rather than being a scientific method of research. Over time it has been used to inform the basis of many sociological and psychological studies, as well as nursing research.

Husserl's particular philosophical approach is still popular with many qualitative researchers, however the practical application of this philosophy to research has been widely debated. Gadamer (1976) suggests that focussing on the epistemological inquiry of how participants experience the phenomenon is pointless, as this cannot be understood in a vacuum, void of the social constructions of the individual. In addition, the objective stance required of the researcher using this approach has been accused of

negatively influencing the development of rapport between the researcher and participant (Lowe & Prowse, 2001).

Martin Heidegger, also of the Frankfurt school, was a pupil of Husserl and developed the phenomenological approach from Husserl's early writings and refuted the central concept of bracketing (Annells, 1996). As an alternative to bracketing, Heidegger explained the position of the researcher in terms of the hermeneutic circle (Walters, 1995). The term hermeneutic phenomenology is thus attributed to Martin Heidegger and is influenced from an ontological perspective concerned with the nature of "*being-in the world*" or "*Dasein*" (Heidegger, 1962, p41). Heidegger acknowledged the influence of context and historical experience of the individual in influencing their sense of *Dasein*. Similarly Heidegger asserted that the researcher and their experiences were integral to the development of the research project from design to analysis, through interpretation and presentation. Heidegger's seminal work, *Being and Time* (1962), is largely attributed as a major developmental stage in the phenomenological method of inquiry (Walters, 1995). Heidegger's work represents a departure from descriptive phenomenology towards interpretive or existential phenomenology. Whilst both descriptive and interpretive phenomenology are still used in qualitative research, the philosophical underpinnings, as well as outcomes of the research are quite different.

Heidegger (1962) explains the influence of the researcher in shaping the research by characterising the phenomena under investigation as necessary for guiding the research study (Heidegger, 1962, p49). Thus hermeneutics presupposes prior understanding of the phenomena on the part of the researcher and recognises the influence of the researcher in guiding and interpreting the meaning of the research (Koch, 1995) interpretation of meanings attributed to situations or experiences, hermeneutics bridges the gap between what is familiar and has gone before, to the new world, relating to the experience or situation.

Like Heidegger, Gadamer rejects bracketing by questioning whether preconceptions of the researcher may be truly set aside by merely adopting an attitude of openness (Gadamer, 1976). Gadamer also acknowledges individuals as historical beings, bringing with them life experiences and prejudices which shape the meaning, interpretation and understanding of new experiences. The hermeneutic circle therefore requires active and sustained engagement with the text by the researcher in order to facilitate deep interpretative analysis which will allow the researcher to move between their own understanding, and preconceptions of the phenomena, towards understanding of the participants lived experience. Thus the fusion of horizons refers to the convergence of the participant's and researcher's vantage points and the researcher's knowledge and understanding of the phenomenon is changed. Knowledge and understanding is then influenced by this process through interpretation and rich description of the phenomena under investigation.

The process of hermeneutic phenomenology requires interpretation of the meaning of the experience or situation so that one can integrate the new experience as part of a new and emerging life-world; a situation referred to by Gadamer as the "fusion of horizons" (Gadamer, 1976). The metaphor of the horizon is described as "everything we can see from our particular vantage point" (Gadamer, p302) with the fusion of horizons describing the range of vision, or understanding from different vantage points. The task of the researcher is to understand the life-world of the participant as he has interpreted it from his horizon or vantage point, so going beyond what is immediately to the foreground and interpreting the meaning of the situation from the participant's narrative (Koch, 1995).

When I considered these aspects closely in relation to my own study, I concluded that bracketing would not be possible, as the aims of my study went beyond description, towards developing an understanding of the lived experience, thus giving my study an interpretive focus. However, orientating myself to be open, in order to allow active engagement with the participants' narratives, required deep reflexive thought to expose my prior assumptions

and prejudices. This reflexive stance allowed me to acknowledge the subjectivity of my interpretations as unique, and understand this process as essential to the interpretative process (Finlay, 2011; Smith, 2003). This constant cyclical process helps to uncover and review the prejudices of the researcher which develop during the process of interpretation (Gadamer, 1989). Gadamer (1989) suggests that it is difficult to objectify one's prejudices as these change constantly throughout the study with the view evolving through an "expansion of horizon" and of the "opening up of new horizons" (Gadamer, 1989, p302). Through a process of interpretation and by adopting a phenomenological attitude, our understanding develops and new prejudices may come to the fore. This allows the researcher to develop "phenomenological attitude" which allows the researcher interact with the participant, being open to new understandings (Finlay, 2011, p 23, Loc 653). Through the process of interpretation, the researcher interacts with the data to uncover hidden meaning and thus their own interpretation of the meaning of the lived experience (Smith, 2007). The position of the researcher and how they interpret the data that is generated is accepted as subjective and integral to the interpretative process (Finlay, 2011; Smith, 2008). The hermeneutic circle is thus central to, and interdependent upon, the development of the phenomenological attitude.

### 3.3.5 The Hermeneutic Circle

The hermeneutic circle involves a dynamic relationship between the researcher and the text and also within the text, as the parts are examined in relation to the whole and the whole in relation to the parts. The cyclical and iterative nature of the hermeneutic process involves a moving back and forth between the constituents of the text and the whole text to allow depth of analysis and the interpretative process to take place. Smith (2007, p5) illustrates the hermeneutic circle in the figure reproduced below.

The Part	The Whole
The single word	The sentence in which the word is embedded.

The single extract	The complete text
The particular text	The complete oeuvre
The single episode	The complete life

Figure One: The hermeneutic circle

Smith (2007, p5) describes the hermeneutic circle as a “dynamic relationship between the part and the whole at a whole series of levels” and asserts that in order to understand the part, one must also have an understanding of the whole. Smith’s figure above (Figure 1) clearly articulates the micro level of the hermeneutic circle which is at the very essence of hermeneutic phenomenological research, however the macro level of the process is less well articulated. In striving for an open, phenomenological attitude as described by Finlay (2011), one must also consider the macro level of the hermeneutic process. The dialogue between the researcher and the text is on-going throughout the research process however, in engaging in on-going reflexive analysis, new understandings are formed and prejudices are exposed. In my study this process was helped through the use of my reflexive diary, and through discussion in my doctoral supervision sessions where my thinking and prejudices were challenged throughout the study. My on-going engagement with the hermeneutic process is illustrated in Figure Two, which I suggest captures the macro level hermeneutic process.

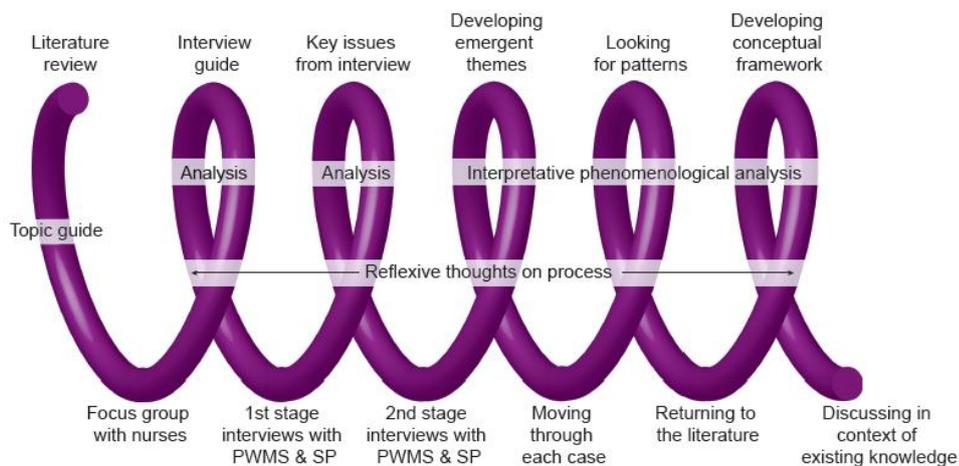


Figure Two: The Hermeneutic Process

This figure demonstrates the on-going dynamic relationship between the researcher and the hermeneutic process. Smith (2007) recognised that hermeneutic interpretation may never be complete and that one may go on forever. However this is neither practical nor desirable and Smith (2007) suggests there comes a point where the interpretation is “good enough” to commit to writing. This point may be understood simply as a stopping off point and that further interpretation is possible. Indeed readers of this thesis will also form their own interpretations. It is in this spirit that the findings of this study are presented as my “stopping off point”, and that further interpretation is required to refine the findings and develop the theoretical framework proposed in this thesis.

When considering an appropriate methodology for my study, hermeneutic phenomenology appeared to be the most appropriate as it adopts an interpretive stance that goes beyond description of the phenomena; thus further understanding of theoretical concepts such as transitional theory could be developed in the context of the person newly diagnosed with MS (Meleis et al., 2000). A hermeneutic phenomenological approach was therefore chosen as the theoretical underpinning for my study as I considered it to be most suitable to meeting the aim of the study and addressing the research questions outlined above. As my study sought to explore the experience of transition to living with MS, the biographical impact of the illness on the self was an important theme giving the study a strong sociological focus.

My research approach therefore has been influenced by the work of Heidegger and Gadamer; however in moving through the research study to analysis of the data I found it necessary to adapt, and considered the work of Smith, Flowers, and Larkin (2009) who developed the interpretative phenomenological analysis (IPA) approach from the earlier works on phenomenology discussed above. In making this decision during the research process it was necessary to reflect upon the implications of the decision, considering the methodological considerations and potential congruence with the conduct of the study to this point. My struggle to find the

path through the research process is not unique and an emerging body of literature on research methodology recognises the need for flexibility (Kincheloe 2001; Warne & McAndrew, 2009).

Recently, the discourse around research philosophy and method has favoured a pragmatic approach referred to as “methodological bricolage” where researchers draw from a range of theories from wider disciplines and approaches to inform the research process (Warne & McAndrew, 2009). The term “bricolage” comes from the French word *bricoleur* which refers to the creative use of resources or weaving together ideas and theory to generate a new way of doing something (Kincheloe, 2001). As applied to research, Kincheloe (2001) suggests researchers draw from a diverse range of theoretical traditions to lay the foundation for their practical application of research theory and are empowered to produce more rigorous studies which provide new insights into sociological phenomena.

The introduction of IPA at the point of analysing the data in my study may then be understood as an example of methodological bricolage. However, as phenomenological studies are often critiqued for their lack of methodological rigour (Paley, 1997) it is necessary to fully explore the convergent methodologies to ensure the philosophical underpinnings are sympathetic to each other. With this in mind, IPA will now be discussed.

### **3.3.6 Background to Interpretative Phenomenological Analysis**

IPA is a relatively recent development in qualitative research and has its roots in philosophical phenomenology with the hermeneutic circle being central to the approach, (Shinebourne, 2011; Smith, Flowers & Larkin, 2009) thus it is an approach that converged with my underpinning theoretical approach which was influenced by Gadamerian hermeneutics. IPA was initially developed in the discipline of health psychology but has more recently been utilised in the wider health and social science disciplines as well as nursing (Angel & Buus, 2011; Flowers, Knussen, & Duncan, 2001; Pringle, Hendry, McLafferty, & Drummond, 2010). As an emergent qualitative

approach, IPA has been considered as having a weak theoretical basis which may over time be developed further (Finlay, 2011). With this criticism in mind, it has been suggested that the strength of IPA lies in the detailed description of the interpretative analysis process given (Smith, Flowers & Larkin, 2009).

The epistemology of IPA is grounded in interpretative inquiry of the narratives of the individual's lived experiences, therefore research questions should be focussed on understandings of experiences and as such be exploratory in nature as opposed to explanatory (Smith et al., 2009). Smith et al. (2009) state that IPA is an approach that is "committed to the examination of how people make sense of their major life experiences" (p1) and as such IPA can be understood as idiographic, as the individual experience and the meaning of that experience is of paramount importance. The IPA researcher is therefore trying to make sense of the participants trying to make sense of their world, with analysis involving the linguistic, affective and physical being, which Smith and Osborn (2003, p51) refer to as the "double hermeneutic", allowing for deep interpretative analysis at the level of the individual.

The idiographic nature of IPA is what sets it apart from other hermeneutic approaches (Finlay 2011). For the IPA researcher gaining an insight into what it is like to experience a particular life event from the participant's perspective is the goal (Smith, Flowers & Larkin, 2009). The researcher's role is to interpret the meaning from the narratives whilst not losing the intentionality of the participant. With this in mind small sample sizes are recommended to allow micro level analysis (Finlay, 2011; Smith, Flowers, & Larkin, 2009). Finlay (2011) also highlights the levels of interpretation which allow importing of relevant theories to aid the interpretation further. However, she warns that any introduction of outside theory must be "because the data invites it, rather than the researchers playing with their pet theory" (Finlay, 2011, Loc 3351).

IPA is an approach to research which could have been adopted from the start of my study as it informs the development of the research questions, use of methods of data collection as well as the focus on the analysis process. I

considered the approach later in the research process, at a point where my data had already been collected. Therefore it was necessary to contemplate how the earlier steps of my research would fit with an IPA approach to ensure the analysis was based on a compatible theory. IPA is grounded in understanding people's experiences and/or understandings of particular phenomena which on the surface appeared to fit well with my study, which sought to understand the biographical disruption in the context of a new diagnosis of MS for those with MS and their support persons.

In order to reconcile the use of IPA in my study I had to ensure that it was consistent with my own presupposition and epistemological stance of social constructionism. Smith, et al. (2009) discuss the congruence of IPA and social constructionism as the approach seeks to uncover the lived experiences of the individual and make explicit the meaning they construct related to the experience within their own social context (Smith & Osborn, 2008). I therefore considered the Gadamerian hermeneutic approach which underpinned the development of my research approach, including questions and methods which led me to developing a very exploratory approach to be in keeping with the IPA approach.

Bracketing or *epoche* was another challenge to reconcile when choosing to use IPA, as this approach, despite being influenced from a Heideggerian perspective, suggests the researchers must bracket presuppositions. I have attempted to bring to the fore my own presuppositions in Chapter Two where I declare my own position within this thesis. However, my own position and the understanding gained from the body of literature as well as the sequential nature of the interviews suggests that, while bracketing may not be fully possible, through on-going reflexivity my presuppositions were highlighted as my understanding developed (See Figure Two). I kept a reflexive diary to help expose and bring to the fore my thoughts, as well as decisions I made in light of these. In reconciling my own position and that of IPA, I considered the position of the researcher in the analysis process which is an interrogative, interpretative phase where the researcher actively engages with the data to extract meaning from the narrative (Smith, Flowers & Larkin, 2009). In

understanding the key role of the researcher and recognising that the interpretation presented in this thesis is one possible interpretation, and others reading the data may pose alternative interpretations, I was satisfied that my own approach could be situated within the traditions of IPA.

Smith & Osborn (2008) suggest that semi-structured interviews are the best method of data collection for IPA studies as they allow the researcher and participant to engage in dialogue with opportunities to probe further where necessary. I had collected the data using semi-structured interviews, either with participants individually, or in coupled interviews with the person with MS and their nominated support person. I used an interview guide with key questions in an exploratory way which led each interview to being individual, allowing the participants to tell their own story. The approach taken in the interviews suggest that my approach is consistent with IPA and is therefore agreeable with the idiographic approach of IPA. Arguably the coupled interviews present a challenge to the ideographic nature of IPA however, in analysing each interview transcript I have considered the themes from each participant as an individual, thus preserving the idiographic approach.

This section has considered the epistemological roots of IPA in relation to the wider phenomenological literature. Situating IPA within the wider phenomenological theory helps to anchor the approach and see it as more than a set of mechanistic steps to analysing data (Finlay, 2011). By considering the key steps in the research process I have demonstrated that the conduct of my research study to date had been consistent with the approaches of IPA. I therefore consider that the guidance on the use of IPA provided by Smith, Flowers and Larkin (2009) could be used without compromising either my approach so far, or the analytic journey ahead. The analysis of data using IPA will be explored in more detail in section 4.11.

### **3.4 Chapter summary**

In this chapter I have provided an overview of the qualitative approaches considered, giving a rationale for the chosen approach of hermeneutic

phenomenology. I have discussed how the approach is congruent with aim of my study and the research questions with regard to their fitness for purpose. I have also considered the epistemological perspectives which influenced my approach to ensure that the choices I made have been based on sound methodological reasons.

The theoretical discussion presented in this chapter has laid the foundations for the choices of research methods which I made subsequently. In the following chapter I will consider the methods of data collection, ethical issues and data analysis process, with reference to the methodological underpinning discussed above.

## **Chapter Four: Research Design and Methods**

### **4.1 Introduction**

The purpose of this chapter is to set out the methods which I used in this study. In doing so this section of the thesis will provide an explanation of the analytical journey I have taken through this phase of my study. I aim to provide a coherent and logical account of the structure and processes which have led me to the selection of the methods of data collection through to interpretation of the data. The chapter begins by examining the ethical issues in this study before considering in detail the methods I used to collect the data for this study; closely examining their congruence to the methodology discussed in Chapter Three.

The theoretical approaches to qualitative data analysis are considered by examining some of the common approaches, before I provide a reasoned argument for the approach used in analysing the data in this study. The steps taken to ensure trustworthiness during this process will be made explicit thus enhancing the credibility of the researcher and the findings presented in Chapter Five.

### **4.2 Ethical Approval**

At the heart of the Research Governance Framework is the need for all research to be independently reviewed by ethical committees to ensure it conforms to ethical standards. With this in mind, this study was reviewed by two ethics committees. I applied for ethical approval from the Faculty of Health, Life and Social Sciences Ethics Committee at Edinburgh Napier University. My study was granted ethical approval in 2006. I also sought ethical approval from the Main Research Ethics Committee (Scotland A, Ref: 06/MRE00/36) but the committee concluded that this study did not require ethical approval on the grounds that it was an evaluation of established practice. It must be stressed in this case, that my study was presented to the ethics committee as a qualitative research study. It has been suggested by

Fontenla & Rycroft-Malone (2006) that researchers perceived ethics committees to be medically dominated with a bias towards quantitative design studies, with some researchers re-labelling their studies as 'audit' in order to bypass the need for ethical approval. However my study was clearly presented as a research study which proposed interviewing patients at a time of potential vulnerability.

Ethical issues in health and sociological research have long been structured around four ethical principles. These four principles are: autonomy, beneficence, non-maleficence and justice (Beauchamp & Childress, 2001). These principles essentially address the individual's right to choose to participate in research (autonomy), the benefit or good to come from the research (beneficence), the individual's right to protection from harm (non-maleficence) and equity and fairness (justice). The Nursing and Midwifery Council (NMC) also state that Nurse Researchers are professionally accountable for ensuring that ethical principles such as autonomy, non-maleficence and beneficence are integral to their practice (Nursing and Midwifery Council, 2008).

A number of guidelines and codes have been produced which address the biomedical ethical principles, outlined above, related to the conduct of clinical trials (International Conference on Harmonisation Good Clinical Practice, 1997; European Clinical Trials Directive, 2001/20/EC 2001; United Kingdom Medicines for Human Use, (Clinical Trials) 2004). However, research in health care is often beyond the scope of clinical trials, therefore additional consideration is required for research which does not relate to the traditional scientific model.

The Research Governance Framework was introduced into the UK in 2001 with a view to improving the ethical conduct of research in health care and thus protecting participants in research (Scottish Executive Health Department, 2006). This is to ensure that:

*“The dignity, rights, safety and well-being of participants must be the primary consideration in any research study”* (Scottish Executive Health Department, 2006, p5).

Ethical issues in qualitative research share many of the concerns of clinical trials in terms of the biomedical principles but it has been argued that the terminology of the biomedical ethical principles is outdated and unhelpful in clarifying the practical application of ethical conduct in research (Green & Thorogood, 2004). The basis of this argument is centred on the fact that biomedical ethical principles emerged from the consideration of ethical issues in medicine, where it is more straight forward to balance the benefits and risks of participation, for example in clinical drug trials. Ethical issues addressed in this chapter will therefore explore the key issues of research governance which are relevant to this study with reference to the biomedical ethical principles. These include ethical approval, informed consent, the risk to participants, and confidentiality and data handling (Scottish Executive Health Department, 2006).

Higginbottom (2004) suggests that ethical issues should not be seen as separate from the research process, rather they should permeate the whole research process. Ethical issues which are relevant to this study will be addressed in detail within this chapter and as they arise throughout the thesis, thus leaving the *‘ethical footprints’* throughout the study (Higginbottom, 2005, p4).

### **4.3 Selection of the research participants**

To explore the experience of the transition period following a diagnosis of MS, I had to consider which participants to select in order to explore the issue in depth. In considering this aspect, I deliberated who was involved in the period around the time of diagnosis. The obvious participant is the person who has been diagnosed with MS and I considered it to be essential to include this group, particularly as the biographical impact of the condition was the main focus of the study. I considered that no other potential

participant could articulate how it felt to be given such a diagnosis. However, through discussion with my supervisors and thinking through the theory, it also became apparent that their support person was also a significant player at this time and that they may offer potentially rich data which would be helpful to understanding the process of transition. I therefore decided to include both the person who had been newly diagnosed with MS and a support person.

Given my initial intentions to explore the support from MS nurses I was still keen to incorporate their views into the study. MS nurses have a specialist remit in providing support and advice to people with MS, therefore I considered that this group of participants had the potential to illuminate the period around diagnosis further. I also considered that data from this group of participants would perhaps give me an insight beyond the theory, of what support people who are newly diagnosed with MS require and as such would add another perspective, allowing me to engage in the process of hermeneutic thought. I conducted a focus group with specialist MS nurses and used the data from the MS nurses to inform the development of the interview guide with the people with MS and their support persons. Therefore, to recruit MS nurse participants to this study, I considered that it was necessary that they had experience of supporting PWMS from diagnosis. This is in keeping with the phenomenological underpinning of the study.

#### **4.3.1 Sampling**

When considering the sampling technique in phenomenological studies it is important to consider the key research questions, as participants must be selected who are able to discuss the phenomena being researched. In studying the biographical impact of MS in the transition period following diagnosis I considered that the participants in my study would require to be newly diagnosed with MS and that the MS nurses would need experience of supporting people at this time.

A previous study which has investigated issues around diagnosis of MS used participants with varying time lapses since diagnosis (Hepworth et al., 2002). This brings challenges to the validity of the study data as treatment and services for people with MS have evolved greatly over the past ten years, therefore the experiences of those diagnosed a long time ago may be vastly different to those being diagnosed more recently. For example, the introduction of disease modifying medications, and the use of magnetic resonance imaging for diagnosis are relatively recent developments in the care of people with MS. To give the study currency to the contemporary healthcare setting, I decided to sample people who have been newly diagnosed with MS.

Initially, I had planned to recruit participants within one week of diagnosis but it quickly became apparent that this short timescale was too challenging to meet. The timescale was then adjusted to being diagnosed within the previous six months with a follow up interview another six months later. In fact, the follow up interviews were completed between six and 12 months after the initial interviews due to me requiring to take maternity leave during the data collection process. Such logistical challenges are well documented in the research literature; the researcher must plan strategies for how to deal with challenges but, most importantly, honesty in reporting the challenges is key to ensuring researcher integrity and ethical conduct (Higginbottom, 2004).

The sampling technique used to select participants in this study was the non-probability technique of purposive sampling. This sampling technique involves selecting participants based on pre-determined inclusion and exclusion criteria (Higginbottom, 2004) and as I had pre-determined criteria (detailed in sections 4.4.4 and 4.4.5) this seemed to be congruent with this type of sampling. However, I also had to rely on staff within the neurology department to screen and approach potential participants for me.

Given that over 180 patients per year are newly diagnosed with MS in the Lothian and Borders area (Rothwell & Charlton, 1998) it became quite

evident that I was not getting as many potential participants as I expected, therefore the sample technique bore some resemblance to a convenience approach with me receiving referrals from staff and then screening them against the pre-determined inclusion and exclusion criteria. I tried to minimise the potential for bias in this type of sampling process by screening each referral against the pre-determined criteria to ensure eligibility before I approached each potential participant, keeping records of all the referrals made to me and the reasons for exclusion. The accuracy of the record keeping in this respect allows my decision trail to be made clear and is auditable.

## **4.4 Access to participants**

Access to the study sites in this study was negotiated through two Health Board Research and Development offices. Management approval was granted for both regions and an Honorary Research contract was awarded for the duration of the study. I also ensured indemnity insurance was available through my professional union.

### **4.4.1 Inclusion criteria for MS Nurses**

Registered nurse

Working in the capacity as a specialist or support nurse in MS

### **4.4.2 Access to MS Nurse participants**

The MS nurses who participated in this study were approached through their national network meeting where I had the opportunity to present my study and ask for volunteers to participate in a focus group interview. The initial contact with the group was in December 2005 when I attended the meeting with one of my supervisors. This initial meeting allowed the potential participants to ask questions and express any concerns. Following a slight change of focus to the study I attended another meeting in 2006 to present the revised study and distribute participant information leaflets. Whilst there was still some concern expressed at my interviewing PWMS at such a vulnerable time in their lives, this meeting gave me the opportunity to talk

about my previous experiences of interviewing terminally ill people, and to a certain extent help to convey my utmost concern and respect for the patient. Even though the MS nurses would not be involved in recruiting the PWMS in the study I felt it was important to reassure them of my integrity as a nurse and researcher. I believe this also had the positive effect of making them feel more willing to take part in the study themselves.

#### **4.4.3 Recruitment of MS Nurses**

At the time of recruiting to the study there were approximately 22 MS nurses in Scotland (including Clinical Nurse Specialists and MS Support Nurses). Participant information leaflets (see Appendix Two) were distributed to all potential participants and they were invited to contact me directly with any further queries prior to participating, although none did so. The focus group with MS nurses took place at their national network meeting in December 2006. Seven MS nurses took part in the focus group.

#### **4.4.4 Inclusion criteria for people with Multiple Sclerosis**

Aged 18 and over

Male or female

Newly diagnosed with MS (within the six months of being diagnosed)

Able to give informed consent

Able to be interviewed by researcher

#### **4.4.5 Exclusion criteria for people with Multiple Sclerosis**

Pregnancy or childbirth within past year (the clinical course of MS is known to be influenced by pregnancy)

Confirmed cognitive impairment

Co-existing chronic illness such as diabetes, epilepsy, Motor Neurone Disease

Previous diagnosis of cancer

#### **4.4.6 Access to persons with MS and their support person**

Following management approval described above, access to potential participants was negotiated with the Consultant Neurologists and outpatient

department Charge Nurses who I saw as the “gatekeepers”. I attended a medical staff meeting to present my study and invite questions and comments from the medical staff in turn asking for their help in recruiting suitable patients. The PowerPoint slides from this presentation are presented in Appendix Three.

I also met with the clinic Charge Nurse, similarly to discuss my study and gain her cooperation in recruiting potential participants. The Charge Nurse was given the information packs to give to potential participants when they attended the neurology clinics to be given their diagnosis. The information packs took the form of a letter of invite and the participant information sheet. I also made a poster for the clinic to post in the consulting rooms to keep my study in the minds of the clinicians (see Appendix Four).

#### **4.4.7 Recruitment of people with MS and their support person(s)**

People with MS who were newly diagnosed were recruited from the Neurology Clinics in East Central Scotland. Each PWMS was also asked to nominate a support person to participate. The aim was to recruit a sample of 10 patients and 10 support persons over a 12 month period. According to a previous study, the annual incidence of new cases of MS in Lothian and Borders region is 12 per 100 000 (Rothwell & Charlton, 1998). Therefore the sample size appeared to be achievable within the given timescale.

PWMS who met the inclusion criteria were informed of the study by the Neurologist in the neurology departments. A verbal description of the study was given to the PWMS by the Neurologist. This discussion was informed and supported by a detailed participant information sheet (see Appendix Five). At this stage the person was asked if they would consider being involved in the study. He/she was assured that whatever their decision, the care they receive would not in any way be affected. If the person declined to participate they were not approached about the study again. If they agreed to discuss participation the Neurologist or MS Nurse asked the participant's permission to give their contact details to the researcher. The person's

contact details were then given to me and I made contact via telephone after at least a 24 hour period, giving the participant time to consider the information sheet provided and in keeping with my ethical framework.

When I telephoned the participant I introduced myself as a researcher from Edinburgh Napier University and confirmed that they had been given the information pack. I invited any questions about the study at this point before ascertaining their desire to participate or not.

Each PWMS was asked to nominate a support person to participate in the study but this was not compulsory. To ensure that the patient's right to confidentiality was not broken, no support person was included in the study without the PWMS's participation. Nine of the participants nominated a support person, mostly these were partners or spouses but in two cases they were the participants' parent. One of the participants chose not to nominate a support person and at the follow up interview one of the support persons declined to take part due to pressure of work and another due to other caring responsibilities.

#### **4.4.8 Reflections on participant recruitment**

The detailed inclusion and exclusion were used to ensure the participants were able to give informed consent and did not have a co-existing adult onset chronic illness. This was important as if participants had previously been diagnosed with a chronic illness they would already have gone through the adaptation process in relation to that illness, therefore the sample would not be homogenous. There is however an exception to this as one participant did have a previous history of a mental health condition. This was reported by the referring consultant as "well controlled" and following discussion with the referring consultant and my supervisors, I decided to include this participant. According to my inclusion criteria I perhaps could have discounted this participant as having a previous chronic illness however inclusion has provided an alternative view of how a physical illness is perceived and accepted in comparison to a psychiatric condition and this is presented in the findings of this study.

As previously stated, I had initially defined 'newly diagnosed' as within one week of having a definitive diagnosis, however the practicalities of applying this criteria to recruitment proved to be problematic. For example, the participants who were diagnosed in the week before Christmas were not contacted and interviewed until early January due to the holiday period and sensitivity of this time of year. Recruitment after the first four participants then slowed causing a further review and discussion with my supervisors. From the time period between March and June 2008 I had no referrals. At this time it was considered prudent to revise the strategy to include people who had been diagnosed within the previous six months.

I contacted the one of the Consultant Neurologists and the Specialist MS Nurse to inform them of the change in recruitment strategy and subsequently obtained a further five referrals, all of whom had been overlooked previously. In reflecting upon the recruitment strategy I perhaps had been a little too idealistic in my aspirations, not acknowledging the competing demands on my clinical colleagues who were doing the initial screening for suitability for me. This is a valuable lesson to be learnt for planning of future studies. On a positive note I had planned additional time into the recruitment phase of the study, having taken on board experiences from previous research where recruitment had been slow; therefore the study was not delayed due to this change in strategy.

Of 13 referrals made to me, one was given the participant information pack but did not contact me, and another two were deemed as unsuitable, as one did not wish to participate which is an important inclusion criteria as one must respect the wishes of the individual to refuse to participate, and another person had been diagnosed seven years previously therefore did not meet the newly diagnosed criteria I had set. Again, the participant who did not contact me after being given the information required a rethink of the recruitment strategy, as information packs were to be given out by the clinical staff and the potential participant was then left to contact me. This strategy was modified to packs being given out to potential participants and

permission gained from the patient to allow the clinical staff to contact me with their details. I then contacted each potential participant a few days later to discuss whether they were interested in taking part. From this, the following referrals were all eligible and agreed to participate.

Although none of the PWMS actively withdrew from the study one participant was uncontactable at the follow up. I considered contacting the neurology department for contact details in case she had moved, but this would have breached her right to confidentiality, as I had assured participants that the department would not be informed about their participation.

One of the limitations of my recruitment strategy was that I am unaware of how many potential participants may have refused to allow me to contact them as I did not ask clinical staff to collect this data. Perhaps in hindsight this would have been interesting to collate and to see the reasons why people chose not to participate, although they may have chosen not to disclose this.

The strengths of the sampling technique in relation to this study were that it ensured the participants had the necessary experience, which was essential for providing a meaningful narrative which could illuminate the lived experience (Holloway & Wheeler, 2002), and that the participants were typical of the wider group of people with MS. Typicality is described by Higginbottom (2004) as important for the findings of qualitative research to be applied to other populations with similar characteristics, thus the results of the study should have transferability to other similar settings. Transferability is therefore considered more appropriate than representativeness and generalisability, terms one would not associate with the methodology of phenomenology.

## **4.5 Informed consent**

Informed consent refers to the process where potential research participants are given information relevant to participation in the study and are then able

to make an informed decision regarding participation (Bryman, 2004). This should include information regarding the benefits as well as risks to participation, along with what their participation would involve (Gerrish & Lacey, 2010). As such, informed consent specifically relates to the ethical principle of autonomy. The Research Governance Framework (Scottish Executive Health Department, 2006) is rather more vague in defining what constitutes informed consent, instead referring to each researcher ensuring that “appropriate arrangements for obtaining consent” are made (Scottish Executive Health Department, 2006, p5). Such appropriate arrangements usually involve satisfaction that a number of key requirements have been fulfilled. These include:

- the provision of adequate written and verbal information which includes a description of the benefits and risks;
- the opportunity to ask questions to the researcher and an independent person;
- the right to withdraw from the study at any time

(Gerrish & Lacey, 2010).

#### **4.5.1 Consent of Specialist MS Nurses**

Following management approval, as described above, I gained permission to attend a meeting of the Scottish MS Nurses Network in May 2006, to inform them about the study and give them the opportunity to ask questions prior to participating in a focus group interview. Letters of invite and information sheets were distributed at this meeting along with my contact details (see Appendix Two). Individuals were encouraged to email or telephone me if they had any further questions. This ensured that if any individual wished to ask a question privately, they had the opportunity to do so, thus respecting their right to confidentiality. The nurses were asked to email me to indicate their willingness to participate. I received seven emails agreeing to participate and no further queries. Prior to commencing the focus group I outlined the aim of the study and offered another opportunity to ask questions before obtaining signed consent from each participant (see Appendix Six). Participants were informed of their right to withdraw from the study at any

time both in the information sheet and verbally. All seven participated in the focus group.

#### **4.5.2 Consent of people with MS and their support person**

Gaining consent from the PWMS and their support person was a more of an on-going process with several stages of consent built in. Process consent refers to the on-going consent to participation and is considered particularly relevant when researchers are engaged in qualitative methods such as interviewing and observation involving participant over time (Usher & Arthur, 1998). Initially participants consented to their details being passed to me. Over the telephone I confirmed verbal consent to interview, and negotiated a suitable time and place for the interview to take place. Written informed consent was obtained immediately prior to participation in the first interview (see Appendix Seven). In keeping with my ethical framework I left a minimum of 24 hours between each step and the participant was informed of their right to withdraw from the study at each opportunity. Consent was re-established verbally prior to the second interview.

Process consent was also considered during each interview as I was attuned to cues from the participants during interviews, which could indicate withdrawal of their consent (Usher & Arthur, 1998). An example of this would be if a participant asked if the interview would be finished soon. This situation did not arise and the interviews came to a natural conclusion.

#### **4.6 Risk to participants**

It is acknowledged that participation in any research study may involve a degree of risk to the participants (Scottish Executive Health Department, 2006). The principle of justice is particularly relevant here, as the fair treatment of participants is of paramount concern. The researcher must consider whether the risks of participation are acceptable, balanced with the potential benefit of the study. The principles of beneficence and non-maleficence are clearly relevant when considering this ethical issue. The Research Governance Framework clearly states that exposure to harm,

discomfort or upset must be kept to a minimum (Scottish Executive Health Department, 2006). In qualitative interviewing, the potential for participants to become distressed is perhaps the greatest risk for participants, whereas in focus groups the potential for confidentiality to be breached by one of the participants is perhaps the greatest risk.

It is recognised that the time following diagnosis of MS is a stressful time for people. Dealing with participants so soon after a diagnosis of MS required the interviews to be handled with sensitivity. Indeed this was one of the key concerns of the MS nurses and the ethical approval documentation highlights “vulnerable” populations as requiring special consideration. Elmir, Schmied, Jackson, & Wilkes (2011), note that much research in health care and nursing specifically focusses on what could be considered “sad” or “sensitive” topics which have the potential to cause upset or distress to participants. I was very aware of this, and had put in place support which could be offered to any participants. Four participants did become tearful and upset during the interviews and in all cases I offered to switch off the recorder and terminate the interview. On each occasion the participant refused my offer, and only wished to take a moment to gather themselves before continuing. Thus my “ethical footprints” were left in this part of my research (Higginbottom, 2005).

Some participants mentioned that the interview process allowed them to get things off their chest highlighting a possible therapeutic benefit to participating in the research. The two extracts which follow highlight what the participants said about the interview.

*I am glad I have spoke to somebody, I feel better myself that I have spoke to somebody.* (Judy, support person)

*[Crying] I don't know. Apart from me falling apart here, it's probably cathartic, or whatever. I am quite resilient.* (Lynne, PWMS)

The possible therapeutic value of research interviews has been well documented in the literature (Elmir et al., 2011; Holloway & Freshwater,

2007). Holloway & Freshwater (2007) suggest storytelling in the qualitative interview may also help participants to develop resilience: as they recount their experiences they develop new understandings. As an experienced nurse with experience of interviewing patients in the palliative care setting for both clinical and research purposes, I had the necessary skills and experience to be able to respond to participants who became upset during the interview with empathy and sensitivity. All interviews were done at a level and pace that participants were comfortable with.

A range of additional support was available for the participants in case it was required. For example, with the participant's consent I would have contacted their GP, MS nurse, community nurse or neurologist to follow up any additional support needs. This issue did not arise, however on conclusion of each interview the participants were reminded of further support available to them, should the interview have raised questions they later pondered on. My contact details were also left with the participant in case they wished to discuss any issues following participation. One participant contacted me following the interview via email, and this was to offer additional information not disclosed at the time of the interview rather than to seek support.

## **4.7 Confidentiality and data handling**

The Nursing and Midwifery Council (NMC) state that nurses are professionally accountable for ensuring that confidential patient information is protected (NMC, 2008). Confidentiality therefore has two elements to it. Firstly the assurance of anonymity is closely linked to maintaining the confidential nature of patient information and secondly the storage and handling of all data which contains personally identifiable details is a major responsibility for the researcher.

Any publications and reports, including this thesis, do not and will not contain any identifiable information to protect participants' anonymity. All participants were allocated participant identification codes to protect their anonymity (Gerrish & Lacy, 2010). It is possible that participants may be able to identify

themselves by the inclusion of excerpts from the interview transcripts but these should not be identifiable to others therefore their anonymity will be maintained.

Data recording and handling was being conducted in accordance with the Data Protection Act (UK Government, 1998) and the principles outlined in the Research Governance Framework (Scottish Executive Health Department, 2006). The audio-recording of the interviews were uploaded onto my computer and then uploaded onto an external transcription service's secure website to be transcribed. The transcription service used is one which is used on a regular basis by researchers at Edinburgh Napier University and they are professionally bound to respect the confidentiality of the material they deal with. On receipt of the transcribed files, I downloaded them from the secure website and deleted any identifying names before saving on my password controlled computer.

On completion of the study all study data will be downloaded from computer drives onto memory sticks and stored with audio files and transcripts in a locked cabinet at Edinburgh Napier University. All data will be treated as strictly confidential. The study data will be held securely until the successful completion of the PhD when all data will be destroyed.

## **4.8 Methods of data collection**

This section details the methods I used to collect the data in this study. Extracts from interview data will be used to highlight key reflexive points as I critique the methods used.

As the data collection in this study was undertaken from three distinct groups, the specialist nurses, and the person with MS and their support person, this required consideration from both a methodological perspective and a pragmatic one for each group.

In considering the philosophical stance of hermeneutic phenomenology, reaching an understanding of biographical disruption in the transition to living with MS required methods of data collection which would facilitate exchange of dialogue between the participants and myself as the researcher. Methods of data collection most associated with hermeneutic phenomenology include methods where the research participants have the opportunity to express their lived experience in their own terms, thus methods such as structured questionnaires, observation and measurement scales are not appropriate and were not considered for this study. Questionnaires have been used in a number of studies which have explored uncertainty with the Mishel Uncertainty in Illness Scale (MUIS) (Mishel & Epstein, 1990) being the most commonly used tool (Crigger, 1996; McNulty et al., 2004; Ritz et al., 2000; Sullivan, 2001). However structured questionnaires would not allow for the participant's experience of biographical disruption to be communicated in a way which was truly participant centred, and thus may have been considered to bias the data. Similarly observation, whilst a valuable data collection method for understanding the context of social settings in ethnographic studies, was not particularly suited as the primary method of data collection to this phenomenological study as I wanted to engage in dialogue with the participants about their lived experience of biographical disruption.

The choice of data collection methods which allowed dialogue between the participants and the researcher was essential to "give voice" to the participants (Larkin, Watts, & Clifton, 2006). This led me to select data collection methods which offered participants the opportunity to engage in open dialogue and to give a narrative account of their lived experiences. Methods of data collection I considered most suited to this approach included focus group interviews and individual interviews. Brocki and Wearden (2006) suggest that both focus groups and interviews are methods which are suited to the aims of interpretative phenomenological analysis. Biographical studies have tended to adopt a qualitative perspective involving interviews suggesting this approach is suited to studies with a biographical focus (Blows et al., 2012; Dickson, Knussen, & Flowers, 2007; Hubbard et al., 2010; McCann et al., 2010; Navon & Amira, 2004; Osborn & Smith, 2006; Werner

et al., 2004). The following sections will consider these methods in more depth in relation to the MS nurses and the people with MS and their support person as well as giving consideration to the issues which arose.

#### **4.8.1 Focus Groups with MS Nurses**

In this study I used a focus group to explore what the MS nurses identified as the support needs of people who have been newly diagnosed with MS and their role in providing support and intervention during the period following diagnosis. In particular, participants were asked to draw from their everyday experiences of supporting PWMS during this time and discuss nature and content of the support activities such as the “newly diagnosed meetings”. The data were used to gain an understanding of the experiences of people who have been newly diagnosed with MS from the MS nurses perspective and this was then used to inform the development of the interview guide for the interviews with the PWMS and their support persons. This process illustrated active engagement with the hermeneutic research process in Figure Two Page 73).

From the researcher’s perspective, focus groups are cost effective as many views can be obtained from one interview. The practical issue of managing to get busy health care professionals together for a focus group was also something I had to consider. The MS nurses, whose locations were geographically diverse, already met regularly four times per year therefore it seemed practical to ask if they were willing to use part of the time at one of these meetings for a focus group. Initially I had presented my study to the MS nurses at their national meeting in order to inform the nurses about the study and access the potential participants. At this time the nurses were encouraged to ask questions about the study. From this meeting I gauged that the nurses appeared to be apprehensive about the motives of the research as they asked many questions about what I wanted to know about their role and how I would expect patients to be able to articulate their role in helping to support them. From this I reflected on how I might feel if a researcher came to investigate the role I had, and understood that indeed this might be threatening if the motives and aims of the research were not

clear to me, so I endeavoured to explain as much as I could about the study without introducing bias. By the end of the meeting it appeared that the initial anxieties were allayed and I had some willing volunteers to take part in a focus group at the next meeting.

The focus group with MS nurses took place at their professional meeting in December 2006. Seven MS nurses took part in the focus group. Typically focus groups consist of six to 12 participants, so they were small enough to be manageable and allow active participation, yet large enough to allow for varying perspectives and focussed discussion (Krueger, 1994). I used a topic guide (Appendix Eight) to ensure that I was able to cover the main issues which related to the aim of my research (Lowe & Prowse, 2001) yet aimed to keep the application of the guide quite loose in order to keep the focus group as unstructured as possible to allow the free flow of discussions between the focus group participants (Smith et al., 2009).

The fusion of horizons is central to the philosophy of Gadamerian hermeneutics, and as previously discussed, may be achieved through engaging in dialogue and sharing understandings. The focus group does appear to be a method which offers this. Krueger (1994, p6) defines a focus group as “a carefully planned discussion, designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment” and is often explorative in nature, informing, research studies, practice and/or policy. Advantages of focus groups are that the interactions between the group members can often stimulate the discussion to facilitate greater depth and a sharing of viewpoints, rather than gaining only one perspective (Kitzinger, 1995). This often helps to clarify similarities and differences between views when participants collectively discuss the phenomena (Bryman, 2004).

The use of focus groups as a means of data collection in phenomenological research is a contentious issue. Some authors argue that from a phenomenological perspective, focus groups present a challenge as this philosophical approach values the unique worldview of the individual, thus

the shared views are not harmonious with phenomenological exploration. Concurring with this view, Webb and Kevern (2001), in their review of qualitative research which has used focus groups, criticise researchers for not providing the essence of the experience from an individual's perspective. It would appear from this criticism that Webb and Kevern (2001) are critiquing from a different philosophical perspective than that of hermeneutics however this is not clearly stated in their article. It could be considered that if I had been using descriptive phenomenology where I was seeking to obtain objective accounts of individuals experiences then this may be true, but I would argue that in using a hermeneutic approach, the focus group allows for the fusion of horizons between the participants to become an active process during the focus group itself and as such is a valid method.

Kitzinger (1995) warns that group dynamics may interfere with open dialogue as quieter members do not engage in discussions as freely as more vocal members. Whilst this was true to a certain extent in the focus group, I found on analysing the transcript that all members participated actively in the discussions which may have been due to the fact that they already met regularly as a group to exchange ideas and information. Trying to achieve equal participation by all group members may have required some manipulation of the flow of the dialogue and whilst this may have been achieved through the use of nominal group technique (Delp, Thesen, Motiwalla, & Seshardi, 1977) I was reluctant to do this as it could have led to a distortion of the data and an upset of the pre-established group dynamics. With this in mind focus groups seemed to be a suitable method of data collection for my study as I wanted to explore with the MS nurses what the common experience of supporting people who are newly diagnosed with MS was.

The focus group interview with the MS nurses provided an exploratory phase to the study with the data informing the development of the interview guide for the participants with MS and their support person. During the interview it became apparent that whilst the MS nurses shared many similarities to their role and service provision there were some considerable differences in

opinion and of the role and service which is delivered to people with MS. However key issues were identified from the focus group interview which established the commonalities of the MS nurse role following diagnosis of the condition. It also highlighted some differences in service provision as well as giving data on what the professional's view of the patient's concerns were at this time. The data from the focus group provided insights which informed the development of the interview guide for the PWMS and the support person interviews (Appendix Nine). Table Three shows the relationship of the themes from the focus group and the interview guide for the interviews with the person with MS.

Themes from focus group	Questions from interview guide related to address research questions
<p><b>Diagnosis event</b></p> <p>Most diagnosis made in clinic setting, with occasional GP. MS nurse not usually present and needs a referral from neurologist or other medical staff Patients not routinely told to bring a relative with them at diagnosis</p> <p><b>Role of nurse</b></p> <p>Support, emotional and informational support Follow up and monitoring symptoms management advice on practical issues such as work, driving and insurance Liaison between hospital and primary care Difficulty in providing support due to uncertainty of condition Provision of support for family and main carer</p> <p><b>Readiness of the individual</b></p> <p>Being a reminder of MS</p>	<p><b>Preamble:</b></p> <p>To begin with I'd like to learn a bit about your journey to being diagnosed with MS. Can you tell me about the events leading to your diagnosis?</p> <p>What did you know about MS at this time? / What did you think having MS would be like?</p> <p>Can you tell me about the time you were given the actual diagnosis? How did you feel / react? (Note: opportunity to explore who gave the diagnosis, setting and offer of additional support.)</p> <p>Did you talk it over with anyone? Who... why etc... What sort of things did you feel you wanted to talk about? (Note: opportunity to explore the person's preferred support person.)</p> <p>Where / who do you turn to, to help with your concerns?</p>

<p>Tentative introduction to support groups</p> <p><b>Lack of resources</b>  Lack of referral resources e.g. OT physio  psychologist  MS seen as poor relation to cancer services</p>	<p>Have you sought any support or help and found it particularly helpful / lacking?</p> <p>Who do you think is your main source of support at this time? (Note: opportunity to explore lay support, primary care etc)</p> <p>If you have access to a MS nurse has that person done anything that has been particularly helpful to you and your family?</p> <p>Is there anything else you think you would like from the MS nurse?</p>
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Table 3: Focus group themes and interview guide for PWMS.

#### 4.8.2 Interviews with PWMS and the support persons.

Interviews are the most common method of data collection associated with phenomenological research and were used on this study (Parahoo, 2006). The advantages of this method include that they allow for active engagement of the participant and researcher in focussed dialogue where the participant recounts their life story as a narrative construction of their experience (Darlston-Jones, 2007). Thus multiple realities can be uncovered through interviewing a number of participants who have had similar experiences. The understanding and meaning attributed by the participants to the experience is modulated by a number of influencing factors including the social and cultural context. Interviews are therefore justified as a data collection method as they are congruent with the ontological stance of social constructionism and biographical research (Darlston-Jones, 2007). Interviews were therefore selected as the data collection method for the people with MS and their support persons.

Semi-structured interviews have the advantage over structured interviews by allowing the researcher to respond to cues in the conversation thus allowing for a deeper exploration of the lived experience of the individual which results in greater understanding through interpretation of the narrative (Bryman, 2004). This approach allows for flexibility as it allows the participant to ‘tell their story’ with only occasional input from the researcher to ensure that the key topics have been addressed. This responsive type of interviewing was sufficiently flexible to cover the main issues contained within the interview

guide but also allow the participants a degree of control over the direction of the interview (Fielding, 1994). A mutual interest in the topic of discussion in the interview is then supported, rather than a more one-sided approach which focusses on obtaining information from the participant and as such is in keeping with the hermeneutic research tradition allowing for a fusion of horizons between the research and participant (Fleming et al., 2003). This approach to interviewing also helped to ensure congruence with the guidance from Smith, Flowers and Larkin (2009) for studies adopting an interpretative phenomenological analysis approach.

An interview guide which covered the main topics of interest was used to guide the interviews but also allow a degree of flexibility to allow the participant to direct the flow of the conversation (see Appendix Nine). The interview guide was informed by the literature review as well as the focus group data from the MS nurses (see Table Three). Each interview began with an opener asking the participant to tell me what had been happening up to the time of diagnosis, thus allowing them to tell their story and relax into the interview. I found that all participants were very forthcoming, requiring little prompting at this stage. This has been referred to as “illness narratives” (Hyden, 1997; Reissman, 1990; Robinson, 1990) or “storytelling” (Koch, 1998) and is considered an effective method in promoting a person centred approach to accessing the lived experience as it allows for the free flow of the person’s experience to emerge in a natural conversational manner (Fielding, 1994). Holloway and Freshwater (2007) also suggest storytelling is a useful method to allow participants to come to terms with difficult experiences as they construct their narrative, thus taking control and being empowered of their situation.

I noticed that the use of the interview guide helped to provide focus and discussion points, but in the early interviews I had perhaps adhered to the guide a little too rigidly. I reflected on the early interviews, noting where I could have probed deeper and noting missed cues and resolved to use the guide more as a reference point, allowing the flow of the interview to be more unstructured and akin to storytelling (Koch, 1998), “giving voice” to my

participants' experiences (Larkin, Watts & Clifton, 2006). As my research progressed I became more confident with allowing the participants to lead the direction of the interview, using the interview guide as a reference point to ensure all the areas relevant to the research aims had been covered.

In qualitative research, particular attention is paid to the possible balance of power in the relationships between the participant and the researcher. It is assumed that the researcher holds power over the participant and that appropriate steps must be taken to reduce such power imbalances (Holloway & Wheeler, 2002). In order to overcome this possible power imbalance I negotiated with participants over a time and venue for the interview to take place that would be mutually convenient, thus giving a degree of control to the participants. Several authors suggest this also helps to shift the power balance towards the participants as they have a degree of control over their surroundings (Holloway & Wheeler, 2002; Parahoo, 2006). I felt it was important to allow participants to choose where to be interviewed so that they felt relaxed and comfortable in their surroundings and so be better placed to engage in the interview process. All of the participants in my study chose to be interviewed in their own homes for both the interviews. This placed me, the researcher, as a guest in their home.

Asbring & Närvänen (2004) suggest that interviewing patients in their own home generally results in interviews that are more open and have greater depth and Hons et al. (2005), favours this setting as it puts the participants at ease and reduces the power imbalances between researcher and participant as the researcher is a guest in the participant's home. The primary participants (PWMS) also assumed a degree of choice over the direction and recruitment of my study as I allowed them to nominate their own support person.

Participants were also given the choice of being interviewed together or separately. Whilst initially it had been my preference to interview the PWMS and their support person individually, as I considered this would facilitate open dialogue and maintain confidentiality, I could not insist on this as

participants were volunteering to take part. Additionally, I also considered myself as a visitor into their homes and as such could not insist on where they should be positioned within their own home. Perhaps this is reflective of my nursing background, rather than my researcher role, however I felt it important to give participants this choice.

As it turned out, five participant couples were interviewed together and the remaining participants were interviewed separately. At the follow up interview I gave the participants the choice again and all but one participant couple chose the same, with one couple choosing to be interviewed together having been interviewed separately the first time. When asking participants' preference in interviewing, those who opted for joint interviews did so by stressing they "had no secrets" and that the MS had affected them both, so it was appropriate to be interviewed together. This is similar to Morris' (2001) experience when interviewing couples affected by cancer, who found that antagonism may arise in individual interviews as the "spectre of secrets" (p 555) is raised by the potential non-disclosure of interview discussions. However, I also found that when interviewing couples together, the support person often prompted the PWMS; sometimes this was prompting to acknowledge the impact of MS on their daily life or other times the prompting was a gentle reminder of key facts, such as dates.

Elliott, Fischer, and Rennie (1999) suggest that multiple perspectives in qualitative research help to provide additional credibility checks, while Forbat and Henderson (2003) highlight the ethical issues of interviewing with two people, such as one participant disclosing information the other wished not to disclose and suggest that these must be considered prior to interviewing two individuals together. In considering the potential conflict of interest which may arise due to the different perceptions of the two people participating in the research study, and the actual phenomenon being explored, it is important to recognise that in narrative interviews, individuals will use the interview process to tell the stories they want to tell, which may differ slightly from the perspective of the other participant or indeed the researcher's focus. This meant that occasionally in the interviews the conversation meandered

away from the research focus, and I went with this for a while to allow freedom of expression, before bring the topic back to the research focus.

Whilst this may appear to be detrimental to the study, differing perspectives of the two people participating is inevitable and not necessarily problematic. For example, when interviewing participants Ruth (P3F) and Brian (SP3M), it became apparent that they each viewed the impact of MS on daily activities differently. This type of situation may put the researcher in a difficult position if alternative perspectives cannot be acknowledged and required careful handling. Forbat and Henderson (2003) also warn of the danger of taking sides in the interview when being stuck in the middle of disagreements.

The couples in the joint interviews discussed openly and frankly with each other their different perspectives. The joint interviews also seemed to “give permission” for the impact of the MS symptoms to be spoken about and shared together. What seemed less apparent in the coupled interviews was any in-depth discussion about the impact of MS on their relationship. Only one couple (Ruth and Brian) alluded to the impact of MS on their intimate relationship, which is obviously an area of sensitive detail, but other than this, the discussions in the coupled interviews mainly focussed on practical day to day issues and experiences and how this affected them.

The individual interviews differed as the participants discussed their own experiences and the relationship with each other in isolation. A few of the participants commented that they had disclosed more detail than they would have done if their partner had been present. This suggests the individual interviews may have added depth to this aspect of my study. One of the limitations is that they did not have each other to prompt in the way the couples did.

Having had the experience of doing both individual and coupled interviews this has allowed me to reflect upon my actual experience, rather than just considering the theoretical arguments. As a learning process in the PhD this has been a valuable experience.

### **4.8.3 Practical issues related to field interviews**

The problems associated with interviewing people in their own homes are poorly documented, however in my experience the interviews were often interrupted by the 'goings on' of daily life. For example I experienced interviewing participants who owned the adjacent kennel, where there were dogs barking continually and phones ringing as it was a home-run business, and an interview being interrupted by the gas boiler man coming to service the boiler. This experience is similar to that of Walker (2011) who stated that she "passively accepted" interruptions to the interview which is also how I felt in the participants' homes.

To have insisted upon complete privacy would not have been practical and would have upset the balance of power. The interruptions however did present ethical dilemmas. Firstly the gas man; although we were in a separate room and the participants were willing to continue when he was working, I was concerned that he may overhear parts of the conversation, thus infringing the participants' confidentiality. On another occasion an interview was interrupted by the participant's gardener and I had to think quickly on my feet as to how to introduce myself. As the participant was also a part-time student I said we were just studying together. The participant later thanked me for not disclosing who I really was.

I also experienced having to travel to quite remote locations which were not available on route planners or satellite navigation, and mobile phone signals were poor. I had to consider this issue in relation to my own safety. I did have concerns about leaving the details of participants with someone as this may have infringed their confidentiality but my personal safety had to be considered. Following discussion with my supervisors and at a research seminar, a practical solution was to let someone know when I was going out to interview and the expected time of my return. I left details of my exact whereabouts in a sealed envelope only to be opened should I not make contact at the agreed time, however this did not occur.

Each of these issues raised ethical and practical issues in the research process. I believe I have handled each issue with pragmatism whilst endeavouring to conduct robust field research within an ethical framework.

## **4.9 Recording of interviews**

All interviews were digitally recorded with the participant's permission and transcribed verbatim. Recording is regarded as being best practice and ensures the rigour of the data collection process but it is recognised that it may also be intimidating for people to have their conversations recorded (Al-Yateem, 2012). Bryman (2004) suggests that to discount potential participants on the basis of refusal to have the conversation recorded may result in loss of potentially valuable information. In practice all the participants consented to recording of the interviews.

I chose not to take notes during the interviews, instead orientating myself towards the participant and their narrative. I felt to take notes would have been intrusive to the interview process. I did however make extensive field notes following each interview, noting aspects such as how I was welcomed, what the dynamics felt like and key issues that were immediately apparent. Sometimes this was done on the digital recorder and later transcribed into my reflexive diary and others I wrote directly into my diary.

During one interview (Ruth and Brian), the recording device failed after 40 minutes of interviewing. I therefore took extensive notes for the remainder of the interview. Whilst I recognise that some of the data may not have been captured from the remainder of this interview, I did manage to write a number of verbatim quotes through the process and wrote up extensive field notes following this interview. In all other interviews the recordings were successful and the process of recording appeared to be unobtrusive to the interviewing process.

For the purposes of accurate interpretation detailed field notes were written up as soon after the interviews and focus groups as possible while the

interaction was still fresh in my mind. Any subtleties of interaction or other factors considered important were noted and taken into consideration later during the process of analysis. This process helped to articulate my role within the interview and with reflexivity.

#### **4.10 Role of the researcher in the interviews**

Prior to commencing the interviewing, I considered my role as a researcher engaged in research with people at a time where they could potentially be distressed and vulnerable. Walker (2011) highlights boundaries between researcher and participant and self-disclosure as key issues for consideration. With this in mind I felt it was morally and ethically prudent to inform participants of my nursing background. Al-Yateem (2012) considered the presentation of the “self” in the context of the researcher, and how we choose to present ourselves has influence on the development of the researcher and participant relationship. I therefore chose to introduce myself as a researcher from the university, with a general nursing background, stressing that I was not a specialist in MS.

I considered that by disclosing my nursing background, the participants may ask my advice or opinion during interviews. This did indeed present during a number of the interviews when participants asked clarifying questions about the information they had been given or asked my opinion or for information about MS treatment. I used my judgement in each situation deciding where it was appropriate to agree with the participant, confirming their thoughts or when to say that as a non-specialist it was beyond my sphere of knowledge. At no point did I offer clinical advice or provide instructional information.

There were also instances where participants discussed their dissatisfaction with the health care system or indeed individual health care professionals. I also had to consider how to deal with negligent practice, if it was disclosed during the interview. Whilst the situation did not arise, it is important to consider this issue in order to conduct oneself in an ethical manner. Should the situation have arisen I would have discussed strategies to allow the

participant to be empowered to deal with it or sought the participant's permission to disclose the information from the interview to the relevant authority. This is in keeping with NMC (2008) guidance on the code of professional practice for nurses. Other sociological researchers may not be bound by such measures. Hewitt (2007) highlights the dual role of the researcher as clinician, also supporting the professional role as overriding the research process.

## **4.11 Data analysis**

The purpose of this section is to set out the approach to data analysis which I used in this study. In doing so, this section of the thesis will provide an explanation of the analytical journey I have taken throughout my study. I aim to provide a coherent and logical account of the structure and processes which have led me to my interpretation of the data. The section begins by examining some of the theoretical approaches to qualitative data analysis, to aid understanding my choices and to articulate my own position. The section will then provide a reasoned argument for the approach used in analysing the data by examining common approaches and providing a rationale for the approach taken. The steps taken to ensure trustworthiness during this process will be made explicit with the aim of enhancing the credibility of the researcher and the findings presented in Chapter Five.

### **4.11.1 Theoretical approaches to analysis**

There are a variety of approaches to qualitative data analysis, each with its own set of theoretical suppositions. In deciding how I would approach the analysis of my data I considered several theoretical approaches, reflecting on how they would complement the theoretical stance of my research, and help me to approach the analysis and answer my research questions. For this study I considered in detail the theoretical approaches to analysis from both grounded theory and phenomenological perspectives. As my study clearly had theoretical influences from both methodologies, this seemed an appropriate consideration to make. Barbour (2008) suggests that it is not how

the data analysis approach is labelled that is important, rather it is how rigour has been demonstrated within the process of analysis. However, in achieving this rigour and satisfying the requirement for theoretical understanding of this step in the research process, it is both necessary and desirable to engage with the theory of data analysis.

I first considered the approaches suggested by Glaser and Strauss (1967), Colaizzi (1978), Giorgi (1985) and Fleming, Gaidys and Robb (2003). What these approaches have in common is that all necessitate becoming familiar or immersing oneself in the data, a state achieved by reading through interview transcripts and listening to recordings several times over. Following this step, the researcher then defines and classifies the themes which are identified from the data. The next stage generally relates to clustering of themes to allow theme categories to be constructed.

The exact nature of the analysis process differs in each of the approaches, as understandably the aim of each is slightly different, with Glaser & Strauss's (1967) aim being to generate or build theory, whereas the others fall short of theory generation by offering rich description of the phenomena with the aim being to advance understanding.

The analysis in grounded theory is founded upon the principles of symbolic interaction which suggest that the sense of "self" is a socially constructed phenomenon composed by individuals interpreting the situation they find themselves in (Barbour, 2008). Thus grounded theory complements the epistemological position of this study by being sympathetic to the theoretical influence of social constructionism.

When adopting a grounded theory approach to analysis, the aim of the analytic process is to generate theory from the shared meanings of the participants developed through exposure to the phenomenon of interest (Morse & Field, 1996). When considering if theory generation is an appropriate aim, Morse (2000) challenges researchers to move beyond seeing their own study as unique and encourages positioning the study within

the existing body of theory and previous research findings. Morse (2000) warns that by failing to do this there is a risk of qualitative researchers not being recognised for making a valuable contribution to science, only adding to what is already known by re-inventing the wheel and thus creating a state of 'theoretical congestion'. In Chapter Two of my thesis I reviewed the current status of literature in chronic illness and highlighted a body of work which has contributed to the theoretical understanding of chronic illness (Bury, 1982; Charmaz, 1983; Corbin & Strauss, 1988; Mishel & Braden, 1988). Therefore my own research had to take a different stance in order to make a contribution to knowledge.

As the focus of my research was to examine the nature of the experience of being diagnosed with MS for the person and their support person, and interpret the meaning of this through the hermeneutic circle, the individual perspective was important to me. To make a contribution to knowledge I aimed to go beyond description and offer an interpretation of the experience of being diagnosed with MS and how this impacts on identity for the participants, based on their narrative and my analysis of the narrative. As a note of caution, the interpretation therefore must be seen as one possible interpretation, and others viewing the data may interpret other meanings from the data (Flowers, Knussen & Duncan, 2001).

Phenomenology shares these underpinning principles as it focusses on how individuals experience the lived world and through exposure, attributes meanings to situations and events (Smith, 2008). Chapter Four explored the phenomenological influences from a Gadamerian perspective which guided the development of my research questions and subsequent research interview guides. Phenomenology, however, was not developed as a research approach, it is a philosophical approach therefore steps to guide the researcher adopting this approach in research have been developed.

Until relatively recently the most common approaches to phenomenological analysis have been Colaizzi (1978) and Giorgi (1985), with Fleming, Gaidys and Robb (2003) gaining popularity within nursing research. Each approach

provides a step by step process to aid the researcher in the analysis process (not necessarily to be followed rigidly). The steps in each are similar, but all appear to assume the researcher knows how to create the themes from the data, with some making frequent references to themes “emerging” as if by some mysterious process. Indeed to the novice researcher this is a mysterious step in the research process and one which created some anxiety to ensure I “got it right”. The lack of detailed guidance as to what each stage actually meant in terms of analysing and interrogating the data was a limitation of these approaches. Fleming, Gaidys and Robb’s (2003) approach initially looked favourable as it was rooted in a Gadamerian approach and suggested each sentence is exposed for its meaning, but on beginning to work with this approach I still found it lacked the detail I was looking for. A note from my reflexive diary illustrates my unease with my developing skill of analysis:

*“I have analysed three interview transcripts now and it seems almost too easy to highlight the key interesting statements and group them into themes. I think I am missing something here. It doesn’t seem quite clever enough. I don’t see where I am being analytic”*

You can see in this extract that I was quite anxious about whether I was missing something, doubting my own ability as a researcher despite having previous conducting qualitative research. I subsequently decided to explore other approaches to qualitative data analysis to see if I could develop a deeper understanding of the process which might in turn help to develop my skill in analysing qualitative data. Through the supervision process and engaging with the wider literature in qualitative analysis I found that interpretative phenomenological analysis (IPA) developed first by Smith (1996) offered the guidance I sought (Smith, Flowers & Larkin, 2009). Finlay (2009) recognises that IPA is a phenomenological method which is helpful to novice researchers, but warns that it should not be seen as a mechanistic tool with no theoretical anchorage. Additionally IPA has been used in a number of biographical studies researching in chronic illness (Dickson et al., 2008; Dickson et al., 2008; Dickson, Ward, O’Brien, Allan, & O’Carroll, 2011)

which suggested a good fit with my own study and congruence with my own “theoretical lens”, therefore I investigated this approach more fully.

As discussed in Chapter Three, a defining feature of IPA is the idiographic nature of the analysis process. IPA advocates analysing each participant’s account respecting the individual nature of that account before moving on to the next case. I found this approach complemented my own intuitive approach to analysis as I attempted not to impose themes and codes from other interviews, instead taking each interview in isolation before comparing across the cases. The process is similar to that of constant comparative techniques in grounded theory research (Strauss & Corbin, 1998) which seems to offer analytical purchase when interrogating the data, as opposed to merely extracting significant statements and assigning themes as I had been doing in my earlier analysis.

The constant comparative method involves a process of coding the data, which can be done either *a priori*, before the analysis is done, thus pre-determining the codes, or *in vivo*, during the analysis, using words which have come from the data (Glaser & Strauss, 1967; Barbour, 2008). The analytic process is focussed on identifying codes within the data, and undertaking constant comparison between data in terms of words or phrases used within the individual stories, and between different narratives and field notes (Strauss & Corbin, 1998). However, in IPA, the process of developing coding is placed firmly *in vivo* so that it maintains an idiographic ontology, often with painstaking analysis of cases (Smith & Osborn, 2008). Smith & Osborn (2008) suggest that themes from each interview may be set aside and each new data set started from scratch to allow the researcher to be open to new themes as they present in the data.

My own approach to analysis has been to try to respect each data set as unique, but by maintaining a reflective journal throughout this process I developed my understanding of the participants’ shared experience, as well as being attuned to divergent cases and new themes. I believe my approach has helped maintain an open stance allowing me to orientate myself to each

participant, recognising where there were similarities and where differences occurred. Importantly, I found that writing up my developing understanding in the reflective journal for each transcript was extremely useful. I believe this helped chart my decision trail as I moved through the analytic process. My approach could be compared to that of writing memos. Birks, Chapman, and Francis (2008) suggest memos are useful for the novice researcher as well as experienced researcher as they help to develop conceptual understanding and abstractions which help to explain the researcher's interpretation of the original data.

#### 4.11.2 The analytic process of IPA

Smith, Flowers and Larkin (2009) identify seven steps in the IPA process (see Table Four). This section provides an overview of my research conduct in relation to the theory for the first six steps. The thesis as a whole may be presented as step seven.

<b>Key steps in Interpretative Phenomenological Analysis</b> (Smith, Flowers & Larkin, 2009)
1. Reading & re-reading
2. Initial noting
3. Developing emergent themes
4. Searching for connections across emergent themes
5. Moving to the next case
6. Looking for patterns across cases
7. Writing up

Table 4: Key steps in IPA process

##### 4.11.3.i Step 1: Reading & re-reading

The first step of analysis using IPA is reading and re-reading the data transcripts. This step is congruent with immersing oneself in the data. As already explained, I had not transcribed the data myself but through listening again to the audio files, and reading through the data transcripts I became

very familiar with the data. After a period of absence in PhD programme, it was useful to repeat this step as there had been some considerable time lapse between collecting the data and analysing it, apart from some early rudimentary analysis. Whilst it could be argued that my time lapse was not ideal, as many qualitative authors suggest data analysis should occur concurrently with data collection, this was borne out of necessity and in fact, proved to be useful as I found returning to the data provided me with a fresh approach, which allowed a more analytical stance.

#### **4.11.3.ii Step 2: Initial noting**

Step 2 involved initial noting, which I found very detailed but also very creative as there are no rules to what to comment on (Smith, Flowers & Larkin, 2009). As I moved through the analysis process and I became more familiar with the process and the data, I found that steps 1 and 2 often merged. During this stage of the analysis I also had the opportunity to attend a workshop on IPA facilitated by Professor Paul Flowers, one of IPA's founding authors. This opportunity provided me with a valuable learning opportunity which gave me confidence in my own analytic ability, as well as the procedural elements of doing IPA. I also had the opportunity to have a short extract from one of my interviews analysed by the group of workshop participants which added further verification of my own themes and codes, thus enhancing the credibility of the process of analysis.

In this step, initial noting includes making different types of comments on each transcript including descriptive comments which help explain interpretative processes and provide a body of comments from which to draw when making the interpretative account of the experience. I found this approach extremely useful in aiding the interrogative process of analysing my data. This was facilitated by asking questions of the data such as: "*what is it like to experience this situation from the participant's viewpoint?*", "*what is the person really saying here?*", "*what is the real issue, the meaning in this extract?*".

Smith, Flowers & Larkin (2009) also suggest examining the narratives from a linguistic perspective to further analyse the meaning of the situation for the participant which has some commonality with discourse analysis. So for example, looking at the use of the personal pronoun in interview transcripts for when participants were describing the impact of MS on the self, did they use “I” or “you”, or considering the emphasis placed on experiences described through the use of repetition and metaphors. Quite often the participants used clichéd terms when referring to how they learned to live with MS, and this may suggest distancing from the actual content of what is being said. For example, “*you’ve got to take each day as it comes*” could suggest that the participant adopts a relaxed approach to accepting MS as part of their daily life, whereas an alternative interpretation may be that the participant’s life is shrouded in uncertainty by not knowing what each day will bring.

The third level of noting is conceptual coding and this is more interpretative, often taking an interrogative form, or a “hermeneutic of suspicion” stance. This process involves personal reflection on the codes to develop the conceptual codes and engages the researcher in active dialogue with the transcript and as such is reflective of Gadamer’s hermeneutic circle, guiding the researcher towards the fusion of horizons from the merging of the participant’s world and the researcher’s understanding and interpretation of that world (Smith, Flowers & Larkin, 2009).

The development of the thematic codes is also part of the conceptual process, where the descriptive notes can be used as source data for this process, the conceptual codes develop this further and codes may then be grouped into clusters with super-ordinate codes emerging through this process. I have provided a copy of an extract from one transcript in Appendix Ten which demonstrates the analytic process described above. This aims to provide authenticity to the process of analysis in my study, as allows the reader to see where the codes have emerged from.

Noting can be done as an interrelated process, however Smith, Flowers and Larkin (2009) suggest that for novice IPA researchers taking each approach to noting the initial codes in turn using different coloured pens to highlight each is a useful approach to develop the researcher's skills in each type of analysis. This was indeed a useful exercise in developing such skills and, as I gained confidence, I found I was able to work through a transcript noting the different types of comments as they arose.

#### ***4.11.3.iii Step 3: Developing emergent themes***

The data set was now larger than the original transcript as it also contained the analytical notes made. This step involves developing themes from the complete data set but places more emphasis on mapping the patterns, relationships and connections from the initial notes of the researcher. Smith, Flowers and Larkin (2009) stress the importance of the interplay between the participants on the researcher here, suggesting the researcher is actively engaged with the lived experience of the participant so that the resultant interpretation is based on the perspective of both. Themes become statements which explain the connection between the participant's transcript and the researcher's interpretation which captures understanding of the experience.

#### ***4.11.3.iv Step 4: Searching for connections across emergent themes***

This step involved mapping themes across the data set looking for similarities, connections, relationships within the data sets. The table of themes presented in Appendix Eleven presents all the themes for each participant and shows how they were mapped to then allow me to see how the themes fit together.

#### ***4.11.3.v Step 5: Moving to the next case***

The whole process described above is repeated for each transcript. As IPA maintains an idiographic ontological perspective, the authors suggest bracketing of the ideas which have emerged from previous transcripts. This is where I have some difficulty with IPA as it does not seem consistent with the approach of Gadamerian hermeneutics which reject the notion of

bracketing, instead embracing the active engagement of the researcher and their developing understanding as part of the process. Indeed, it is also at odds with the suggestion of the authors of IPA themselves who support the notion of hermeneutics. However, the case by case approach I believe is useful and I attempted to expose my developing understanding by making notes on my developing understanding before moving on to the next case. This standpoint embeds the subjective nature of the analytical process of my study and demonstrates my active engagement in the hermeneutic circle (see also Figure 1, p92). Thorne (2000, p68) refers to this standpoint as the “theoretical lens” of the researcher which is important in the analysis phase.

#### **4.11.3.vi Step 6: Looking for patterns across cases**

This step involved mapping themes across the data set looking for similarities, connections, relationships within the data sets. Through a process of abstraction I identified the patterns of themes, clustering similar themes together and developed new names for each cluster which captured the essence of the theme and developed a new super-ordinate theme category. Smith, Flowers and Larkin (2009) suggest it is also possible that one of the initial theme categories will become a super-ordinate theme if it captures the essence of the other themes in the category, a process they refer to as subsumption.

Polarization is used by Smith, Flowers and Larkin (2009) to refer to a process of analysing the data for divergent cases, where data within a theme may illustrate polarisation of experiences within. For example, in my data the image of the wheelchair in MS and the prospect of using a wheelchair was viewed differently by the participants, with some being horrified at the prospect of using a wheelchair and others seeing this as a positive aid which helped to promote their independence.

Given that I selected participants with MS and their support persons to be interviewed, the IPA method allowed me to examine the data for similarities and differences in how MS is experienced from each of the participant’s perspectives. Since I had given the participants the choice of being

interviewed individually or together, the different combinations of data sources presented challenges for the analysis process but also had advantages as the multiple perspectives of the experience were exposed. The difference in interviews was also interesting as the couples who were interviewed together prompted each other at times during the interview, arguably revealing more than they would have if interviewed separately, but those who chose to be interviewed apart also reported telling me more than they would have about the effect on their relationship, had they been interviewed together. The benefit of having the different perspectives of the same phenomenon offered triangulation which allowed the development of a more detailed account. Elliot, Fischer and Rennie (1999) also suggest that multiple perspectives in qualitative research help to provide additional credibility checks.

## 4.12 Credibility

Establishing credibility in qualitative research is fundamental to enhancing the rigour and therefore trustworthiness of the study. This is also congruent with the guidelines for publication of qualitative research by Elliott, Fischer and Rennie (1999) who suggest that by providing one's own theoretical and personal influences in advance and as they present throughout the study, readers can evaluate the researcher's interpretation of the data and also consider that there may be alternative interpretations (see Table Five below).

<b>Guidelines for Qualitative Research</b> (Elliott, Fischer & Rennie, 1999)
1. Owning one's own perspective
2. Situating the sample
3. Grounding in examples
4. Providing credibility checks
5. Coherence
6. Accomplishing general v's specific research tasks
7. Resonating with readers

Table 5: Guidelines for Qualitative Research

#### **4.12.1 Owning one's own perspective**

Through situating myself in the study in Chapter One I have declared my advance understandings. Declaring my emerging understanding and how this influenced the process of my research has been in part achieved through the keeping of a reflective journal, which often took the form of notes in texts, analytical notes against the interview transcripts as well as more formal reflection in the journal itself. The process of supervision and the various opportunities for progress review during the PhD also provided opportunities to think reflectively about my study and my own developing understanding.

#### **4.12.2 Situating the sample**

A description of the study participants has been given Chapter Five with a summary presented in Tables Six and Seven (page 131). This information provides background information on the gender, age, and relationship status of each participant and when the interviews took place in relation to time since diagnosis. The context of the study has also been outlined within this chapter. This information has provided the context to situate the sample of this study in relation to the guidance from Elliott, Fischer and Rennie (1999).

#### **4.12.3 Grounding in examples**

I have provided a copy of an extract from one transcript in Appendix Ten which illustrates the analytic process I undertook and my interpretation of the data. The examples which are presented in Chapter Five to support each theme provide further examples to support the analytic process. These measures aim to provide authenticity to the process of analysis by allowing the reader to see where the themes have emerged from.

#### **4.12.4 Providing credibility checks**

Elliott, Fischer and Rennie (1999) suggest several ways a researcher may provide credibility checks and these include using multiple qualitative analysts and comparing more than one qualitative perspective. I was fortunate to be able to attend an IPA workshop run by Professor Paul Flowers at Glasgow Caledonian University where 18 participants analysed a

small section of one of my interviews. Whilst it is acknowledged that this was a very small sample, it was a very useful exercise which highlighted the congruence of my own analysis and provided additional insights into the data and the use of IPA that I had not considered. In addition to this through the supervision process my supervisors also oversaw the majority of my transcripts with annotated analytic notes and probed deeply at supervision sessions.

The inclusion of both the person with MS and the support person provided the different qualitative perspectives which allowed comparison to assess the credibility of the data. I did not conduct member checking as I considered that the disruption to the sense of self may not always be within the consciousness of the individual. However I offered each participant a copy of the transcript for their own record, but all participants declined this offer which suggests that member checking may not have been welcomed.

#### **4.12.5 Coherence**

In Chapter Six I provide a summary of the findings within the conceptual framework which has been developed from the data on this study. The conceptual framework presented in this thesis provides a new understanding of the experience of being diagnosed with MS, and the implications for the sense of self for the individual, and their support person. In keeping with Elliott, Fischer and Rennie's (1999) principles of good practice, I also provide a narrative description of the framework.

#### **4.12.6 Accomplishing general vs specific research tasks**

Elliott, Fischer and Rennie (1999) warn against overstating the claims from the findings of IPA studies. Within this study I have highlighted the number of participants and interviews conducted along with the geographical context. This allows the reader to consider the findings of this study within the context of their own practice setting. No claims are made for wide generalisation of the findings from this study. Acknowledging these limitations as well as the

other limitations highlighted in Chapter Seven aims to address this element of Elliott, Fischer and Rennie's (1999) guidance.

#### **4.12.7 Resonating with readers**

In this thesis I have attempted to provide a rich description of the experience of the participants and to have provided an interesting and informative read through the thesis. It is for the reader to judge if the result has engaged their interest, or left them cold, as described by Elliott, Fischer and Rennie (1999).

### **4.13 Chapter summary**

This chapter has addressed the research design and methods adopted in this study, justifying the approach and methods used and has provided a critical appraisal of the methods which has drawn from published literature and the experience of conducting the research. The qualitative approach of phenomenology has provided the philosophical underpinning of this study which is grounded in the social constructivist perspective of the researcher. The chapter has provided justification for the methods used in the study, whilst acknowledging their strengths and limitations. I have provided a transparent account of the decisions made during the study thus providing a detailed audit trail (Koch, 2006).

Key ethical issues outlined in the Research Governance Framework (Scottish Executive Health Department, 2006) which are pertinent to this study with reference to the biomedical ethical principles have been discussed with reference to the conduct of the research and consideration for the research participants. The practical steps taken to address the ethical issues in this study have also been discussed in this chapter. However, as Higginbottom (2005) suggests that ethical issues should permeate the whole research process, additional ethical issues have been addressed throughout the thesis, thus leaving "*ethical footprints*" throughout the study (Higginbottom, 2005, p4).

The process of data analysis has been discussed in some depth, paying particular attention to the congruence of the research methods with the IPA approach (Smith, Flowers & Larkin, 2009). The following chapter will present the findings of the study using the theme headings which have emerged from the analysis process.

## **Chapter Five: Findings**

### **5.1 Introduction**

In this chapter I present the findings from my analysis of the interview data from the seven specialist MS nurses, the ten individuals who were diagnosed with MS and the nine support persons. The focus group interview with the MS nurses provided an exploratory phase to the study with the data informing the development of the interview guide for the interviews with the participants with MS and their support person. This chapter outlines the key themes from the focus group and explains how this influenced the development of the interview guide.

As described in Chapter Four, of the ten people with MS (PWMS), nine were interviewed twice, the second interview taking place six months to a year following the initial interview. The follow up interviews allowed a deeper exploration as to the participants' perceptions of the impact of MS and the meaning MS had for them as individuals. The initial interviews allowed for preliminary analysis and key aspects to be followed up during the return interview. This iterative process necessitated on-going active engagement with the hermeneutic process which is illustrated in Figure 1 (p92).

The process of analysis for the persons with MS and the support persons followed the principles of interpretative phenomenological analysis (IPA) and has been described in detail in Chapter Four (Smith, Flowers & Larkin, 2009). This chapter presents my interpretation of the interview data and is presented with extracts from relevant participant interviews to help to illustrate each theme. I have supported the findings in this chapter with a detailed account in section 4.11.3 of Chapter Four of how each theme was constructed, thus providing a clear audit trail of the steps involved and the decisions I took during the analysis and development of themes. All participants have been given a pseudonym to protect their anonymity.

The findings from the analysis of the interviews with PWMS and their support person are presented in sections 5.3 to 5.5 of this chapter. As IPA demands an ideographic approach to the analysis of data, combining the data from the two participant groups may seem at odds. However, the shared experience of being diagnosed and the disruption to the individual's sense of self gave rise to similar themes emerging from both participant groups. As explained in Chapter Four, the data from each participant were subject to individual analysis in order to ensure the uniqueness of the perspectives of the different participant groups was preserved (Smith, Flowers & Larkin, 2009). I judged this to be important as I had interviewed some of the participants together in paired interviews. Whilst there were shared themes, the idiographic approach afforded by the use of IPA also highlighted some themes which were unique to each participants group. For example, the "anticipatory carer" theme was relevant to only the support persons.

## **5.2 Key findings from MS nurse focus group**

The process of analysis for the specialist nurse focus group adopted a thematic approach to identify the commonalities of the MS nurse role following diagnosis of the condition, as well as providing data on the professional's view of the patient's concerns at this time. Four key themes emerged from the focus group including; "*the diagnostic event*", "*the role of the nurse*", "*readiness of the individual*" and "*lack of resources*". The findings from the analysis of the focus group with the MS nurses are presented in the following sections.

### **5.2.1 The diagnostic event**

The focus group began with an open discussion about where people with MS were generally given their diagnosis, and which health care professionals were involved. The discussion revealed that, in most cases, people were told of their diagnosis in the neurological clinic by a neurologist, but occasionally this may happen in the inpatient setting, either in specialist neurology wards or general medical wards. One participant reported that occasionally the

patient's general practitioner (GP) would be sent a letter and they would inform the patient of their diagnosis. The data also suggest that the actual practice of delivering the news may be variable, as different specialities may handle breaking the news differently. The data in the following extract highlight that whilst the diagnosis is usually communicated to the patient by a member of the medical profession, the setting and clinical background of the clinician may vary.

*“The clinic that they are given the diagnosis at might be a general medical and then they are referred to a general physician and he's the one that puts them through their tests and often gives them their diagnosis and then refers them on to the specialist. Other times they come to the neurologist first of all or to our specialist consultant as well.”*

(Nurse, 2)

The experience of the person telling the patient about their diagnosis may be significant, particularly if the patient has questions about MS that they would like to ask. Additionally, where the person is not experienced in MS, referrals to the MS nurse may be missed as the following extract highlights:

*“Our area has quite a number of neurologists and not all of them specialise in MS so I always usually get a referral if the person specialises in MS and the person diagnosed lives within my area. Sometimes even though I've written to each neurologist and said that I'm there covering that health board area sometimes the referrals are missed.”*

(Nurse, 1)

The focus group participants also highlighted that patients were not routinely invited to bring a support person along to the consultation in the clinic setting. Often the patient attended alone. This means that once the person has been told they have MS they then have to make their way home or to work alone. For some people this may be exactly what they wish for, but for others it is

reasonable to assume that the support of a friend or relative may be welcome at this time. Data presented in section 5.4 from the interviews with PWMS highlight concerns about this.

### **5.2.2 The role of the nurse**

The theme of the role of the nurse emerged as there was a lot of discussion around their role in providing support around the time of diagnosis. The participants in my study were in broad agreement that they were not routinely present at diagnostic consultations; rather, they received referrals from the neurology consultants for follow up. However, one area provided a “one stop clinic” where the person may be diagnosed and see a number of different specialists at the same clinic on the same day. In this clinic the specialist nurse was present at the diagnostic consultation in order to provide support immediately after.

*“I’ll sit with the consultant and they get their diagnosis and then I’ll take them and talk to them at greater length after that.”*

(Nurse, 2)

The support role of the nurse is evident in this extract; however, the support role extends beyond the initial diagnostic event to providing support in the early stages, covering a range of aspects such as information about MS, to insurance advice and how to deal with telling family and friends including children about the condition. Being able to tailor the timing and amount of information to each individual was seen as particularly important for people who are newly diagnosed.

*“There’s just a very huge wide range of needs that people have when they’re newly diagnosed and I think our role is to try and gauge how much they need, when they need it and to form the relationship that means they’ll come back for more.”*

(Nurse, 5)

This extract highlights the importance of being person centred, in order to form a therapeutic relationship with the person with MS so as to know when to offer support and when to provide information. Having the time to spend with patients was seen as an important factor in developing a therapeutic relationship:

*“We have the time to listen whereas the GP only gives seven minutes or whatever and a double appointment only gives them 14.”*

(Nurse, 7)

One factor which may block the development of the therapeutic relationship is that some of the participants suggested that people who are newly diagnosed did not wish to see them as they were a reminder of their diagnosis.

*“If they’re keeping well, just seeing an MS nurse just reminds them that they’re ill.”*

(Nurse, 1)

This section has highlighted variable practices around the time of diagnosis. The role of the nurse in this section highlights the support role of the MS specialist nurse. The data highlight some of the complexities of engaging with people who are newly diagnosed with MS, suggesting that skilled and experienced judgment is required to determine how best to support each individual.

### **5.2.3 Readiness of the individual**

The readiness of the individual refers to the data which alluded to the nurses’ suggestion that some participants were not ready for certain steps following diagnosis. A good example of this was whether people should attend a six week course for people who have been newly diagnosed with MS. There were differing perspectives on whether people should be advised to attend the newly diagnosed support groups, with three participants stating they did

not advise their patients to attend. One of the participants explained why in the following extract:

*“I would never advise anybody who is newly diagnosed to go to a support group because you’re seeing people at different stages and they might not be ready for to see that...”* (Nurse, 3)

However, not all the nurses were agreed on this and some of the specialist nurses were involved in planning and facilitating such courses. This does reflect quite a differing approach to the provision of support for people who are newly diagnosed. The data from the people with MS in section 5.5.3 also highlight the experience of attending the newly diagnosed group from their perspective.

#### **5.2.4 Lack of resources**

A lack of resources was a source of frustration for the participants in the focus group, with a general feeling of neurological services receiving less funding than other services such as cancer:

*“Cancer services have so much they can access and have got such teams nowadays, they even have finance they can access. We have nothing for chronic conditions.”* (Nurse, 3)

The interface between health and social care appeared to heighten the delay when requesting resources for patients. The participants described instances where they have referred to other health care services such as occupational therapy and community based services and have experienced long delays.

*“...often people need something right there and then it may be for just a short while but they still need it there and then and not six weeks down the line when their referral finally takes place.”* (Nurse, 5)

This often resulted in the specialist nurse being the liaison person advocating on behalf of the patient to get the resources they need.

*“Sometimes you’re advocating on behalf of the person for services that they should be having or need to be having but there would be difficulty in pushing for themselves.”* (Nurse, 2)

The number of specialist nurses available also was perceived as a problem. There was some discussion with several participants around the recommended number of patients to nurses, with some having far in excess of the recommended number but this was not universal. One participant highlighted the link between the service they can offer and the case load they carry:

*“The more nurses you’ve got working with a client group the more you offer them and the more service you give.”* (Nurse, 3)

With one participant reporting a case load of 750 patients and others being nearer to the recommended 300, it is easy to conclude that some nurses will have more time to spend with their patients and act on their behalf than others.

This section has highlighted the perceived limited human, material, and financial resources that may influence the experience of being able to provide support for people newly diagnosed with MS. The nurses’ role within this is identified as liaison and advocate, lobbying on behalf of people with MS to get the resources and services required.

### **5.2.5 Summary of findings from the MS nurse focus group**

The data from the focus group provided insight from the specialist nurse perspective, which has highlighted a number of challenges in providing support to people affected by a new diagnosis of MS. During the focus group it became apparent that whilst the MS nurses shared many similarities in

their role and the service provided to PWMS, there were some differences in opinion and of the role and service which is delivered to people with MS. However, key issues were identified from the focus group interview which established the commonalities of the MS nurse role following diagnosis of the condition. It also highlighted some differences in service provision around the time of diagnosis.

The data from this part of the study were used to inform the development of the interview guide for the PWMS and the support person interviews. This is presented in table format in Appendix Twelve. The remainder of this chapter will now focus on the findings from the interviews with the PWMS and the support persons.

### **5.3 Key findings from the PWMS and the support persons**

This section of the thesis will present the findings from the interviews with the PWMS and their support person. The data from the interviews are presented in an anonymised format which is in keeping with ethical guidance for qualitative research. A participant identifier was used to anonymise the participants in the data files. These identifiers were codes which indicated if the participant was a person with MS (coded as "P") or a support person (coded as "SP"), the chronological number of recruitment, and a male or female identifier. Pseudonyms were given to each participant to personalise the qualitative data in the findings and discussions of this thesis. The table of participants is presented below.

PWMS Participant Identifier	Pseudonym	Age	Support person Participant Identifier	Pseudonym	Age bracket	Relationship to PWMS
P1F	Julia	25	SP1M	Richard	25-30	Partner
P2M	Billy	35	SP2F	Jean	50-60	Mother
P3F	Ruth	42	SP3M	Brian	50-60	Partner
P4M	Steven	36	SP4F	Judy	30-40	Partner
P5F	Sheila	34	SP5F	Maggie	50-60	Mother
P6F	Janice	42	SP6M	Allan	40-50	Partner
P7F	Lynne	49	SP7F	Pearl	70-80	Mother
P8F	Lorna	40	SP8F	Nic	30-40	Partner
P9F	Eileen	45	SP9M	Danny	40-50	Partner
P10F	Nancy	44	None			

Table 6: Participant details

The PWMS and their support person were interviewed at two time points in this study; the first being between two weeks to seven months from the time of diagnosis and the second six to twelve months later. Chapter Four described the sampling and recruitment process in detail. The timing of the interviews for each participant is detailed in Table 7 below.

Participant number	Pseudonym	Length of time since:		
		Symptoms diagnosis to	Diagnosis to 1 <sup>st</sup> interview	1 <sup>st</sup> to 2 <sup>nd</sup> interview
P1F	Julia	9 weeks	9 weeks	6 months
P2M	Billy	3 years	4 weeks	8 months
P3F	Ruth	7 years	4 weeks	6 months
P4M	Steven	7 years	3 weeks	6 months
P5F	Sheila	9 months	2 weeks	Lost to follow up
P6F	Janice	20 years	4 months	7 months
P7F	Lynne	3 years	7 months	4 months
P8F	Lorna	6 months	5 months	4 months
P9F	Eileen	3 years	2 months	12 months
P10F	Nancy	2 months	1 month	12 months

Table 7: Timing of interviews from diagnosis

Whilst it may be argued that the differences in the timing of the interviews may present difficulties in understanding the data (Flowers, 2008), the transition to living with chronic illness is not a scientifically timed event, therefore I would argue that the interviews which were conducted with a greater time difference allowed the participants to have more time to consider the diagnosis and make meaning of their lived experience. Flowers (2008) highlights a number of issues with multiple interviews but considers that they

may contribute to helping to establish rapport between the interviewer and interviewee, as well as offering the potential to add to rigour, as data from initial interviews may be confirmed or refuted.

The three superordinate themes which emerged from the interview data are presented in the following sections of this chapter. It is worth noting that each of the superordinate themes has a number of sub-themes and related themes which were grouped together into one major theme (see Appendix 11) but all had a cross cutting theme of the impact on the self. To be classified as a superordinate theme, the theme occurred in at least half of all of the participants' interviews. The three superordinate themes are: *“road to diagnosis”*, *“the liminal self”* and *“learning to live with MS: an uncertain future”*.

## **5.4 Road to diagnosis**

The title of this particular theme reflects the notion of a journey towards the moment of diagnosis. As the research was focussed on the biographical impact of the diagnosis of MS, I invited participants to start each interview by telling me their story of being diagnosed and this emerged as a defining moment for them. All the participants interpreted this as telling me their story of the time leading up to and including being diagnosed. As a result it was not surprising that this theme was the most common theme and was present in the data from all the participants.

Along their journey, the participants had different experiences in terms of the impact of symptoms and levels of engagement with health care services. All the participants had a period of time prior to diagnosis, when they wondered what was causing their symptoms. For some participants this time period extended over many years, from a first episode of symptoms which had not been given a conclusive diagnosis, to other participants who had been diagnosed within a few weeks of their first episode of symptoms. Regardless of the timescale, there was a period of time for all participants where symptoms were experienced prior to a confirmed diagnosis of MS. Three

major sub-themes were identified in this superordinate theme. These were: “knowing one’s body: knowing one’s self”, “being diagnosed: crossing a threshold” and “a shared journey”. Table 8 below illustrates sub-themes and clustering which lead to the development of the superordinate theme. Each of the intermediate themes will now be discussed with supporting interview extracts.

<b><i>In vivo</i> themes (free coding)</b>	<b>Intermediate theme</b>	<b>Superordinate theme</b>
Relief at diagnosis Knowing why Stress of not having a reason for symptoms Comfort in knowing	Being diagnosed: crossing a threshold	Road to diagnosis
<i>Looking for an answer</i>		
Information seeking		
Horrified at prospect of MS		
Arousing suspicions		
Pre-warning of diagnostic consultation		
Validation that something is causing symptoms		
Re-evaluating what is important to one’s self		
<i>This is something serious</i>		
Uncertainty		
Fear of the unknown		
Validation of symptoms		
Not all in the mind		
Less of a stigma than mental health issues	Knowing one’s body, knowing one’s self	
Knowing the self/ knowing own body		
Experiencing symptoms – something is wrong		
Disembodiment		
Need for support		

Table 8: Table of themes for “Road to diagnosis”

#### **5.4.1 Knowing one’s body: knowing one’s self**

“Knowing one’s body: knowing one’s self” reflects the interrelated nature of the experience of abnormal bodily symptoms amongst the participants. These were either sensory or motor, and the person’s knowledge of what was normal for them, with the perception of the self. All the participants’ accounts highlighted experiences of bodily sensations which triggered their suspicions that something may be physically wrong and that they needed to seek medical advice. Each individual described in great detail the events that led up to being diagnosed, along with the details of the diagnostic consultation itself. This included reference to events that had happened a number of years ago that the recent diagnosis had brought back into focus.

This was perhaps most powerfully presented by Janice, who had previously experienced symptoms over 20 years ago:

*“It all started 20-odd years ago. I had, it was when I was a student nurse, I had an episode of pins and needles going down my left hand side of my body and when I was bending my neck and it persisted for three months. So I went to the GP, got referred to a neurologist, but by the time the appointment came through from the neurologist the symptoms had disappeared. So I didn’t do anything... So it was only this year, at the end of January we were going out for a walk... and I bent down in the car to put my boots on and I felt pins and needles on my right hand side, so that took me right back to 20- odd years ago.”*

(Janice, PWMS, int 1)

In this account Janice describes her symptoms re-occurring some 20-plus years later, which acted as a stark reminder of her experiences from before and were the stimulus for her to seek medical help. The phrase *“that took me right back”* suggests the symptoms acted as a trigger, pulling her consciousness back to a time when she had perhaps been worried, but because the symptoms had resolved she put it to the back of her mind. It could be postulated that the suspicion of recurrence was immediate, as the symptom pattern was similar, suggesting to Janice this was a problem which needed urgent attention.

In a similar case spanning seven years, Steven sought medical advice for his symptoms which were later identified as a first episode of MS. Again the detailed description given supports the view that this was a significant life event and not a trivial event easily forgotten:

*“I first noticed something was wrong that was seven years ago and just suddenly it came on. I could hardly walk so I had to go to the doctor’s, in fact it actually started on my foot here. There was a numb, numbing sensation here on my toe, my big toe and it was like that for a few years. And it just suddenly spread up my foot and then spread*

*up my leg. And from there it jumped across to my other foot and my other leg. And then I thought this is something serious so I'm going to have to go and see about this."* (Steven, PWMS, int 1)

There is a notion of a desire to find out the cause of the symptoms from Steven's account where he states that he suspected "*this is something serious*", and recognised he ought to seek medical advice. Recognising symptoms which require further investigation was commonly alluded to in the interviews, and is characteristic of the road to diagnosis of MS. Where the normally taken-for-granted body does not do as one expects, or symptoms occur which cause loss of sensation, and motor function, individuals with such symptoms are prompted to act upon their suspicions. In both Steven's and Janice's cases, no diagnosis was given during their first experience of symptoms. This was not a shared experience as others were diagnosed within a few weeks of the onset of symptoms.

However, not all symptoms were recognised as significant, either by the person themselves or the medical staff. As a result of this, symptoms were often attributed to other causes. One of the participants described how, prior to being given a diagnosis of MS, he put his symptoms down to clumsiness:

*"If I dropped something, I'd be sitting you know one time I had a glass in my hand, I was picking it up off the tiles and it slid right out of my hand and smashed the glass I went daft at myself for doing that."*

(Billy, PWMS, int 1)

The problem of seemingly minor and non-specific symptoms appears to be fairly common and troublesome in the participants' road to diagnosis. Occasionally this led to journeying up a dead end, where the person with early symptoms felt they had been dismissed by health care professionals or their symptoms were put down to stress or another concurrent condition. In Billy's case, he had a history of schizophrenia, therefore he and his mother felt the road to diagnosis had been difficult, as some of his symptoms had been put down to his existing mental health condition:

*“So first of all we eliminated the drugs, you know, they sent the Clozapine and got them to do a check, they done more blood tests and they ran tests so eliminated the Clozapine as a side effect, causing a side effect and then because there was no reason for it they said psychosomatic.”* (Billy, PWMS, int 1)

Billy was told the symptoms were psychosomatic and this was a particular struggle for him and his mother who had to be very persistent to get a confirmed diagnosis. Their experience of dealing with Billy’s mental health problem led them to recognise the difference in the new symptoms and raised their suspicions of a physical cause. Here, knowing one’s body and knowing one’s self was key to recognising what was normal and what was not. Whilst it should be recognised that dealing with people with co-morbidities may present some difficulties in seeking a diagnosis, other participants also found this a challenging aspect on their road to diagnosis, and even started to doubt their own symptom experience. As Ruth explained:

*“My worst fear was that there was nothing wrong with me at all and this was all in my head...”* (Ruth, PWMS, int 1)

A fear of not being believed was highlighted in the literature review in Chapter Two and was also experienced by Sheila, who reported that she felt that her integrity was being questioned and she was being treated as a timewaster:

*“...when I had the head scan done and I went for the results, went to see [the doctor] and he says to me, he says, do you believe that you’re unwell. And I thought, well I wouldn’t be here wasting your time if I was fine.”* (Sheila, PWMS, int 1)

Sheila’s account illustrates her impression that the medical staff dealing with her thought she was a timewaster, or that her symptoms were of a psychosomatic nature which was similar to Billy’s experience. The sense of

*“knowing one’s body”* and what is normal and not normal for the individual is reflected in both Billy and Sheila’s accounts and caused them to persist in seeking a definitive diagnosis for their symptoms. Sheila’s statement *“I wouldn’t be here wasting your time”* is suggestive of a strong sense of ownership and empowerment in her position and, a strong sense of her “self”. In her persistence, she refuted her identity being linked to being a timewaster.

In the face of being labelled as having symptoms *“all in your mind”*, some of the participants welcomed the diagnosis of MS as they then had a label; a reason for their symptoms and because of that were legitimised in the quest for medical support for their valid symptoms. This is explained further in section 5.2.2.

The road to diagnosis appeared to require a level of persistence to seek confirmation of a diagnosis for the symptoms of MS, as Sheila’s and Billy’s accounts above illustrate. This again was a fairly common phenomenon, partly due to the non-specific symptoms which may occur in early presentations of MS. Nevertheless, this does cause additional stress for the person with MS as they search for answers:

*“So I was never away from the doctors actually. I even took an AIDS test because I was that worried about what it was. And all of my blood tests were coming back negative, healthy. Blood pressure healthy everything was healthy yeah? And I was just looking for an answer and that’s why I took an AIDS test. Because I thought there must be something wrong with me.”* (Steven, PWMS, int 1)

Steven went to great lengths to find a reason for his symptoms, such was his need for confirmation. In this description, Steven was steadfast in his belief that there was a reason for how he was feeling, despite the medical tests he underwent all coming back clear. Such persistence and perseverance suggests a strong sense of knowing one’s body and standing firm in that belief, such is the want to know “why”. I got a sense that not knowing why

symptoms were occurring was a common source of frustration as illustrated by Lorna's account:

*"I didn't know, I didn't get any results and nobody was telling me anything about what was going on. I had no feedback about whatever and I was phoning my GP and they said 'no they hadn't heard anything."* (Lorna, PWMS, int 1)

Lorna's repetition here of not being given information suggests this was a particularly frustrating time. Her statement "nobody was telling me anything" gives a sense that she felt information was lacking.

Some of the participants described suspecting they had MS before they received a confirmed diagnosis. This was often due to seeking their own information about the symptoms of MS. Sources of information ranged from internet websites, to friends and books. Here, Sheila had sought information from a medical text which indicated one of her symptoms may be attributed to MS:

*"When I had the optic neuritis, I had so many months and so many months to try to deal with that, that when the MS came up anyway, it was really no surprise, because it was... I'd been thinking about that anyway. Because I read in the medical book that... it said in the medical book that they're often uncertain as to why optic neuritis happens."* (Sheila, PWMS, int 1)

This meant that when the diagnosis was confirmed it did not come as a complete shock:

*"So I think it's always been there anyway. You know, so I had all the months to deal with this and I kind of knew anyway."* (Sheila, PWMS, int 1)

Despite the presence of symptoms raising suspicion and being the trigger for health seeking, not all participants sought out information or suspected MS as a possible diagnosis. As a result, the confirmation of the diagnosis of MS came as a shock for these participants:

*“I felt a lot better and so I just never thought for one moment, although I was going... It never even crossed... why I was going to a neurologist, you think you would have thought wait a minute here but you just think, you kind of don’t want to start kind of self diagnosing as well because you could find... It could end up things that it might not even be so you just kind of think Oh! Well they’re just doing this as it could be this, you know, essentially but we don’t know but that it might help that and you just think Oh! Well that’s fine but you don’t think for one second that it’s going to be something serious like...”*

(Nancy, PWMS, int 1)

This extract illustrates how the diagnosis of MS seemed to be a complete shock for Nancy. Nancy also acknowledged that despite being referred to a neurologist, this did not trigger the suspicion of a potentially serious diagnosis and she did not actively seek information either. Her statement, *“you don’t think for one second that it’s going to be something serious”* highlights how Nancy did not consider a potentially serious condition as a possibility.

To summarise, the accounts presented showed that the presence of symptoms usually triggered an awareness of something not being right, and as such, caused the initiation of health seeking actions such as visiting the GP. This embodied experience requires individuals to have an awareness of what is “normal” for them in order to establish “abnormal” experiences. This may be especially important in people who have co-morbidities. “Knowing one’s body: knowing one’s self” links the embodied experience of symptoms with the knowledge of what is normal for the individual, with the perception of the self as they journey along the road to diagnosis.

What is particularly striking is that the participants' journeys to diagnosis were different, with some symptoms not specific enough to warrant action for many years. For a number of the participants in this study, the road to diagnosis required some assertive behaviour to come to a confirmed diagnosis. The unpredictability of the road to diagnosis presented many problems for the condition being diagnosed. The individual's level of assertiveness, combined with the subjective interpretation of the symptoms, may determine whether help seeking is initiated or delayed. As I will discuss throughout this chapter and in the discussion chapter, this may have implications for how MS impacts on the individual's early understanding of the meaning of being diagnosed with MS and how it will affect their sense of self.

#### **5.4.1. i A shared journey**

The findings in this theme provide insights from the support persons' road to diagnosis and propose "a shared journey" as a way of understanding the lived experience of support persons at this time. To a certain extent, their journey echoed that of the person with MS in the "knowing one's body: knowing one's self" theme, yet the experience of the support person was from a different perspective; that of concerned observer, not quite apart, yet not quite the same. All the support persons who participated in this study reported having concerns about the cause of the symptoms, or wanting to find out the definitive diagnosis. Whilst the person with MS was the one experiencing the symptoms, concern over the cause of the symptoms was a shared one. For the support persons, this journey was often an emotional one, where they sat alongside the person with MS, sharing some of their anxieties, worries and concerns:

*"Up until the actual diagnosis both of us were sitting there knowing, or individually thinking that there was something else more wrong with Ruth."* (Brian, SP, int 1)

In this account, Brian's sense of concern for his partner was clear. Describing them as "both sitting there knowing" supports the shared element of the

experience, yet his description of them “individually thinking” suggests an isolated or individual aspect to the experience which is shared but not the same. Brian’s suspicions that there was “something else more wrong” echoed the suspicions of the persons with MS described in the “knowing one’s body: knowing one’s self” theme above, thus further supporting the notion of the road to diagnosis being a journey that is shared, rather than being travelled alone. Not knowing the cause of the symptoms played to the individual’s imagination, bringing about fear, worry and concern for their loved one:

*“But as far as the doctors were concerned, as Lorna said, it was frustrating I know for her and it was frustrating for me that it went on for a couple of months, not knowing why she was going for an MRI and what they were looking for.”* (Nic, SP, int 1)

Similar to Brian’s experience, Nic’s account above, illustrates shared concern in relation to the time lag whilst waiting for a diagnosis, and not knowing why tests were being done. The emotional impact of this experience was evident as she stressed the sense of frustration both for her and her partner. The support persons interviewed almost exclusively described the emotional impact of the road to diagnosis in negative emotional terms. Terms such as scary, worried, fearful, and angry were commonplace in the data. This finding strongly supports the suggestion of the road to diagnosis being emotionally burdensome for the support person. Often they were left out from key consultations and did not appear to have any identifiable source of support around this time.

For Jean, who was Billy’s mother, her experience brought feelings of anger and guilt that she did not do more to push for a diagnosis. The road to diagnosis in Billy’s case was complicated by Billy’s previous mental health problems, where his symptoms had been attributed either to being psychosomatic or a possible side effect of medication. Allowing his symptoms to be attributed to this was a source of frustration and guilt for his mother:

*“I am quite angry at myself for accepting that it was just the tablets but because it coincided with the blips of Billy taking his tablets that allowed me to accept that it could have been the medication. So I am angry at myself and the health service because they are qualified, I am not. Therefore, and it has been mentioned that it had crossed someone else’s, two other people’s minds but they were thinking oh God, let’s fingers crossed it is not that, I wish somebody had pushed and then we could have found out what it was.”* (Jean, SP, int 1)

Having a diagnosis of something physical appeared to be a relief for both Jean and Billy, perhaps due to their previous experience of the stigma of a mental health condition. The data from the support persons suggest the road to diagnosis is a shared experience with the person with MS and that this is an emotionally troublesome experience where there is a strong desire to know the cause of the symptoms. Not knowing was difficult, as one of the participants with MS suggested it was like being in “limbo”. In summary, the “shared journey” is a theme which supports the unique but complementary experience of the support person on the “road to diagnosis”.

#### **5.4.2 Being diagnosed: crossing a threshold**

The theme “being diagnosed: crossing a threshold”, relates to the reactions from the participants to being informed they have MS. Many of the participants provided very detailed descriptions of how they were told of their diagnosis and what their reaction was. The emotional reaction to the news depended on the meaning the participants attributed to having MS. “Crossing a threshold” uses the metaphor of leaving one room and entering a new room to describe the experience of being given a diagnosis where one moves from “not knowing” to “knowing” the cause of the symptoms which have been experienced. My assumption was that being given a diagnosis of any chronic condition could be classified as “bad news”, an assumption which was confirmed by Steven who identified being told he had MS as the “worst news” he had had:

*“Nah I'm quite brave I've been through quite a few things in life and I thought I could cope with that. But that's probably the worst thing I've had, the worse news I've ever had.”* (Steven, PWMS, int 1)

Steven's view however, was not always shared by all participants, particularly if they were worried about conditions which they viewed as worse than MS. Both Sheila and Eileen had been very worried their symptoms had been due to a malignant brain tumour, therefore the diagnosis of MS was perceived as a lesser of two evils:

*“I'm just glad I didn't have a brain tumour. Or a stroke, I thought I'd taken a stroke because of this on this side of the face.”*  
(Sheila, PWMS, int 1)

Both of these participants had a health care background, which may have influenced their perceptions of MS. An understanding of the person's previous experience and background therefore may be relevant to how they handle being told they have MS. With this in mind, I was struck by some of the experiences of being given the diagnosis which did not appear to be particularly sensitively handled:

*“...he asked, he did ask me if I knew what MS was, and of course I did. And he also asked me if I wanted to ask any questions and I couldn't think of... I just couldn't think, so he continued to, just like, obviously tell me things that I presume other people had... like from the experience other people ask, because I was like, ‘Oh, God’...”*  
(Ruth, PWMS, int 1)

In Ruth's case, the clinician did ask if she knew what MS was but thereafter she was unable to take anything else in. It may also be relevant in Ruth's case, that she attended the consultation on her own. During her interview she described her diagnostic consultation in great detail and reflected that she wished she had taken her partner with her as she had done on previous

occasions. However, she had no prior indication that this consultation was to be significant.

*“Oh, that was awful, and Brian wasn’t there. They’re not going to send me an appointment saying, “Oh, by the way, this is an important one”, you know...”* (Ruth, PWMS, int 1)

Ruth had previously been a smoker and went on to describe how when she came out of the consultation her mind was in a whirl. She said that if there had been a tobacconist close by she would have bought a packet of cigarettes and started smoking again. Ruth’s partner also expressed his disappointment at not being there for Ruth when she was told her diagnosis. He suggested the wording of her letter should have advised her to bring someone with her:

*“ “Can you attend the Western General for a meeting”, and then just tell her she’s got MS. Well, it’s... I do feel they could have worded it, “Can you bring somebody with you”, or something like that. I don’t know... It still boils down to a lack of information coming through so that we could make an informed decision.”* (Brian, SP, int 1)

Ruth’s and Brian’s accounts suggest that having the support of a partner or someone close at the diagnostic consultation would be desirable, however, in their case, due to the lack of information in the appointment letter, they were unable to make an informed choice as to whether Ruth should have someone with her. The tone of Brian’s account suggests he was not happy at being unable to support his partner at this critical time. Another participant’s experience was made more traumatic by the method of information giving as she was informed over the telephone:

*“I got a phone call and it was late February this time and it was during the evening because we had [a friend] around for dinner and er he called me and he said ‘oh I’m glad we’ve contacted you at last.’ And he said ‘you know we thought initially it was just an episode of some*

*sort of neuralgia, but actually you've got MS.' I'm like I've got what! I just... he said 'I'm sorry I'll have to get you in to speak to you'. And I was just like blown away. Just... that was it, that phone call - what!! You know."* (Lorna, PWMS, int 1)

Lorna's account showed little apparent consideration from the caller as to what was happening in her life at that moment. The diagnosis was given when she was in the middle of a sociable evening with her partner and a friend. The impact of this call is evident from her description of the event, where she uses the metaphor of being "blown away" which suggests the impact of losing her footing and feeling out of control when realising the seriousness of the condition she had. Later in her interview, Lorna described how the method of giving her the diagnosis had further implications for how she then handled telling her family, who lived at a distance, of her diagnosis. After being diagnosed in November one year, Lorna waited until the following August, when she could travel to see her parents to inform them about her diagnosis in person as she was reluctant to inform them over the telephone.

*"I've only recently told them, around August time, I went up to see them, I won't tell them over the phone."* (Lorna, PWMS, int 2)

Negative reactions to the diagnosis were more common among participants but one participant in particular was angry about his diagnosis having been withheld for seven years:

*"Because in life you've got different paths and you get told something and you've got different paths. And you choose a path but I never had that option seven years ago. I was on the same path and I never went off that path but I definitely would have went down another path. Socially and maybe even work wise."* (Steven, PWMS, int 1)

For Steven, not being told his diagnosis, or even suspected diagnosis of MS on the first occasion angered him, as he felt he had been robbed of the chance to make informed life choices. He was in a relationship which he stated he may not have been in had he known his diagnosis. Steven's

account suggests his sense of self was very closely linked to his perception of what a life with MS might be. His use of metaphor suggests he would have made different life choices had he known which would have meant his current situation would be different. He would not be the same person.

However, for some participants being given a confirmed diagnosis was welcomed almost, as not having confirmation left them in a state of “limbo” (Eileen, PWMS). Whereas once a diagnosis was confirmed it opened up a range of supportive services, including health care and insurance claims.

*“Is it a relief to have a diagnosis... ..if you get that then the whole support services and information opens up to you.”*

(Eileen, PWMS, int 1)

Eileen’s account above supports the use of the metaphor of a “threshold” as support services and information “opens up” once the diagnosis is confirmed and this is seen as a positive aspect to having a confirmed diagnosis. The level of comfort from knowing why symptoms occur was very simply articulated by Billy when he stated that he felt better for knowing there was a reason behind his symptoms rather than them all being in his mind.

*“I feel a bit better in a way I have been told I have got something.”*

(Billy, PWMS, int 1)

However, for some participants, a sense of loss was evident where they mourned their previous existence, free from MS and symptoms. For Sheila, she expressed this as wishing to go back in time, to days which held happy memories, perhaps mourning the loss of her ability to do this now or the potential threat MS posed to her physical ability:

*“There’s nothing else I can do is there? Can’t turn back time. I often say that, you know, I wish I could go back to last year. You know, when I was fine and taking the dog out through [the] Park and the nice summer days and you can’t go back to that.”*

Sheila's account had an almost melancholic tone to it as she described walking her dog in the park. She acknowledged she could not go back in time but also did not express any sense of hope; rather she presented a very fatalistic view of her situation. The sense of loss in being able to do the things she enjoyed as well as her sense of helplessness was evident and suggested a change in her sense of self, as a person who was less able to enjoy the simple pleasures and thus was changed. In crossing this threshold, not only was this a troublesome concept for the sense of self, but once crossed there is no going back.

In summary, the participants' accounts indicate that being told of the diagnosis is an especially significant moment in time for people. Being diagnosed with MS is a defining moment in the individual's life where they are given a reason and an identity for the cause of symptoms they have been experiencing. How individuals reacted to being told they had MS was influenced by the meaning and significance the diagnosis had for them. What was significant is that the meaning attributed to the diagnosis appears to be deeply linked to their perception of MS in a wider context of their previous experiences. I have used the metaphor of crossing a threshold from one room to another, which offers an interpretation of the experience of the participants moving from one room which is familiar to them, to another room where new knowledge and experiences open up and have the potential to change their sense of self. Once crossed, the threshold cannot be uncrossed, as the knowledge and experience gained cannot be unlearned. This represents an epistemological shift as the individual gained knowledge of their diagnosis. For some individuals this was a troublesome concept, but for others, it was welcomed as they were no longer left in limbo. The data presented here also suggest that how the individual was supported and treated on the road to diagnosis and how the diagnostic consultation was handled may influence the person's perception as to whether this news came as a shock or a relief. The data presented in this theme support the notion of

conceptualising being diagnosed with MS as a crossing threshold in the lives of people affected by MS.

## 5.5 The Liminal Self

The title of this theme reflects the amalgamation of the many *in vivo* codes and intermediate themes which related to the impact of MS on the participants' sense of self (see Table Nine below). The previous theme points to the moment of diagnosis as a significant event in the participants' journey where they now had a clear cause for the symptoms they had been experiencing.

<b><i>In vivo</i> themes (free coding)</b>	<b>Intermediate theme</b>	<b>Superordinate theme</b>
Living in the shadows	A self disrupted	Liminal self
Hidden self		
Emotional impact of diagnosis		
Feeling of not coping		
Facing mortality		
Re-evaluating what is important to one's self		
Self as mother <ul style="list-style-type: none"> <li>Threat to mothering role</li> </ul> To tell the children or not	Disruption to roles and relationships	
Self as partner <ul style="list-style-type: none"> <li>Changes to established roles</li> </ul> Changes to intimacy		
Self at work <ul style="list-style-type: none"> <li>Changing work patterns</li> </ul> Limited disclosure Reactions of colleagues		
Anticipatory carer		
Stigma of diagnosis	Self and others with MS	
Realisation of fears		
Fear of disability		
Spectre of MS		

Table 9: Table of themes for "The Liminal Self"

All participants reported a sense of disruption to their perception of their self and a period of negotiating the new perception of their self into their biography. As the biographical impact of MS was the main focus of my research, a number of the questions related to exploring how the participants understood their experience of having MS, the meaning they attributed to their experience and this informed the development of the theme. As the

previous theme focussed on the “road to diagnosis” where the moment of diagnosis became the defining moment of transition across an imaginary threshold, from the taken-for-granted self to the self with MS, this theme focusses more on giving consideration to the meaning attributed to being diagnosed with MS, and how this interrupts or disrupts the sense of self, resulting in a liminal state of being.

### **5.5.1 A self disrupted**

“A self disrupted” relates to the individuals’ notion of their sense of self, their “taken for granted self” into disarray, and their “self” being a disrupted person by being diagnosed with MS. Previous conceptions of the self that participants had constructed (biographies) were now challenged and new narratives of the self emerged; these new biographies now included the “self” as a “self with MS”. The participants mainly described the impact of this on their sense of self as a disruptive element, one where they were living a life relatively secure in their sense of who they were, and how this related to the world around them, but the diagnosis of MS usurped this understanding and caused them to question certain aspects of their understanding of their biography. The sub-theme of “a self disrupted” illustrates how this sense of self is usurped whilst the person struggles to maintain their previous biography of their self. An account from Julia clearly articulates the impact having MS had on who she was as a person:

*“I don’t think I’ll ever be the same person I was kind of thing. You get stuff that you wouldn’t have thought anything about before. I mean MS I didn’t know what it was and you’ve now got all that experience. I mean I still try and be me kind of thing at the end of it but you still come across things that you never had before and find I can’t always do the same amount I used to do.”* (Julia, PWMS, int 1)

Here Julia described how having MS changed her sense of who she is and acknowledged the irreversible nature of this change due to her experience and new found knowledge of MS. There was also a real sense of this change

in sense of self being unwelcome, as Julia struggled to maintain her former sense of self. In her account Julia said she will “*still try and be me*” which is quite different to a more assertive “I am still me” and suggests a sense of fluidity to her sense of self congruent with a liminal self. Her sense of self appeared to be linked to her lack of ability to do the things she used to, due to the restrictions imposed upon her by MS. I interpret her holding on to her old self as an indication that she was struggling to fight against this force that was taking over who she is. This will be discussed more fully in the theme “impact of MS on daily life”.

Eileen captured the changing biographical narrative she constructed about herself reflecting on her previous notions of self with the new self with MS as part of that self:

*“You sort of think of yourself as invincible and I have worked, had a family, I’m always active, I do tons of things and so you see that a wee bit of superwoman quality in yourself, I think we all do. And seeing that maybe there’s another angle to that now is that every time I think... when I’m looking at myself I think well also there’s a bit now that’s added on that’s got MS onto it, so that’s another facet of my personality or being me now.”* (Eileen, PWMS, int 1)

In contrast to Eileen’s apart acceptance of MS as part of who she is, trying to put MS to the back of the mind was a phrase that was used in a few participant interviews and I suggest did not indicate denial but rather may be viewed as linked to their struggle to maintain their sense of self:

*“I’m trying to be more relaxed, trying to put things to the back of my mind but I’m not, I don’t want it [MS] to change me.”* (Julia, PWMS, int 1)

Some of the participants found the initial struggle of accepting MS as part of who they are difficult, and struggled with existential questions such as “why me”, which were also linked to their own perception of their self as healthy or

fit or strong. Having a condition such as MS was at odds with that perception of the self. This was captured well in Steven's account:

*"I just felt sorry for myself, I know that's bad and selfish but, just so many questions come into my mind like why? Because I'm really careful about what I do. I mean I'm a qualified sprayer and I work with loads of different, dangerous chemicals. I even watch what I'm eating and I couldn't understand why I've got something like that."*

(Steven, PWMS, int 1)

Similarly Janice struggled with the idea of being seen as "ill", as her experience of being diagnosed with MS was not in keeping with her idea of an ill person and this resulted in a degree of cognitive dissonance where she is neither ill nor well.

*"I'm not ill. I'm not ill as in ill that you need somebody to come and do your housework and things."*

(Janice, PWMS, int 2)

Janice's sense of self was disrupted and she could not easily comprehend the meaning and significance for her "self"; her assertion of not being ill and requiring assistance may be understood as an attempt to distance her "self" from the perception she has of an ill person. This linked to her own biographical understanding where she did not identify with the concept of an ill person and struggled to assimilate how MS became part of her "self". Being unable to identify with being an ill person or healthy person leaves Janice "betwixt and between", otherwise described as in a "liminal state of being". Janice's use of distancing continues when talking about other people's perceptions of what someone with MS is like. In the following account she again tried to maintain her "self" as separate, or different, to her idea of what others think:

*"I think a few people know a few people who've had it or know somebody who's had it but they're seeing the other end. They're not seeing this end yet."*

(Janice, PWMS, int 1)

In distancing herself from the possible reference points of people with MS who are profoundly disabled (*“the other end”*), Janice strove to maintain her “self” as different, and was clearly not comfortable linking her own identity with the identity of those who have severe disabling MS. The invisibility of the early stages of MS is also of relevance as Janice highlights, “they’re not seeing this end yet”. In addition to Steven and Janice, four of the other participants linked their identity to personal traits such as being strong, or healthy, or active, or independent which seemed to me to be a way of them expressing their identity and an attempt to distance from a new “self” with MS.

This theme has considered the impact MS had on the participants’ sense of self. The accounts presented above to illustrate this theme support the notion of “a self disrupted”, where participants enter a liminal period of negotiating the new perception of their self into their biography.

### **5.5.2 Disruption to roles and relationships**

Being able to maintain specific roles seemed to be important to the participants in this study and was related to the roles and relationships they valued in the context of their own lives. Previous literature has linked identity with social, familial, and employed roles and this appeared to be relevant to the participants in my study and this theme highlights “disruption of self: roles and relationships” as of significance to people who are newly diagnosed with MS and their support persons.

#### **5.5.2. i The self as mother**

The sub-theme of “the self as mother” emerged from the data from the participants who were mothers. This included those participants with MS and the support persons. There were no fathers who had MS nor were there any fathers of the participants with MS in this study. For the participants who were mothers, their role as mother appeared strongly linked to their identity

and they all mentioned their mothering role in relation to their experience of MS. The impact of MS on the mothering role differed as the participants were affected by the symptoms of MS to a greater or lesser degree.

Eileen described the impact her main symptoms of neuropathic pain and fatigue had on her relationship with her teenage children:

*“But sometimes if I’m tired and sore it’s inevitable and if I’m in pain I can be a bit crotchety with the kids. They are completely oblivious... in their own teenage way [laughter]. They don’t give me any slack whatsoever [laughter].”* (Eileen, PWMS, int 2)

In Eileen’s account, she recognised that MS did impact in some way on her relationship with her children but appeared to minimise this by saying her children were “completely oblivious”. However one of the participants shared a harrowing account where she had a young son who had started to self-harm. She attributed his actions partly to her having MS and not being able to do all the things she used to as his mother.

*“But I think it [MS] may be a factor in him self-harming. Because I think it’s very hard for any child who has been with a parent who’s been able to do everything, taking them everywhere and I probably did too much for him, if that’s possible, but to find that your mother can’t really take you anywhere, or do as much with you I think that’s probably quite hard to accept.”* (Lynne, PWMS, int 2)

The sense of guilt that is present in this account also suggests that this situation is not just hard to accept for her son, but that it is difficult for her as a mother to accept her now limited role. Balancing the need to inform the children and maintaining the mother role was challenging and finding ways to explain was also difficult, as Janice found:

*“I told them and explained to them and I think the first thing I said was I’m not going to die from this, it’s not like cancer.”*

(Janice, PWMS, int 1)

In this extract, Janice's first priority as mother was to reassure her children that she was not going to die from MS. This may be interpreted as the strong protective maternal instinct that is part of one's identity as a mother. The protective element of the mothering role was also apparent in Nancy's interview, where she had decided not to tell her three children about her diagnosis. They knew she had been unwell and had been for a scan but were not aware of their mother having MS. Nancy explained this in the following extract:

*"I haven't told the kids because... I just... I don't want them to think that, you know, they can't do this or that because of me or [Mirren] who's 11, she'll probably blab to somebody [laughs]... or use it as some sort of tactical weapon, which she's very good at so, you know."*

(Nancy, PWMS, int 1)

By not telling her children about the diagnosis, Nancy was able to maintain a façade of "everything as normal", thus maintaining her sense of self as mother, doing all the things she normally would with her children without her children thinking they had to treat her differently because she had MS. What is interesting is that both Nancy and Janice had children of similar ages, yet they both decided differently on whether or not to tell their children about MS. The age of the children may be a factor in when a person decides when and what to tell them about the condition; however I did not explore this aspect in depth. What was apparent though, was that none of the participants spoke of help or support in how to talk to their children about MS.

Whilst the participants with MS responded to the threat to their mothering role differently, the data support the interpretation of MS as a possible disruption to the self as mother. One of the limitations of this study was that there were no participants with MS who were fathers, therefore no claims can be made as to whether this finding would relate in the same way to fathers. However, it can be assumed from the findings that MS poses a threat to the mothering

role and may cause disruption to a mother's sense of identity linked to that role.

There were three support persons who were parents of the person with MS in this study; all were mothers. Their concern for their adult child was expressed in very maternalistic ways, as they expressed a desire to take the pain away from their child. In both Maggie's and Pearl's cases, they wished they could have traded places with themselves as the person with MS.

*"I'd rather have it, I'm sixty now, I would rather take MS than Sheila have it now. It's not silly thoughts is it, it's what you want, you don't want your own to suffer with things you know."* (Maggie, SP, int 1)

Maggie and Pearl both mentioned their age as a reason for wanting to take the place of their child, which suggests they viewed MS as a condition which stole youth from the person. This gives a sense of roles being reversed, where it is expected that the life spans of the mothers allow them to care for dependent children for them to grow up as independent healthy adults. As parents age, the social norm is that the parent ages and becomes more infirm. The disabling effect of MS challenges the social norm, where the adult child becomes more dependent on the parent again. For Maggie who worked in a care home for the elderly, there was a sense of injustice at her daughter being diagnosed with MS:

*"And you know, I was getting at work... I was looking at the old ones like, what ninety odd some of them, with their hip replacements, getting up and going home and I do say, how dare they be like that at 95 and Sheila's got MS. And I was looking at them thinking, a bit begrudgingly. How have they got to ninety odd and I still think, that's stupid isn't it?"* (Maggie, SP, int 1)

The constant comparison of the daughter with MS and the ageing person suggests that MS may be seen as a prematurely ageing condition, which steals youth from those affected. For Maggie, viewing others who are older

and recovering from treatable conditions arouses feelings of begrudgement that her daughter cannot be cured of MS.

The self as mother became an important theme as there were a number of participants who were mothers in this study. For those mothers who had MS, the experience of having MS posed a threat to their identity of self as mother. For those participants who were mothers of the participants with MS, their sense of self as mother was challenged due to the unbalancing of social norms related to the aging process.

### **5.5.2. ii The self as partner**

The theme of “the self as partner” was present to a lesser extent in my study. This may be in part due to the sensitive nature of discussing how chronic illness impacts on relationships and intimacy in our culture. Nevertheless, the impact MS had on intimate relationships was mentioned by four of the participants with MS and I considered this quite important, as it may be that some participants felt less comfortable discussing such topics. The narratives described in this theme illustrate the emotional or psychological impact of living with MS to the “self as partner” and some physical changes which make experiencing intimacy more difficult.

One of the participants highlighted a new insecurity in her relationship, which she attributed to having MS. She described moving from feeling happy and secure, to having nightmares her partner may leave her and questioning why he would wish to stay with someone who had MS:

*“I kept having nightmares that he was like going to leave me. And this went on for a good week, and I thought – oh, every night I thought he was going to leave me – and that’s it.”* (Julia, PWMS, int 1)

*“We’re just happy and – but yeah, I think that hit me, like why would he want – or who would choose to have that, more than anything else – who would choose to be with someone that’s – it’s not ideal.”*

(Julia, PWMS, int 1)

In these two extracts Julia displays a sense of vulnerability and she questioned why her partner or anyone would wish to be with her now that she had MS. The disruption the diagnosis of MS brought to her sense of self caused her to question why her partner would wish to continue being in a loving relationship. Her description of herself as someone who is “not ideal” also suggests that she felt impaired in some way.

In contrast to Julia’s vulnerability in her relationship, Steven described how being told he had MS caused him to question the relationship choice he had made. He suddenly started thinking about marriage and children when previously this had not been part of his life plan. This caused him to reconsider his choice of partner as marriage and having children suddenly became important to him. The sense of disruption to who he thought he was and how he lived his life was evident from this account:

*“But now I’m starting to think about having kids, getting married stuff like that. I was not thinking of that like four or five weeks ago but, I’ve certainly been thinking that the last couple of weeks. Because I’ve not got any kids and my girlfriend doesn’t want any kids. So, there’s a lot of things that’s went through my mind over the last couple of weeks.”*

(Steven, PWMS, int 1)

However, in his follow up interview this initial disruption had lessened and Steven was more at ease with the choices he had made and his partner. The sudden questioning of the individual’s relationship status was evident in the interviews of both the PWMS and the support person. However, for one participant, Lynne, being diagnosed with MS left her feeling trapped in an unhappy marriage as she felt helpless and dependent:

*“I think probably our marriage had run its course. [Pause] In some ways I feel that before I was – when I was getting my independence back, I could see a different future.”*

(Lynne, PWMS, int 1)

This was a particularly harrowing interview, where Lynne described her marriage. She had returned to work a few years prior to being diagnosed with MS, and felt like she was regaining her independence. This account illustrates how Lynne saw a new future for herself and her son but this had now been thwarted by being diagnosed with MS. Her aspiration for a new life after marriage had been quashed, as she felt she could no longer realise the plans she had. Lynne's account suggests her experience of being diagnosed led to her feeling trapped in her relationship.

In addition to the impact on the relationship with the partner, some of the participants also reported difficulties with intimacy in their relationship as a result of the symptoms of MS. Janice described how areas of her body had become numb so that when her partner touched her she could not feel it, thus a loss of intimacy through experiencing the touch of her partner was a problem:

*"I had lack of sensation on my right side as well and he was touching my leg or my tummy or whatever and I couldn't feel it. It was like, I had a section with my oldest one and there's a bit on my section down just up from that and I know I'm touching but I can't feel anything, it's exactly the same. The nerve sensation's gone."*

(Janice, PWMS, int 1)

Lack of sensation during intimacy was a distressing problem where the participants knew they were being touched but could not experience the closeness of the touch. Ruth described her experience of numbness in the following extract:

*"I've not much interest in sex at the moment. Sex is not one of the biggest issues. Never been an issue, I have gone off it lots of times. There are times when I have been interested but I am numb. I felt your hand on me but not other parts. That was upsetting."*

(Ruth, PWMS, int 1)

Here Ruth reflected that whilst she had lost interest in sex before, the current situation was different as her desire for sex was present, but this time she was not able to feel her partner. Ruth described being unable to experience intimacy in the same way as before as upsetting.

For some of the participants, having MS also impacted on the ability to perform intimately in their relationship. For Steven, his interest in sex was also not an issue but his ability to achieve an erection was impaired. He attributed this problem to having MS; however, in his case he was able to receive medication although that was something he struggled to accept initially:

*“I think when you’ve got MS it doesn’t quite work as right, eh. I think anyway, I think that’s what it is. That’s what the doctor seems to think it is...”*

*I never, ever thought I would see the day that I’d need to take anything. But I do.”* (Steven, PWMS, int 2)

Steven’s statement, *“I never, ever thought I would see the day that I’d need to take anything”* may be interpreted as him linking his use of medication to his sexual prowess being impaired, which is linked to a disruption in his sense of self.

Although this theme was not identified by all participants, its significance may be considered in terms of the sensitivity of the topic and also perhaps my own level of comfort in exploring these issues, which may have inhibited disclosure. I was not as comfortable with this line of questioning, although I had tried to explore the impact of MS on close relationships during the interviews. In relation to the theme of disrupted self, I have shown the data support MS as a disruptive factor in upsetting the equilibrium in the sense of self as partner, either through emotional vulnerability or through the physical changes which affect either the ability to experience intimacy or the ability to perform.

### 5.5.2. iii The self at work

The “self at work” was a theme which was identified early in my analysis of the data. In considering the impact of MS on the self I specifically asked the participants to consider how being diagnosed impacted on their work life. The literature review in Chapter Two highlighted the sense of self being linked to occupational roles, therefore this was a relevant line of questioning. Balancing the demands of a professional or work role with the impact work has on the symptoms of MS was also a challenge for the participants who were employed:

*“I have this condition and if I’m, again, having a bad spell I’ll just say to them [work colleagues], but the reality is, you know, when you’re actually at work people do, you know, they do forget, they’ll give you sympathy but then they forget and you’ve got to be full on.”*

(Eileen, PWMS, int 2)

Some of the participants reported having to adapt working practices in light of their MS. For Julia, this related to her loss of short term memory. Previously she used to be able to remember all her work tasks whereas now she found she had to write things down:

*“I always had a good memory. I always... Like if it came to work and things I never used to write things down, I used to keep it all, what I needed and stuff and that was a big shock to...”*

(Julia, PWMS, int 2)

Not only was Julia’s memory loss significant and posed a threat to her professional role, she linked her good memory as an intrinsic characteristic of who she was and the loss of memory disrupted that sense of self. Most of the participants were reluctant to openly disclose they had MS to their employers or co-workers; however for some this was unavoidable. The perception they

had was that they may be discriminated against in the workplace, as Ruth's account illustrates:

*"We work in teams and some managers won't want me. Makes me feel pretty shite. I spoke to HR who have been good. They have arranged for an Occupational Health appointment. It makes me feel inferior. I want to do my job and not be pushed aside."*

(Ruth, PWMS, int 1)

In Julia's experience she faced open discrimination, with another person being employed to do her job when she was off ill and she now had to report to that person:

*"I just find just because I'm not in the same position that people don't really come to me with work, you know, it all goes through someone else and it's just all... I just feel like I'm more pushed out, you know, kind of thing and people don't really see me as, I don't know, responsible or anything."*

(Julia, PWMS, int 1)

In Ruth's and Julia's accounts there is a strong link between their professional role and how they view their self. Ruth states that being not wanted in a team would make her feel "*inferior*" whereas Julia feels "*pushed out*" in her job. The link to fulfilling professional roles, being unable to do so due to MS, and the impact on the sense of self and self-esteem is evident from this data. Julia's statement that "*people don't see me as, I don't know, responsible*" also gives a sense of her feeling as though others now view her capability as less than before she had MS.

These excerpts suggest that MS may require some adaptations to work life, whether that is time off during a relapse of symptoms, or adjustments to daily working to accommodate the symptoms of MS. The descriptions from the participants also suggest this impacts on the sense of self, as work partially defines the self. In addition, the individual's sense of self seems fragile to how others treat them at work, as both Ruth's and Julia's accounts illustrate.

### 5.5.2. iv The anticipatory carer

The anticipatory carer captures the interpretation of the support persons' accounts that described their anticipation of a change in the nature of the relationship between themselves and the person with MS, from partner or parent, to that of carer. All of the support persons reported a slight change in the relationship, whereby they had taken on certain chores that had previously been the domain of the person with MS, with three of the support persons clearly identifying themselves as carers at the time of the study. The data were rich in narratives that expressed an anticipation of being a carer at some point in the future.

*"I have had to think about it from the point of view that I may, at some point, be in a position of being a central carer in Lorna's life and that initially was a big mental shift. But then I had to think about well yes, but Lorna does what she can for herself now, so she's not there yet and she may never be there and if she is we'll support her to do as much as she can for herself."* (Nic, SP, int 1)

In this account, Nic refers to the prospect of her relationship with Lorna becoming one of main carer as a "big mental shift" which suggests a degree of cognitive struggle with this change of role and subsequent change of identity. There is also a sense of uncertainty in this narrative which suggests that even though there is the prospect of becoming a carer, it may never happen, therefore my conceptualisation of this as an "anticipatory carer" identity helps to explain this liminal state of the support person. For some of the participants however, their role had begun to change already. Due to the overwhelming fatigue his partner had been experiencing, Richard described how he now took on many of the household chores:

*"Well, trying to do everything I basically can for her. I mean, I've told her she should probably have kept going off sick, because she worked for*

*another month after that before she even went to her GP and got a month's sick line, as you probably know.”* (Richard, SP, int 1)

Richard's account referred to doing chores around the house, rather than providing personal care for his partner. This was also alluded to by Nic in the previous account. Richard's narrative also suggests the support person provides supportive care, as he stressed the need for his partner to take care and not work so much in order to reduce the impact of fatigue. Anticipating the impact of certain activities on the symptoms of MS and taking steps to minimise these became part of the role of the support person, almost like a buffering role. This was common in most of the support person accounts where they acted to try to reduce the impact the symptoms of MS on their loved one. This suggests a rather selfless and altruistic nature to the support person role, however it was evident from the data that the symptoms of MS did place a strain on the relationships between the person with MS and the support person. Brian and Judy indicated that they had considered leaving their partner as the symptoms of MS had placed considerable strain in the relationship:

*“There was a time when I thought [Ruth] was being lazy but it is easier now we know. It affected our relationship to point of me thinking about walking out.”* (Brian, SP, int 1)

Brian's account suggests that since knowing the cause of the fatigue his partner had been experiencing, he was able to understand and make allowances for this, rather than thinking she was simply being lazy. This suggests that whilst it is important for the person with MS to understand how it affects them, it is also necessary for the support persons to be informed, in order to support the person with MS adequately. Judy's narrative illustrated this very well, as her partner constantly asked her questions about MS as he struggled himself with the diagnosis:

*“He kept asking me these questions at the beginning and I couldn't help him... I had to make him phone the doctor to go and see the*

*nurse but he was asking me all these questions and I says I don't know. So one day... I says to him I want you to phone that MS nurse and get an appointment, I had to be quite firm because I was getting bombarded with all these questions and I couldn't help him."*

(Judy, SP, int 1)

Judy's account highlights the role of the support person in helping the person with MS to access relevant information and support; thus, knowing what is available is important for the support person as well as the person with MS. Her narrative indicates a feeling of being helpless in her role, as she could not respond to his questions about MS. The emotional impact of being the support person was also highlighted in the data as many of the support persons alluded to feeling isolated or not having anyone to listen to their worries. This suggests an emotional burden of care for the anticipatory carer, which highlighted the need for support of the support persons as they also shared the experience of learning to live with MS. Nic's description of not wanting to share her worries with her partner highlights this:

*"If you're in the capacity as I am as a support person for Lorna, having somebody to go to and talk to about it independently of the person that you're with or that you're supporting is quite important to have. Somebody who is outside that, so you can be honest about how you feel without feeling guilty and without certainly burdening the person who has the diagnosis."*

(Nic, SP, int 1)

Nic's account not only highlights the need for support in the form of someone to talk to about her own fears and worries, but by stressing that this needs to be independent so that she can express herself honestly it suggests that in supporting the persons with MS, she is perhaps having to shield her own feelings about MS to maintain a façade of coping. Not being a burden, and "just wanting to speak to someone" were common phrases that were alluded to by the support persons, which further supported the interpretation of the anticipatory carer role as one which requires support. For one of the support

persons interviewed, the interview itself appeared to have a therapeutic value for her:

*“I am glad I have spoke to somebody, I feel better myself that I have spoke to somebody. I’d not have said half of what I have said if Steven was sitting there.”* (Judy, SP, int 1)

The research interview allowed this participant to speak freely about her feelings without fear of upsetting or burdening her partner. Up until this point she had not had this opportunity.

The “anticipatory carer” theme has highlighted the impact of being diagnosed with MS on the role of the support person as they anticipated a shift in their identity from partner or parent to carer. The findings presented here suggest this is not an easy transition, rather the person’s sense of self is disrupted from the taken-for-granted roles in their established relationship to an incomplete transition to “anticipatory carer”, which again supports the main theme category of the “liminal self” being relevant to the support persons of those with MS.

### **5.5.3 Self and others with MS**

This theme was prevalent across all the participants, as they described how they viewed others with MS. A number of the participants in this study had attended the local “newly diagnosed” MS support group. This tended to be a six week short programme of information-giving sessions where people who had been recently diagnosed may find out more about their condition and meet others in a similar circumstance. However, the reality of attending these groups sometimes had a negative impact on the individual’s sense of self and perhaps even their psychological wellbeing, as Lorna’s account quite clearly illustrates:

*“So I kind of thought well shit, is this a good place for me to be? Because then these started putting all these kind of images, you know*

*it just started to play havoc with my mind. This could happen to me now, this is real and... I think it was more counterproductive rather than... although it was nice to kind of see that you weren't on your own, well actually you know these were people like myself who had just been recently diagnosed and they were in different states from what I was and it brought it home to me I suppose – a hammer punch kind of thing.”*

(Lorna, PWMS, int 1)

Lorna's vivid description illustrates how seeing others forced her to face up to having MS and consider the possibilities for her own future. Until then, she had been able to suppress this potential reality. Now, after seeing others with more disabling MS than she had, she reported this was playing havoc with her mind. Her use of metaphor linking the experience to a “hammer punch” and it playing “havoc” with her mind suggests this was a traumatic experience. Both Lorna and Sheila selectively decided to attend the newly diagnosed sessions based on the topics being discussed, with another participant, Nancy, deciding she did not wish to attend at all. This may be interpreted as an attempt to preserve the sense of self against an image of a future self as a disabled self. Physical disability and the need for a wheelchair in particular seemed to be a commonly-feared consequence of MS for many, but not all the participants.

Steven's account below highlights his sense of self as linked to his physical attributes of being fit and sporty. His hospital stay exposed him to potential realities of a life as disabled:

*“I can just remember being in the hospital and seeing people around me in wheelchairs. And me being hardly able to walk and it was quite scary in fact. Because I'm quite a fit guy and I like to keep fit and I like to do lots of different sports. Swimming, martial arts, loads of stuff but I like to work as well. I've not been one of these dole kids if you like, I've always worked. And knowing I've got MS is a worry because I don't want to be sitting about in the house.”*

(Steven, PWMS, int 1)

In this excerpt, Steven portrayed his perception of himself as fit and sporty and was frightened by what he saw in hospital as this may represent a future self. Seeing others with more severe physical disabilities as a result of MS was a factor which struck fear for the sense of self in the participants; a fear for their future self and how MS might affect them, almost like seeing a vision of their future like “the ghost of Christmas yet to come” (Dickens, 1843).

In this section I have described how the participant data illustrate how seeing others with MS impacted on the participants’ sense of self. Evidence from the data showed that participants were sensitive to exposure to others with obvious signs of disability associated with MS. It was almost as if seeing someone else with disabling MS was like confronting a possible future, which was too disturbing to process.

The main category “disruption of self: roles and relationships” is broken down into sub-themes which illustrate the complexity of the sense of self and how being diagnosed with MS touches upon each facet for the self. All participants reported a sense of disruption to their perception of their self which often related to the roles they played, either in families or professional working lives. The data also supported the interpretation of the sense of self being disrupted further by seeing others with MS, which was perceived to be more debilitating than that experienced by the individual. The taken-for-granted self seems constantly to be challenged, with the individual being forced to confront a new reality of the self with MS. This suggests the sense of self is not a stable state, but a state which is under constant threat from further symptoms of MS. Therefore, being diagnosed is just one part of the person’s journey with MS.

## **5.6 Learning to live with MS: an uncertain future**

The previous themes of “road to diagnosis” and “the liminal self” articulate the participant’s journey towards living with MS as part of their new self. Whilst being diagnosed was the pivotal moment in this journey, the theme “learning to live with MS: an uncertain future” explains how the participants described the experience of living day to day life with MS. Learning to live with MS and uncertainty had initially been two separate themes, but as I explored the themes in depth I found they were inextricably linked and thus were better understood as sub-themes of one theme category. Table 10 provides an overview of the development of the theme from the *in vivo* codes, to intermediate themes, towards the superordinate theme.

<b><i>In vivo</i> themes (free coding)</b>	<b>Intermediate theme</b>	<b>Superordinate theme</b>
Being let down by NHS	Negotiating health care	Learning to live with MS
Familiarising with medical world		
Negotiating health care system		
Rules of engagement		
Knowing how to navigate through the services		
Getting on with things	Impact of MS on daily life	
Threat to control		
Symptom monitoring – hyper vigilance		
Ways of coping		
Threat of disability		
I'm always going to have this	Living with uncertainty	
Remaining positive		
Spectre of MS		
Difficulty planning future events		
Moving forward		

Table 10: Table of themes for “Learning to live with MS”

The narratives discussed in this superordinate theme illustrate the profound impact the symptoms of MS had on the participants’ daily lives in respect of their physical functioning, as well as the threat of further deteriorating functional capacity through being disabled, due to the symptoms of MS. For the support persons, the theme represents their concerns of the uncertain future for both their partner and their own self as carer. The support person’s role as anticipatory carer was described as a separate sub-theme in the previous section. Negotiating health care was also a sub-theme in this category as participants explained their experiences of, and difficulties in, accessing health care for MS related support. The findings presented in this

theme provide a rich context for understanding the lived experience of learning to live with MS and uncertainty.

### **5.6.1 Impact of MS on daily life**

MS impacted on the daily life of all the participants with MS, to a lesser or greater degree, depending on many factors such as the severity of symptoms or the perceived severity of symptoms. For some of the participants this meant having to make small concessions to their activities and for others the impact meant significant lifestyle changes were necessary. There was a sense that re-assessing their lifestyle choices may be an on-going process as the course of the condition progresses. Thus, a sense of not knowing what the future holds was evident when making such adjustments to living. For Julia, like most of the participants, the symptom of fatigue meant that she had no idea from day to day how she would feel and quite literally had to lay down to MS:

*“... Like sometimes I have to say, you know, I actually can’t do this because I’m tired. I don’t think he always realises why I come in and I go to my bed, but I literally need to go to my bed even if it’s just for a wee while, just for a rest. I think there’s been times he doesn’t really get that.”*

(Julia, PWMS, int 2)

The expression “literally need to go my bed” suggests that she cannot fight against the fatigue and it has such a force that she must lie down to it and rest. This extract equally highlights the impact of MS on the relationship as one partner cannot experience the hidden symptom of fatigue, thus it is a symptom that is poorly understood for many who experience it. Similarly, the impact of MS on daily life extends to the roles within the family home that the participants had traditionally assumed. Lynne described her experience of providing Christmas dinner for the family. She still wished to do this as she always had done, but despite making some efforts to make things simple she

now acknowledged that at some stage in the proceedings someone else may have to step in:

*“Christmas we’d have family round here. I had my mum and dad and my brother-in-law. I took as many shortcuts as I could but by the time the food was ready to dish up I was too fatigued to do that and someone else had to take over and that was that.”*

(Lynne, PWMS, int 2)

Whilst fatigue was a symptom which was common to all the participants with MS in this study, other symptom patterns were more individual, which is a feature of the condition. For Julia, she had previously experienced loss of eye sight, which was her first main symptom of MS which led to her being diagnosed. As a designer, Julia’s eyesight was important to being able to do her job. Being faced with the threat of losing her eyesight again was a source of constant worry for her as captured in this account:

*“That my eye sight will go again I think, that worries me because every morning I wake up and my eyes are really double and I know there’s something I can do with my eye to get it straight and I don’t know if I’m using my eyes properly and if I’m compensating in some way so that it will be straight and it worries me one day I’ll wake up and I can’t get it back or something because that’s pretty horrible.”*

(Julia, PWMS, int 2)

Loss of control over body and eye sight in particular posed a threat to Julia’s career choice. Because of her symptoms she is vigilant to change every morning, can she see? What can she see? MS is a threat that may steal her sight while she is asleep. The above extract also indicates the meaning of her eyesight in terms of her being able to do something and her “not using her eyes” properly, which suggests she thinks she may be able to delay the onset of the loss of eyesight or have some degree of control over it. Julia refers to the thought of not being able to see as “pretty horrible”, which illustrates the implications for her of losing her sight and that whatever she

does to help retain her sight may not be enough. For another participant, Steven, who also experienced loss of sight, the main impact of this symptom was on his ability to work and to participate in sports:

*“I lost part of the sight in one of my eyes and that’s down to MS. And I’ve had that for at least two years and that’s, I’ve been struggling at some sports with that as well. I’ve been struggling to work, as well as other factors. Being weak and a bit tired at the end of the day but this is the early symptoms so I don’t know what I’ll be like in a few years and it’s a bit worrying.”* (Steven, PWMS, int 1)

In this account, Steven described how his symptoms were affecting him now, but also expressed concern over what the future holds for him. He saw his current situation as the “early symptoms” of MS and feared a worsening of symptoms, the nature of which is unknown. The findings in this theme also touch upon the sub-theme of the “self at work”, as the participants described how they felt they had to consider the possibility of a change in job role or complete change of career, depending on what the future held for them living with MS. With Julia’s career as a designer being so dependent on her eyesight, the threat to this caused her some distress as she faced the possibility of contemplating a new career:

*“I mean I just I do want to say well from now on I won’t stress about daft things, it’s just hard. I mean I’m sure everyone stresses about things. Partly throughout this time it’s been like that – ‘oh, maybe I should give up my job’ kind of thing, and I’ve still been – I’ve just never done anything else, kind of thing, so you would just find yourself in the same situation with some other company, kind of thing. You just don’t know, and that’s probably more stress than anything, so sit tight and see what happens, kind of thing.”* (Julia, PWMS, int 2)

In order to reduce the impact of fatigue on her ability to work, Julia found it necessary to adapt her working pattern by arranging to work from home for part of the week. Whilst working from home reduced Julia’s commute and her

fatigue, this arrangement brought a new problem of social isolation from work colleagues and to a certain extent left her feeling excluded:

*“I mean I pretty much have everything set up so I can work just the same as what I would in the office. It’s sometimes a bit lonely, [laughs] start kind of wandering about the house kind of thing because you’re in your back room just kind of sitting there but you can still talk to everyone from work because we’re all on messenger and everything so anything’s that happening you can still find out what’s going on and things.”* (Julia, PWMS, int 2)

In her account, Julia changes from personal pronoun when describing her home working physical environment, to the third person when talking about the social impact of working at home, which intensifies the sense of isolation she feels. While electronic communication helps to reduce the isolation, there is a sense from Julia’s account that it is somehow not as effective as actually being with others in the office environment. Similar to Julia’s account, being socially isolated from daily life and activities was a sub-theme which was captured in the data from Lynne’s and Lorna’s interviews. For Lynne, who was the most physically disabled of the participants, her MS meant that she was not as able to travel around, even short trips to the shops or hairdresser became major events and she lost contact with most of her friends:

*“I used to have what I thought was a good group of friends but they have since disappeared.”* (Lynne, PWMS, int 1)

In her first interview, Lynne expressed disappointment that her friends had stopped calling, and her simple sentence above illustrates how her friends did not meet the expectations she had and let her down. However, in the follow up interview, being in a wheelchair opened up new experiences in Lynne’s daily life as she made new connections which may not have come about if it were not for her disability:

*“There is a great connection of people who are in wheelchairs going about shops and it’s almost as if there’s a network and they always speak to each other and you wouldn’t have noticed that, but they must all have gone through similar experiences, and you can’t really believe how shallow and rude some people are in that there was one man that I spoke to and he had several times had shopping baskets put in his face because people don’t see you if you’re in a wheelchair. And I didn’t appreciate the invisibility aspect and I can see that now.”*

(Lynne, PWMS, int 2)

In this account, Lynne clearly is at ease with herself as a wheelchair user, and as this forms part of her identity it has provided opportunities to share experiences with other wheelchair users, thus creating a sense of community and belonging. What is also interesting about this extract is that while people with MS who are wheelchair users are possibly the most visible, Lynne describes her experience of being in a wheelchair as being invisible to others. So the experience of the community of wheelchair users is juxtaposed against being invisible within society, as well as the being most visible representation of a person with MS.

For one participant, Julia, having MS also meant she made a significant change to her appearance by cutting her long hair off:

*“This is going to sound kind of trivial, but I cut all my hair. It was really long. I had long hair, and I thought, you know I can’t spend hours straightening this hair and doing it. That’s just one thing I got rid of, and thought that’s one less thing to do, that I used to spend a lot of my time doing.”*

(Julia, PWMS, int 1)

When I asked if she liked her new short hair, her reply was tentative, suggesting cutting her hair was a practical step which perhaps wasn’t a happy decision:

*“I’m getting used to it. No, I do like it. It’s just the difference.”*

(Julia, PWMS, int 1)

In the first account where Julia introduced the topic, introducing it as “kind of trivial” suggests that the issue may seem trivial, but to her it was quite a significant change. Additionally, she stresses the length of her hair through repetition, perhaps to give a sense of the magnitude of this change to her self presentation. Her self-image is now changed along with her sense of self as a person with MS. Her decision however, was described as a change necessary to reduce the time she spent on tending to her hair, thus reducing this daily activity.

Not all changes to participants’ daily life were due either to actual symptoms or personal decisions. For the participants who were drivers, having to inform the DVLA about their diagnosis is mandated by law. This meant that they had their driving licence revoked, albeit temporarily. Whilst this would pose restrictions for all individuals affected, for one of the participants in this study, having her licence revoked was an affront she found difficult to bear:

*“I’ve just contacted the DVLA about – because they said by law I have to do that, and I just got a letter back yesterday saying we’ll have to take your full licence off you, I’m like what! You know and you have to get a medical one, you haven’t got your full... You’re not allowed to drive a mini bus. I think well I do that at work and there’s nothing wrong with me, you know and so I was quite taken aback by that. It’s like tarring everybody with MS with the same brush type of thing.”*

(Lorna, PWMS, int 1)

For Lorna, who had relatively mild symptoms of MS, the restrictions posed to her driving linked strongly to her sense of self. Driving a mini bus was something she did without any problem and she found it difficult to accept that would no longer be part of her role. She used the metaphor of tarring everyone with the same brush to illustrate how she felt about being excluded from this activity.

To summarise, the findings presented in this section show that MS had a significant impact on daily life, and affected the many activities that participants had been used to doing and had taken for granted as simply part of what they did. The findings suggest the nature of the symptoms often dictate what activities of daily life may need to be reconsidered by the individual, either immediately, or at some point in the future. The participants' accounts illustrate that MS overshadows their daily life in their wider social and work related networks, resulting in a degree of social isolation. In addition to the physical impact of MS, there are certain legal aspects, such as the DVLA driving licence, which may also take decisions out of the individual's sphere of control. The data suggest the experience of living with MS appears to be bound to the experiencing of restrictions imposed in one's life and a feeling of lacking control over the course of the condition.

### **5.6.2 Living with uncertainty**

Living with uncertainty was a theme which was common across the all participants in this study, both those with MS and the support persons. Uncertainty also appears to be a strand which transcends many of the theme categories, suggesting it is a subject of some importance in the lived experience of those affected by MS. In the "disrupted self" theme, I presented data to support the sense of self as a liminal self, constantly subject to a changing biographical narrative depending on the perceived impact of the symptoms of MS. Similarly the "impact of MS on daily life" was subject to uncertainty. In this sub-theme however, I give precedence to the theme of uncertainty in its own right, as the participants' accounts supported a view of uncertainty as a feature in itself:

*"You don't know what's going to happen. There could be nothing for the next X amount of years or there could be something next week, you don't know. So I think it would just be take it as it comes."*

(Janice, PWMS, int 1)

Janice's account above suggests an overwhelming sense of uncertainty to her life and typifies the relationship between the individual with MS and their inability to look to the future with certainty. The future is filled with possibilities and threats to one's ability, so taking each day as it presents itself is one way of being able to cope. A further aspect to this was finding the concept of life filled with uncertainty difficult to understand. Julia explained this succinctly in the following account:

*"But I mean the MS thing I think, I don't know, you can't really think about what's going to happen next or anything, just try and... I can't get my head around it I don't think."* (Julia, PWMS, int 2)

The uncertainty of MS itself was difficult for this participant to comprehend, again supporting the concept of uncertainty as an overwhelming aspect of living with MS. This account illustrates a degree of cognitive dissonance that was common to many of the participants who were not significantly disabled by MS and did not feel ill. Therefore, the prospect of living with a serious and potentially profoundly disabling condition was difficult to comprehend.

Uncertainty of the future appeared to be a feature which overshadowed life with MS, causing the participants to weigh up the many possibilities without being forced at this stage to take action. As Steven's account illustrates:

*"It's early doors, it is early doors. Re-evaluate my thoughts, I'm still thinking about things and I'm not the kind of guy that just jumps into things. So careful thought over anything I do, mostly anyway."* (Steven, PWMS, int 1)

Anticipating having to make significant changes to living and lifestyle arrangements was also prevalent in the support person narratives. For some, this included considering moving house to accommodate future physical impairment:

*“Initially we kind of had this... not panic, but we kind of thought oh maybe we should move flat and go to somewhere at ground level and you know, on the basis that we have to prepare. And then you kind of calm down a bit and you think well wait a minute, we're fine! Fine, we don't need to do that now.”*

(Nic, SP, int 1)

Nic's account highlighted the initial reaction to the diagnosis of MS was to consider the possibility of physical disabilities severe enough to warrant moving from their second floor flat. In some ways this reaction was similar to the persons with MS, whose immediate thoughts about MS were of being in a wheelchair. Once the initial anxieties subsided, more rational thoughts took place. One of the participants however, put the diagnosis of MS into perspective by rationalising that as they had lived with the symptoms of MS for some time prior to receiving a confirmed diagnosis, there was no need to make rash decisions:

*“Our whole world's not going to revolve around the fact that Billy has got MS, we're going to accept it and get on with it and deal with it. We have actually dealt with it for three years to be honest this is actually nothing new, it now just has a name.”*

(Jean, SP, int 1)

Taking each day as it comes was a sentiment which was repeated by a number of the participants in various forms. For Steven, Janice, Lorna and Nancy, their approach to uncertainty meant that planning for the future was more immediate rather than a future many years ahead. The data suggested a sense of the participants being uncertain as to how MS would affect them and placed a significant threat to visioning the future. For Nancy, the threat of being less able was a significant factor in her uncertain future:

*“Instead of planning a few years ahead what you're going to be doing next year, you think more to enjoy now, kind of thing, or the next few weeks or months. The emphasis is more on that, such short term. And take advantage of being able to do things. Not with a view that I*

*might not be able to do them next year, but just to have that slight thought, I suppose, that you might not be able to do it as well.”*

(Nancy, PWMS, int 2)

Even when her symptoms had receded the threat was still palpable:

*“Everything’s calmed down now but is it suddenly going to flare up again? What do I do if it does?’ You just hope for the best and it’s just like it was, flared up the last time or is it going to be worse?”*

(Nancy, PWMS, int 2)

The prospect of deteriorating health, and in particular functional ability, was commonly feared by the participants in this study. Not knowing when and to what extent this might be, again left them with an uncertain future where they might require support:

*“I don’t really need any support now. Now that I know I’ve got quite a mild case, I’ll be OK for a wee while. But if I start deteriorating I might need more support but right now I’m not too bad. I can still move about, I can still do what I was doing before. A bit slower, but generally I’m fine the now eh?”*

(Steven, PWMS, int 1)

Steven’s worries centred around the prospect of needing support with his mobility and also bodily functions. Classifying himself as having a “mild case” of MS suggests that Steven may have been using hope as a strategy to cope with the uncertainty he faced. In hoping that his MS is mild, Steven may be able to think more positively about his future and view threats to his physical ability as lesser than if he had a more “severe case” of MS. Thus, maintaining a hopeful outlook acts to preserve the sense of self. However, this did not seem to be particularly successful strategy in Steven’s case as earlier in his interview he had described his fear of being in a wheelchair due to his MS:

*“I know it’s [MS] not life threatening, people always say that it’s not life threatening but then I’ve always said if I was in a wheelchair it’s life*

*threatening to me personally. Because I couldn't have anybody running about after me, I've always said that and I've always thought that.... Well in a way my life is ruined because I cannot, I'm not mobile. So I wouldn't want to ruin anybody else's life."*

(Steven, PWMS, int 1)

For this particular participant, despite using hope as a way of coping with uncertainty, the prospect of being in a wheelchair overshadowed his thoughts on what his future with MS may hold. Steven's conflicting accounts of how he viewed MS suggest that it is a challenging situation which has resulted in some degree of psychological conflict where he wants to hope for the best yet he fears the worst. Thus his experience of uncertainty was not a constant state rather it was a fluctuating state dependent on his immediate narrative. The coping strategies Steven adopted and his attitude towards having MS was very much linked to his sense of self. He mentioned throughout the interviews that he saw himself as a strong person, almost suggesting that having MS was a sign of weakness he found difficult to accept:

*"I'm quite a strong minded person. Other people might disagree with that but I am, I am quite strong minded. So basically it's been myself really like with the bulk of it, that's got me through it."*

(Steven, PWMS, int 2)

In this account, Steven reiterated his self as a man of strength, and asserted this as linked to his self-reliance, in adapting to living with MS.

Coping with uncertainty was approached in different ways by the participants. In contrast to hope, trying put thoughts or worries about MS to the back of one's mind was another strategy adopted by some of the participants:

*"I try not to think what could be, you know, in 10/20 years' time. You might always have it in the back of your mind, you might worry that it could deteriorate, but it's not really at the fore front."*

(Julia, PWMS, int 2)

Similarly, Lorna suggested that to worry about what might happen all the time was a pointless and futile task, and alluded to the fact that living with the uncertainty of MS was no different than the uncertainty of life generally. This point was illustrated in the following extract where Lorna reflected that she might get run over, which suggests we do not know what fate awaits us, therefore uncertainty is always a feature of life:

*“It's like in a way that it might never happen you know. And you're not... getting run over by a car or something like that you know, you can't be sitting around thinking about things that might never happen.”*

(Lorna, PWMS, int 2)

Both Julia's and Lorna's accounts illustrate their approach to dealing with the uncertainty they faced due to MS and presents a pragmatic, almost matter of fact approach. However, this contrasts with the previous accounts where the fear of what might lie ahead for the participants was a common theme across the interviews.

The accounts presented above support the suggestion that the experience of uncertainty was a common feature of living with MS, which affected many of the participants. The data also highlighted that uncertainty is not experienced as a universal phenomenon, rather it is a subjective and socially constructed experience which is often uncomfortable and leads individuals to try to adopt certain ways of coping to minimise their discomfort in the uncertain state. Additionally, the experience of uncertainty by an individual is not a constant state; rather it is a state that fluctuates depending on the context of the condition and the person experiencing it. The data from Steven's interview suggest this state may fluctuate within a short period of time. Being able to interview the participants at two time points highlighted this slight change in the perception of uncertainty.

### **5.6.3 Negotiating health care**

Previous themes have highlighted how, once the participants have crossed the threshold into life as a person with MS, the symptoms of MS become part of everyday life, and part of their identity. This sub-theme of “negotiating health care” reflects the participants’ experiences of accessing and engaging with health care services in the primary, secondary, and tertiary settings following their confirmed diagnosis of MS. This theme was predominantly of relevance to those with MS, but also to a lesser extent to the support persons. The theme of “road to diagnosis” highlighted many issues relating to timeliness of appointments as well as communication issues. From the narrative accounts, the participants in this study described on-going difficulties in accessing timely and appropriate information and support, often not knowing which service to consult when. Negotiating health care thus became an important aspect of their life, which sometimes required an assertive approach to ensure they were seen and heard.

Learning how to negotiate their way through the health care system was almost like learning the rules of a game – the terms of engagement, and as such were important to understand. When describing her consultation with a locum GP, Janice recounted her frustration at what she had been told to do when she had new symptoms and what happened when she followed this advice:

*“One of the first things he said to me was, “You have got a relapse and you’ve got MS, you have to expect these things”. And I just kind of looked up and I said ah ha and I explained what it was and he said, “It does sound like an episode of the MS but you should really be phoning the MS nurses”. So I said that when I saw the neurologist I did ask the neurologist if anything else happens who do I get, the clinic or the GP. She had said Dr [Neurologist] says is go via your GP, the GP’s first port of call. But he was not...”*

(Janice, PWMS, int 1)

Despite receiving instructions from the specialist MS service as to who to contact for support and acting upon this, the encounter described by Janice

above suggests that the response was less than satisfactory. In telling Janice that she, “had to expect these things”, the GP in a way belittled her experience. Being in the early stages following diagnosis each experience is new and concerning, therefore it is not unreasonable to expect that some reassurance in these stages may be necessary. Janice considered that she consulted the GP promptly based on guidance she got from the specialist MS nurse:

*“I did go to the GP sooner rather than later because after speaking to him I phoned up the MS nurses and spoke to [MS Nurse] and she gave me guidance about how, you know, questions to ask yourself and is it getting worse, wait so long and decide is it getting worse, is it staying the same or has it got better. And I thought right that’s fair then because I guess that gives a guide. But I thought as well if I’m not going to the GP where’s this getting recorded?”*

(Janice, PWMS, int 1)

This account shows that Janice clearly considered the advice given to her. Her question as to where her symptoms were being recorded gives a sense of vulnerability and suggests that perhaps she simply needed to report her symptoms and have this noted to reassure her. Several participants reported the value they placed in the information and support provided by the specialist MS services. For Steven, seeking help from someone who was a specialist was particularly important:

*“A doctor would give you some information and then somebody like yourself with a calming voice. That knows specifically about what you’ve got and knows about the symptoms basically. Not somebody that’s just a trainee basically or somebody that does other diseases.”*

(Steven, PWMS, int 2)

In this extract, Steven asserted how important it was to him that he received advice from a specialist, rather than a general practitioner. However, specialist services do not come in unlimited supply; this affects the

accessibility of services for people with MS. Many of the participants discussed time lags between referral and appointments both on the “road to diagnosis” and in this theme. However, occasionally the time lags were reasonably short (four weeks):

*“I got told I would be passed on to the MS specialist department or whatever they’re called, I can’t remember know, but because I was actually fine at that time it, you know, it wouldn’t be... it wouldn’t happen immediately, that it would take a while. So I’ve got an appointment for February, [laughingly] which is faster than I thought because when doctors tell you it will take a while you immediately think like a long, long time.”* (Ruth, PWMS, int 1)

Delays in receiving support however, were experienced by the participants in this study:

*“To some extent I’m finding that however good the NHS is in some things, they are very lax at coming forward to help. Like waiting for four months for an OT to come and I still never heard, apart from a first letter a while back, so I think for things like that it could do with recommendations ... So in that way I feel let down by the system.”* (Ruth, PWMS, int 2)

In Ruth’s account she explains the difficulties she is facing with her restricted mobility and, despite waiting for four months for an assessment, the help and support she needs was still outstanding at the time of the interview, for which she blames “the system”. Her feeling of being let down indicates a feeling of personalisation of being let down and gives a sense of helplessness in her situation. However, some of the participants displayed a more empowered approach to engaging with health care services. Janice kept a diary of her symptoms so that when she had her yearly check up at the specialist MS clinic she could accurately recall how she had been. Being prepared for consultations in order to make the most of the short time available was important to several of the participants. Eileen was protective of her time, not

wishing her husband to accompany her so she could ask questions relevant to herself. Both Eileen and Lorna prepared themselves by searching for information about MS. Lorna described preparing to ask relevant questions during her consultation:

*“I did a bit of research on the multiple sclerosis website and got a lot of good knowledge for myself and then opened up questions which I made sure I prepared before I went to see him.”*

(Lorna, PWMS, int 2)

Trying to make the most of the time with the MS specialist through being prepared, suggests that participants value this consultation as a reliable source of expert information and that this is important to them.

This theme highlights the context of health care provision and the social structures that influence how people with MS interact and negotiate their way through the complex system. The context of health care provision was often the subject of criticism from the participants in this study, while at the same time individuals within the system were seen as worthy of praise, as the participants placed their confidence in health care practitioners. Arguably, one must question how this dichotomy exists.

## **5.7 Chapter summary**

This chapter has presented the findings from the analysis of the interview data. The focus group provided a useful exploratory phase to the study, with the data informing the development of the interview guide for the interviews with the participants with MS and their support person. These interviews were subject to IPA, which allowed for a deep interpretative process of analysis. It should be acknowledged that the interpretation is my own and that other perspectives may bring new analysis and insight into the data presented.

The findings presented in this chapter have highlighted the biographical impact the diagnosis of MS has on the person with the diagnosis and their main support person. The data suggest that being diagnosed was a significant life event which was the trigger for the individual to engage in meaning making which centred on what the experience means for the sense of self. The uncertain and unpredictable nature of MS, coupled with the newness of the diagnosis itself, meant that participants acknowledged a changed sense of self with an uncertain new self emerging. This indicated to me a sense of a liminal way of being, and I have therefore used the concept of liminality to aid the interpretative analysis of the data. The following chapter will expand this discussion and set it within the context of existing literature, before proposing a new conceptual framework to help further explain the lived experience of biographical disruption in people affected by a new diagnosis of MS.

## Chapter Six: Discussion

### 6.1 Introduction

The aim of the study was to explore the experiences of the person newly diagnosed with MS and their support person in order to develop an understanding of the lived experience and in particular the impact on the individual's sense of self and how individuals affected manage the transition to living with MS. The narrative approach taken, allowed the study participants to reflect upon their lived experience as they constructed narratives around that experience. These narratives helped to communicate the meaning of the experience for the individual's biographical narrative. The study used an interpretative phenomenological approach to explore the lived experience of the study participants.

In Chapter Five I presented the interpretations from my analysis of the narratives of the participants in thematic form. This chapter discusses these interpretations and positions the findings in context of what is previously known from the relevant theoretical and empirical literature. The literature discussed in Chapter Two highlighted the existing theoretical understandings of biographical disruption in chronic illness and the lived experience of persons with MS, however little was known about the shared experience of the person with MS and their support person. The findings presented in this thesis have identified key themes which add to existing knowledge of identity theory in chronic illness and as such make a contribution to knowledge. I develop a number of arguments that are relevant to extending the understanding of biographical disruption in chronic illness by drawing from wider identity theory, borrowing from other disciplines, and examining this in the context of the findings from my study. The hermeneutic research approach enabled me to understand and interpret the narratives of the participants, allowing me to explain how the diagnosis of MS affected the "*being-in-the-world*" of the participants. I also present a conceptual framework which builds on previous theoretical positions of chronic illness

and biographical theory, to further illuminate the understanding of the lived experience of living with MS in the initial stages following diagnosis.

My study adds to the body of existing knowledge by developing the meaning of being diagnosed with MS for the self, and identifying the processes that individuals go through on their journey to living with MS as part of a new biography. To articulate this new knowledge, I have developed a conceptual framework which builds on previous theoretical positions of chronic illness and biographical theory to further illuminate the understanding of living with MS in the initial stages following diagnosis.

This chapter focusses on a discussion of the components of the conceptual framework within the context of the wider literature on chronic illness and biographical theory. In developing the conceptual framework I have drawn from a number of key theories including: the theories of biographical disruption (Bury, 1982) and loss of self (Charmaz, 1983), as well as van Gennep's (1960, cited in Bigger, 1962) rites of passage theory and the theory of threshold concepts by Meyer & Land (2003) in the field of higher education. This brings together my experience as a dual professional in nursing and higher education. I believe this wider perspective has enriched the study and my development of the conceptual framework.

I also reflect on the research methods used, discussing the particular limitations and strengths of the research process, and reflect on my development as a researcher. My research adds to the body of knowledge by developing our understanding of the experience of being diagnosed with MS in relation to both the person with MS and their main support person. My findings contribute to the existing knowledge base by highlighting the concept of the liminal self as relevant to the participants' lived experience.

This chapter begins with a discussion of the findings in relation to the extant literature, clearly arguing for the development and contribution to knowledge in relation to our understanding of biographical disruption in those affected by a new diagnosis of MS. The implications for nursing practice, research and

education will be highlighted. The chapter then focusses on a reflexive analysis of the research methodology, identifying the strengths in the approach used and highlighting the study limitations for the reader to consider. The chapter concludes with some personal reflections on my development throughout the research process.

## **6.2 Threshold concepts and the liminal self in MS**

The concepts and themes presented in this chapter, combined with my active engagement with existing theory, have been developed to propose a conceptual framework of "*Threshold concepts and the liminal self in MS*". The process of circular interpretative activity involved demonstrates my active engagement of hermeneutic analysis as my analysis of the data informs further engagement with previously published literature. Biographical disruption was the concept which guided the research by informing the development of the research questions and choosing an appropriate methodology and methods to study this concept within people affected by MS. Inherent in this concept are experiences of uncertainty: uncertainty of the self and uncertainty of the condition of MS.

In the current study, the participants described their experiences of biographical disruption and the uncertainty that clouded their sense of self as something which seemed to be a very fluid concept. Sometimes they felt assured within themselves and at other times a strong sense of vulnerability and fear for the future was evident. It was clear from the data that their sense of self was in a transitional state, and the impetus for this transition was the diagnosis of MS. There has been a wealth of previous studies on the self in chronic illness and also focussing on MS. Previous studies which have explored the impact of a diagnosis of MS have tended to involve participants with a wide ranging length of time since being given the diagnosis (Johnson, 2003) or not been focussed exclusively on the experience of people with MS (Bury, 1982; Charmaz, 1983). This poses limitations on the findings of such studies as participants have to rely on memory of being diagnosed with MS, and with the passage of time, diagnostic procedures and attitudes to giving

patients information may have significantly changed. The findings from my study have captured the lived experience of being diagnosed with MS as close to the time of diagnosis as was possible within the constraints of the study. I argue that this has led to a much nuanced description of the lived experience which has highlighted a liminal self in MS, as being significant as the person remains in the liminal state for some time.

Previous studies of chronic illness have tended to present trajectory interpretations to transitions to living with a chronic condition, almost suggesting a linear process to such transition (Corbin & Strauss, 1988; Shaw, 1999). Corbin (2001) acknowledges a varied trajectory including acute exacerbations similar to MS relapses. Kralik et al. (2006) challenge such notions of linear transitions suggesting instead that learning to live with a chronic condition requires a fluid interpretation with movement in a number of directions. This suggests a much more chaotic approach to transition theory.

Bury's work on biographical disruption (1982) and Charmaz's (1983) loss of self theory contributed significantly to current understanding and have indeed been of major influence in this study, as has an understanding of Mishel and Braden's (1988) uncertainty theory. The data from the current study support the notion of a transition to living with MS and that this transition has a disruptive impact on the individual's sense of self, but the uncertain nature of the condition is significant. The transition to being a "self with MS" is overshadowed with uncertainty as the participants struggled to make meaning for the sense of self, with MS thus suggesting a more chaotic interpretation of the experience as suggested by Kralik, et al. (2006). The data presented in the previous chapter highlight the impact of biographical disruption on every aspect of the self but also suggest a sense of the self being in limbo, a liminal state as the uncertainty overshadows the transition; the new self being overshadowed by the prospect of the effects of a relapse of MS. It is with this interpretation that I argue in this thesis for a new conceptualisation of the self in MS as a liminal self with the diagnosis of MS conceptualised as a threshold concept.

A detailed discussion of the biographical impact of newly diagnosed MS on the individual and their support person and how this impacts on their transition to living with MS can be understood in relation to the metaphor of a threshold and the concept of the liminal self. This thesis proposes a conceptual framework, "*Threshold concepts and the liminal self in MS*" as a new way of understanding and perceiving the lived experience of people affected by a new diagnosis of MS. A thorough explanation of the conceptual framework and how it relates to the main theme findings are presented in this discussion chapter.

### **6.3 Road to diagnosis: the preliminal journey**

The road to diagnosis reflects the notion of a journey towards the moment of diagnosis. The data presented in Chapter Five illuminated the period prior to diagnosis as being the beginning of biographical disruption where participants were experiencing symptoms but not yet being aware of what was causing their symptoms. Three major subthemes were identified in this superordinate theme (see Appendix 11). These were: "Knowing one's body: knowing one's self", "Being diagnosed: crossing a threshold" and "A shared journey". These themes gave a sense of early disruption to the individuals' sense of self which I have conceptualised as the preliminal self (van Gennep, 1960, cited in Bigger, 1962). The preliminal self in MS will be discussed within the context of the existing body of literature.

#### **6.3.1 The preliminal self in MS**

The findings presented in Chapter Five, and discussed in this section, provide support for the notion of an early awareness of the self being undermined by the experience of troublesome symptoms which indicate the possibility of an illness or other unknown condition. The embodied experience which instigated the need to seek medical advice as well as the experience of seeking that advice led to the sense of self being challenged and, as such, early disruptions to the sense of self, are evident. I propose this phase of the road to diagnosis be conceptualised as the "preliminal self". The

concept of the liminal self draws on the work of the anthropologist van Gennep (1960, cited in Bigger, 1962) whose seminal text on “rites of passage” defined three periods of liminality which bear relevance to the findings of my study. Van Gennep (1960) classified the phases of liminality as preliminal (rites of separation), liminal (rites of transition) and post-liminal (rites of reincorporation). The lived experience of biographical disruption on the road to diagnosis suggests the beginnings of a separation from the individual’s conceptualisation of their taken-for-granted pre-symptomatic self, a liminality of the self, proposed as the “preliminal self with MS”. This also concurs with the findings of my study which suggests early disruption of the sense of self is characteristic of the preliminal phase of a threshold concept.

### **6.3.2 Embodied experience**

The experience of bodily symptoms was a key feature of the lived experience during the pre-diagnosis phase which, for many of the participants, was characterised by a prolonged period of suffering with non-specific symptoms which were often put down to stress or clumsiness. The evidence presented in the current study supports the notion of a journey towards the moment of diagnosis, with my interpretation of the participants’ journey conceptualised as the “road to diagnosis”. As the most common theme in the data, all the participants described the period preceding diagnosis, where they experienced bodily symptoms which caused them to wonder what was causing their symptoms.

For some participants this time period extended over many years, from a first episode of symptoms which had not been given a conclusive diagnosis, whereas other participants had been diagnosed within a few weeks of their first episode of symptoms. For the participants, the time from symptom experience to diagnosis varied from two weeks to 20 years, which is similar to Koopman & Schweitzer's (1999) study of the experience of people prior to diagnosis of MS, in which the time from symptom onset to diagnosis spanned a range of 6 months to 22 years. Such a variance in the time to diagnosis can in part be explained by the unpredictable and non-specific

nature of early MS symptoms, but it does raise issues for the lived experience of the individuals experiencing the symptoms. This also supports earlier work on chronic illness where different trajectories often preceded the confirmation of diagnosis (Asbring, 2001; Asbring & Närvänen, 2004; Kralik et al., 2001).

The embodied experience of unfamiliar symptoms may be conceptualised as “troublesome” and as such cause worry over the cause of the symptoms. The presence of symptoms, described by the participants in section 5.2.1, is what prompted them to seek help from medical services. In this part of the participant journey, there was, as yet, no label for the symptoms, simply an awareness of something not being quite right and the possibility that it might be “something serious” and as such the sense of self may be rendered fragile as the symptoms may pose a threat to the person’s existence, and way of being-in-the-world (Steven, PWMS, section 5.2.1). These findings support earlier work by Johnson (2003), who discovered that, even prior to the confirmation of diagnosis, people begin to raise suspicions and worry over what might be the cause of their symptoms, with some considering MS as a possible diagnosis. This stage is described by Corbin and Strauss (1988) as prediagnostic limbo and is a stage which is common in other chronic conditions, such as chronic fatigue syndrome, that have with symptoms which may be described as “non-specific” (Dickson et al., 2008).

Encountering troublesome symptoms encapsulates one of the main features of the lived experience of the sub-theme presented in section 5.2.1 *knowing one’s body: knowing one’s self*, where the participants described in great detail the experience of physical symptoms that led to their seeking help from the medical professions. Help seeking behaviour itself was not a focus for this study, rather, my analysis has focussed on the meaning of the symptoms for the sense of self, and exploring the lived experiences in relation to that focus. The participants’ experiences during the pre-diagnosis phase resulted in an uneasy unbalancing of the self and a quest for information and support (Corbin, 2003; Wilde, 2003). The embodied experience of MS-related symptoms signals a rite of passage from being a person in good health to ill

health which is associated with a separation from former taken-for-granted conceptions of the self (Bury, 1982; van Gennep, 1960 cited in Bigger, 1962).

Several authors have explored the connection between embodied experience and the self in relation to biography (Finlay, 2003; Williams, 2000). In relation to the person with MS, Finlay (2003) explored the dynamic relations between body-self-world in her phenomenological study of “Ann”, a woman with advanced MS. The embodied experience of the symptoms of MS were inextricably intertwined with the sense of self and being-in-the-world and whilst this study adopted a case study approach with one individual with advanced MS, the findings bear relevance to the early stages and support the theme *knowing one’s body: knowing one’s self*. The findings in my study concur with Finlay’s (2003) earlier case study, as I summarised the theme *knowing one’s body: knowing one’s self as* linking the sense of self as integral to embodied experience of symptoms, with the individual’s knowledge of what is normal for them, and the perception of the self as they journey along the road to diagnosis as factors which are closely intertwined. Such articulation of the link between embodied experience and “knowing the self” helps us to understand the connection between the body and the self in maintaining biographical equilibrium. When the embodied experience is upset by symptoms, the balance for the self is equally affected, suggesting a relationship between the body and the self.

### **6.3.2 Being discredited: undermining the self**

The impact of the symptom experience on the sense of self and the reactions of others was evident in the road to diagnosis, as some of the participants had experienced a feeling of their symptom accounts being discredited, and feeling as though they were viewed as timewasters. Often participants faced having their symptoms questioned, which they framed as a questioning of their integrity and undermining their sense of self. The eventual confirmation of a diagnosis was then often received as a relief that the person was not “making it all up” or it was not “psychosomatic” as had been the suggestion for Billy who also had a history of mental health issues. In their study of

people with chronic fatigue syndrome, Dickson, Knussen and Flowers (2008) described similar findings of their participants being discredited or undermined by others and suggested this also led to an internalisation of the doubt which they described as “scepticism and the self” (p465). Such internalisation of scepticism was also evident from the participant narratives in my study, as four of the participants described doubting the authenticity of their symptoms or having these doubted by others. Kleinman (1995) attributes such experiences as being related to the dominance of the biomedical model of the treatment of chronic illness, as diagnosis, treatment and prognosis are based upon known illness trajectories. The difficulty with conditions such as MS is that the symptoms are often vague, may mimic other conditions and the trajectory remains uncertain even after diagnosis.

There are few previous studies examining the pre-diagnosis phase of MS, however Koopman and Schwiezer (1999) explored the experience of newly diagnosed people with MS and found they experienced a “labyrinth which connected them to multiple voices and led them on various paths” (p17) often with significant delays between being seen by specialists. Some of the participants in my study had a particularly difficult road to diagnosis, peppered with visits to various members of the health care professions including general practitioners and specialists including ophthalmologists, psychiatrists, and ear, nose and throat specialists before being seen by a neurologist. Bury (1982) suggested that lay perceptions of symptoms and the decision to seek help do not necessarily coincide with those held by professionals and as such often result in missed early warning signs. For Steven, the missed opportunity to diagnose his MS seven years previously was a source of anger and resentment. His account questioned the medical staff’s authority to withhold information about him which he felt he should have been given.

In her seminal paper on loss of self, Charmaz (1983) identified being discredited as a factor which contributed to the loss of self. Thus the reactions of health care professionals can be understood to have an influence over how this period in the road to diagnosis is experienced by the

individual. My interpretation of the findings of my study suggest the sense of self may be seen as a fluid concept, subject to change in the mind of the person, influenced by the experience of the condition itself, and from the reactions and actions of others around them, including, family, friends and the health care professionals.

The biomedical model therefore does not fit well with the patient experience and serves to “delegitimise” the illness experience and experience of symptoms (Kleinman, 1995). Kleinman (1995) suggests through delegitimising symptoms such as pain and fatigue, symptoms commonly experienced by people with MS, this intensifies their suffering. I argue that my data supports Kleinman’s assertion that the biomedical model of chronic illness is dominant in the participants’ experiences of MS and that by being so, it impacts negatively on their sense of self, by delegitimising and discrediting the self.

To summarise, this section has proposed the conceptualisation of the preliminal self in the road to diagnosis of MS as a useful concept in developing our understanding of the lived experience of people leading up to the time of diagnosis of MS. The preliminal self is a state of being where the taken-for-granted sense of self is beginning to be unbalanced by the recognition that the symptoms may be caused by a potentially serious condition. Other factors contribute to shaking the individuals’ taken-for-granted sense of self, such as when the authenticity of symptoms is questioned. This serves to provoke an assertion of the self as the former self, thus illustrating the fluidity of the self at this stage.

### **6.3.3 A Shared Journey**

The data from the experience of the support persons highlighted their exposure to troublesome knowledge at this time before diagnosis, as section 5.2.1.i drew attention to the support person’s experience on the road to diagnosis being a “shared journey”. In this previous section I explained the lived experience of the support person as that of a concerned observer, not

quite apart, yet not quite the same. Few studies have focussed on the shared experience of support persons, or as they are more commonly referred to in the literature, “carers” or “significant others”. However in a study relating to the onset of dementia in people with MS and their significant others, Kelly (2010) found that the experience of the significant other was also similarly altered. Drawing on Bourdieu’s theory of habitus (Bourdieu, 1984), Kelly likened the altered state of personhood as like learning to play a new game where the rules are unknown and the game players are unprepared. This earlier work supports the findings of my study and my interpretation of the lived experience being a shared journey where the person with MS and the support person experience the journey together, learning the rules of engagement as they go along.

Corbin & Strauss (1988) described partners of people with chronic illness as playing an important role in the process of reconstructing their identity, however the data from my study also show that biographical disruption may extend to the support person as typical roles in the relationship are challenged by the prospect of living with MS. Esmail et al. (2010) also highlighted the challenges to traditional roles with partnerships, particularly when these were related to gendered roles such as man as breadwinner and female as carer.

One of the early subthemes from my analysis was “waiting and worrying” and while the support person’s experience differed from the person with MS in that they did not have an embodied experience, the knowledge of their loved one experiencing unexplained symptoms caused worry in most cases. However in one of the couples, the impact of early symptoms included fatigue, and this caused a major stress between the couple as the support person struggled to understand the experience of fatigue from the person with MS’s perspective.

## 6.4 Being diagnosed as a threshold concept

The confirmation of a diagnosis of MS was a pivotal moment in the participants' lives in my study. Although many had been experiencing symptoms prior to diagnosis, some for many years, the confirmation of the diagnosis was the point where they began to try to make sense of and gain meaning from what their diagnosis meant for their own sense of self. The struggle for meaning displayed by the participants signified that this was a troublesome concept, even when the diagnosis was welcomed after a prolonged period of wondering what caused their symptoms. The data also suggest that this relief was temporary, further supporting the diagnosis of MS as being a threshold to a liminal way of being in the world.

In the philosophical novel, "Sophie's World" (Gaarder, 1995) Sophie was prompted to ask philosophical questions about her existence and the existence of the world which was described as "jolting her out of her everyday existence" forcing her to confront something new about herself and her existence. Similarities may be drawn with the person who is diagnosed with MS as the diagnosis causes existential turmoil and prompts them to see life through a new lens. The previous section has discussed troublesome knowledge in the form of experiencing the symptoms of MS as provocative and instigating a preliminal state. In this section I make the case for the moment of being given a confirmed diagnosis of MS to be understood as a threshold concept where the person is jolted out of everyday existence, similar to Sophie's experience, into a new state of existence which is unbalanced and unsure, a state I have conceptualised as "the liminal self in MS". The liminal state may be temporary or on-going for some time.

In his seminal paper "Betwixt and Between: The liminal period in rites of passage", Turner (1964) used the metaphor of a threshold to explain the preliminal self as the separation from the old self begins and the person "stands at the threshold" between their previous way of structuring their identity, which has become invalid as the individual is faced with new

characteristics to be incorporated into the self (Turner, 1964). Although threshold concepts have been more widely discussed in higher education literature (Meyer, Land, & Baillie, 2009; Meyer & Land, 2003, 2005) where they have been used to describe the difficult and troublesome experience of becoming part of an academic community, the similarities in process are useful in helping to further understand the diagnosis of MS as a threshold concept. Meyer and Land (2003) expanded the theory to develop our understanding of the transition point as the person in the preliminal phase stands on the threshold of a new life world and a new self. Threshold concepts are defined as having the following characteristics: they are transformative, irreversible, integrative, bounded and troublesome (Meyer & Land, 2003).

As stated previously, some participants had been suspecting that something serious was wrong. My early subthemes reflect this as I had interpreted them as “suspicious minds”, and “something serious”. The data from the support persons also supported this interpretation as many of the participants had become suspicious there was something wrong. Equally some participants were looking to the diagnosis to confirm that their symptoms were not all in their minds. Thorne (1993) identified the diagnostic event as particularly significant for people with chronic illness, as not only were they given a name for the cause of their symptoms, but the diagnosis gave a signal as to what the future may hold. My data show that the diagnostic event has significant implications for the self, and I have conceptualised this as being the threshold to a new self.

The diagnostic event clearly represents the demarcation whereby the individual moves from a place of familiarity, the old self, to somewhere beyond, which is unfamiliar, unknown and uncertain. This bears similarities to Kelly’s (2010) notion of game playing, without knowing the rules of the game, being a person with MS without really knowing what that means for the self. In the context of this study, the threshold concept relates to the individuals’ road to diagnosis as a troublesome journey which was often characterised by a number of unexplained symptoms presenting. In many cases this is for a

number of years, with the confirmation of the diagnosis of MS being the threshold where the demarcation occurs. Being diagnosed with MS is thus a conceptual gateway, a threshold to a new world of understanding of what it means to have MS, to live with MS, or to experience being with someone with MS. The data from my study support the experience of being diagnosed with MS is transformative for the self, as it forces a shift in the perception of the self through the individual making sense of the meaning the diagnosis has for their sense of *being-in-the-world*.

Most of the participants mentioned fears of physical disability and wheelchairs as their first reactions to being told they had MS, and this clouded their perception of what it was to be a person with MS. This is most likely due to the fact that people with MS only become visible in society when they have obvious signs of the condition and supports earlier findings by Johnson (2003) who highlighted the emotional reactions and fears of people newly diagnosed with MS. The image of a disabled self with MS was particularly troublesome for most of the participants; however one participant (Lynne) who had significant physical impairment causing her to walk with the aid of a stick, and use mobility aids when out shopping, viewed these as ways of maintaining her independence and as such were not so troublesome.

The emotional reactions to being given a confirmed diagnosis of MS varied from shock and fear to relief for both the person with MS and the support persons who were interviewed. For some of the participants in my study, having the diagnosis was seen as opening a gateway to support services. However for others the diagnosis came as a blow. I consider the responses to the diagnosis suggest a changed understanding and interpretation of meaning related to the diagnosis, and propose the metaphor of crossing a threshold as a useful concept for understanding the initial impact on the self as the person moves from being a person with symptoms to a person diagnosed with MS as they encounter potentially troublesome knowledge. The findings and interpretation presented here are supported by previous studies which have explored the experience of being diagnosed with MS, which have highlighted being given a name for the condition as contributing

to a reconstruction of identity (Finlay, 2003; Mozo-Dutton, Simpson & Boot, 2012; Toombs, 1995).

Being diagnosed with a chronic condition is widely accepted and discussed in the literature as a defining moment in the chronic illness trajectory (Asbring, 2001; Bury, 1982; Charmaz, 1983; Dickson et al., 2008; Kleinman, 1995; Schumacher & Meleis, 1994; Thorne, 1993). The findings from my study concur with the wider literature as the confirmation of a diagnosis of MS was a pivotal moment of transition in the participants' lives. My study adds to knowledge by drawing on the data presented in section 5.2.2 which appear to capture an awareness from the participants that they are standing on a threshold of a new life world which includes a recognition of a new self. Previous literature on the lived experience of people with chronic illness has identified this stage as significant for the individual's sense of self and that it is not a simple as stepping over a threshold, either in the sense of time taken to do this, or in relation to the level of emotional, spiritual or psychological comfort (McNulty et al., 2004). Indeed this proposition concurs with Meyer and Land's (2003) conceptualisation of the characteristic of threshold concepts as "troublesome".

The transformative element of this experience may then be usefully related to the biographical transformation that is seen in the data presented in my study where the participants' sense of self was transformed by the knowledge of the diagnosis of MS. This was evident in the data from both the person with MS and the support person where the diagnosis of MS took a symbolic nature which represented the possibility of change to the different roles each person played. Section 5.5.2 highlighted the different roles that were disrupted by the diagnosis of MS.

There is no disputing the diagnosis of MS is irreversible, unless in cases of misdiagnosis which are rare. Additionally Meyer and Land (2003) suggest the irreversibility relates to the acquisition of new knowledge, which once known cannot be forgotten. In relation to the findings of this study, once the

participants had been told of the diagnosis, this knowledge could not be unknown and as such is irreversible.

Meyer and Land (2003) further explain that gaining the new knowledge may not be a comfortable experience, a factor supported by my data. This point holds significance for health care professionals dealing with people around the time of diagnosis as it is easy to become desensitised to the impact the diagnosis has on the person. For example, one of the participants in the current study attended the consultation where she was given her diagnosis alone, having previously taken her partner for support, but as the appointment did not indicate the need for support she was left upset and in some distress having then to make a long journey home alone on a bus. Being sensitive to the implications of the diagnosis may make something simple, like suggesting a friend or relative accompanies the person to the consultation, result in the individual feeling supported at this time.

Land, Meyer and Baillie (2010) explain that the transformation may be sudden or prolonged, which again bears similarities to the road to diagnosis in MS which helps to further illuminate this phase. Some individuals are diagnosed following dramatic symptoms and others follow a long protracted road often over a number of years. As such I propose the metaphor of crossing a threshold as a useful concept for understanding the initial impact on the self as the person moves from being a person with symptoms to a person diagnosed with MS. The experience of transition to living with MS can therefore provoke individuals to challenge previous notions of who they are (Koch, Jenkin, & Kralik, 2004).

The findings from my study, presented in the previous chapter, suggested that the threshold concept of being diagnosed with MS was not always as negative as previous theories have suggested. In chapter two I highlighted the negative terminology of biographical disruption and loss of self as potentially problematic for people with MS, who despite their medical diagnosis, appeared “well”. The proposed use of the metaphor of crossing a threshold from one world to another is therefore more helpful in being

inclusive to the lived experience of people with all types of MS. The uncertainty of the trajectory of the condition is however problematic for individuals in their attempts to reconceptualise the self and thus achieve biographical equilibrium.

In summary, conceptualising being diagnosed with MS as a threshold concept contributes to developing understanding of the transitional nature of the road to diagnosis for people affected by a new diagnosis of MS and as such offers a new perspective through which to view the theory of biographical disruption in chronic illness.

## **6.5 The Liminal Self in MS**

The liminal self in MS describes the impact of the diagnosis on the individual's sense of self as they process the information and begin to attribute meanings for the self as being a person affected by MS. The discussion in the previous section outlined the concept of being diagnosed as the threshold concept on the road to diagnosis: the moment where they had knowledge of MS being part of their lives, either as the person diagnosed with the condition or as the support person of someone with MS. This section will focus on the findings which support the notion of the liminal self in MS.

Chapter Two provided an overview of the concept of liminality which refers to a stage where participants "stand at the threshold" between their previous way of structuring their identity, which has become invalid as the individual is faced with new characteristics to be incorporated into the self (Turner, 1964). This stage of liminality is often referred to as "betwixt and between" where the sense of self has become unbalanced and is ambiguous (Barrett 1995; Turner, 1964). Turner (1964) suggests this phase is a transitional phase where the person is in a "state of progressive movement" to "becoming" a new self (Turner, 1964, p46). In terms of biographical disruption the threshold may be the moment of diagnosis where the individual moves from being a person with symptoms to a person with an identified condition. The diagnosis process and event may thus be understood as a rite of passage into a new

community where one's identity is bound by the social norms and culture that have been built around the diagnosis.

Liminality has been used as a conceptual framework to explore the rites of passage through transition to other illnesses such as cancer (Blows et al., 2012; Navon & Amira, 2004) however this has mainly been used as a framework to explore and describe the processes of transitioning, rather than deep exploration of the conceptualisation of the self in illness. Barrett's (1995) autobiographical research also highlighted the relevance of liminality in persons with MS. In higher education, Meyer and Land (2003) and Meyer, Land and Baillie (2009) have developed their theory of threshold concepts to conceptualise the liminality of identity on new academics transitioning from discipline areas to higher education. Land, Meyer and Baillie (2009) explain that the transformation may be prolonged, which again bears similarities to the liminal self in MS and helps to further illuminate this process.

In this section I argue that conceptualising the self is at least partially shaped by the social context of the individual illustrated by the participants' perceptions of their new self and their life stories. The liminal self helps to conceptualise and further articulate an understanding of the experience of biographical disruption of people transitioning from health to chronic illness (Kralik et al., 2006). This transitional experience must also be situated in a social context with visible and invisible symptoms of MS signalling to the person's social network that he or she has "something wrong" with them. Changes to physical ability through the impact of symptoms such as fatigue, pain and/or impairment to motor function signals to the person that they are not the same person they were and this section of the thesis discusses the meaning of this experience within the concept of the liminal self.

Being able to maintain specific roles in society seemed to be important to the participants in my study and was related to the roles and relationships they valued in the context of their own lives. For the participants in this study, the disruptions to the roles each play as part of daily life had a significant effect on their identity. Previous literature has linked identity within the context of

the family unit, social relationships and work roles and this appeared to be relevant to the participants in my study. Considering the experience of becoming a person with MS in the new conceptual framework of the liminal self allows us to understand the impact of MS on identity reorganisations and view this as a precarious transition with the liminal self a consequence of the diagnosis.

### **6.5.1 A Self Disrupted**

The findings presented in Chapter Five (section 5.2.1) suggest that, although the being diagnosed with MS was not always a negative experience, it was certainly disruptive to the taken-for-granted sense of self. The lives of people closely affected by a diagnosis of MS are permanently changed as a result of their experience (Barrett, 1995; Cheung & Hocking, 2004; Mozo-Dutton et al., 2012). The sub-theme of “a self disrupted” presented the evidence to support the participants’ notion of their sense of self, their “taken-for-granted self” being disrupted. The participants in my study mainly described the impact on their sense of self as a disruptive element. They were living a life relatively secure in their sense of who they were, and how this related to the world around them, but the diagnosis of MS usurped this understanding and caused them to question previous understandings of being-in-the-world.

The personal narratives of the participants used terms such as “invincible” and “strong” to describe their pre-MS self. Such biographical narratives the participants had constructed about their self were now challenged, as new narratives emerged; these new biographies now included the self as a self with MS and support the notion of the beginnings of an ontological shift to being a person affected by MS, and coming to know what that means for the self and being in the world. Kralik, Visentin and van Loon (2006) suggest the unexpected diagnosis of the chronic condition may be seen as an enforced transition of the self from the healthy person to ill person and as such is an unwelcome and disruptive factor.

Previous studies in chronic illness described a similar disruption to the pre-illness sense of self (Asbring, 2001; Dickson, Knussen & Flowers, 2008; Pringle, 2011). In relation to participants with chronic fatigue syndrome and fibromyalgia, Asbring (2001) described a partial transformation of the self, where the individual neither saw themselves as the person they were before the diagnosis, nor did they identify fully with the illness state suggested by the diagnosis. This feeling of being neither the pre-diagnosis self or the new self affected by MS was also described by the participants in my study, suggesting Asbring's (2001) findings have relevance to the person affected by MS. Being neither their "old self" or a "new self" was similarly described by Dickson, Knussen and Flowers (2008) in their study of people with chronic fatigue syndrome, with "identity crisis" one of the main themes. Whilst chronic conditions such as chronic fatigue syndrome and fibromyalgia may bear some similarities in that they have uncertain trajectories, the nature of MS is significantly different in that symptoms may be both visible and invisible, with the risk of disability, such as becoming wheelchair bound, or having trouble with bladder and bowel control, being feared by those with the condition (Crigger, 1996).

Many studies of chronic illness have used transition theory as the theoretical underpinning (Meleis et al., 2000). Whilst transition theory addresses the individuals' responses to change as a process, it has been critiqued as being linear in focus with transition from one point to another being the main focus (Kralik, et al., 2006). Meleis et al., (2000) however highlight the flexible sense of self as characteristic of the individual in the midst of the transition. The data presented in Chapter Five concurs with Meleis et al.'s (2000) earlier theory, as the liminal self shows the individual's sense of self being in a state of flux, as each aspect of the self is renegotiated in light of the diagnosis of MS. One of the key features of the liminal self in MS is that reconciliation of the self remains incomplete. This may in part be explained by the unpredictable nature of MS and uncertainty over its trajectory.

The data from my study supports the notion of the liminal self, in the immediate post-diagnosis phase as there are often limited symptoms and

possibly no obvious outward signs of illness. This did lead to a degree of cognitive dissonance for some of the participants as they struggled to reconceptualise their new self, with their new self not fitting with previous conceptions of what it means to have a chronic condition such as MS and their now lived reality. Such difficulty leaves the sense of self unresolved and as such in a state of limbo or “no man’s land” (Draper, 2006). The liminal self therefore describes this state of being in a more powerful manner than existing transition theory allows and extends the understanding of biographical disruption. Kralik, Visentin and van Loon (2006) suggest longitudinal studies are required to capture the full biographical transition experience.

Narrative reconstruction therefore may be a process that evolves with a period of biographical instability, which I propose may be usefully conceptualised as “the liminal self in MS”. It is suggested that liminality may be an ‘adaptive, enduring phase’ characterised by a search for meaning and challenges to identity (Blows et al., 2012, p5). This permits the fluidity of the participants’ biographical narratives to move between the old and new self. As a change to one’s biographical narrative which may be unwelcome, such fluid movement back and forth, may be seen as a protective process which allows the individual to engage in narrative reconstruction when they are psychologically prepared to do so. This postulation however requires further exploration to provide evidence. As illustrated in the data presented in Chapter Five, the impact of being diagnosed with MS extends far beyond diagnosis as this initiates a complex series of interrelated experiences. The complicated transitions between the old self and new self and moving beyond can often be compounded by a compulsion to preserve the old self and resist identifying one’s self as a person with MS (Charmaz, 2002).

In their qualitative study of people with middle to late MS, Grytten & Måseide (2005) found that there was a strong desire from their participants to maintain previous biographical narratives such as being the ‘breadwinner’, which act as a protective buffer to the disruption of the self. My study suggests that individuals with MS struggle to maintain their former sense of self, supporting

my claim that readiness to engage in narrative reconstruction may be an evolving process where the sense of self is “betwixt and between” the old self and the new self (Turner, 1964, p46). Grytten & Måseide’s (2005) study also refers to the liminal self as significant to individuals engaged in a renegotiation of the self and suggests this influences their readiness to disclosing their diagnosis of MS to others.

The findings of my study are in keeping with what is already known about biographical disruption in chronic illness based on the work of Bury’s (1982) biographical disruption theory and Charmaz’s (1983) loss of self, however the conceptualisation of the liminal self in MS adds to the contextual understanding of the impact the diagnosis of MS has on those affected in the period of immediate transition. Thus the period of liminality may be seen as a period of growth of understanding and meaning-making in relation to an emerging self, which does not fully support Charmaz’s conceptualisation of chronic illness as a series of losses.

### **6.5.2 Stigma and the new self**

The disruption to the person’s sense of self due to MS is critical in developing their understanding and influencing their willingness to engage with others and to disclose their diagnosis to others. Similar to previous studies, my study found that individuals may be uncertain about whether or not to disclose their condition, how much information to give to others about their diagnosis, if they give any at all, and to whom (Grytten & Måseide, 2005; Hubbard et al., 2010; Joachim & Acorn, 2000). Previous studies of people with MS have explored the perception of stigma in relation to the illness experience and disability and found that those affected often use selective disclosure to counteract stigmatization in social encounters (Grytten & Måseide, 2005; Joachim & Acorn, 2000). Goffman (1963) conceptualises stigma as an ‘undesired differentness’, an attribute that is unwelcome, making the person with the condition different from others in society. Goffman’s (1963) concept of the ‘spoiled identity’ is particularly relevant to the liminal self in MS as the self is disrupted and the individual struggles to

reconceptualise the self internally and may struggle further if they experience being rebuffed by others, otherwise being stigmatized.

Joachim and Acorn (2000) studied the experience of stigma in people with chronic illness including MS and found that individuals with invisible symptoms were more likely to consider concealing their diagnosis and continuing to maintain their pre-diagnosis activities. Their participants considered that although disclosure might reveal information that may cause adverse reactions from others, concealing their diagnosis with the threat of being found out also brought risks. Either way, risks include being rejected and stigmatized, having difficulty handling the responses of others, and losing control (Charmaz, 1991). Similarly, Grytten & Måseide's (2005) qualitative study of 14 participants with middle and later stages of MS also drew on Goffman's (1963) concept of stigma and Charmaz's (1983) loss of self to explain the development of disrupted interactions with others and coping strategies which created a 'protective capsule' around the self as a result of the perceived stigma related to the diagnosis of MS. Grytten & Måseide (2005) reported that by purposefully concealing their diagnosis of MS, individuals seek to protect their sense of self through selective disclosure.

While people with a visible illness may have less choice about disclosure than those with symptoms that are invisible, individuals can be seen to hold on to their sense of self by attempting to keep their pre-illness lifestyle and identity intact by either maintaining as many pre-illness activities as possible and/or by disguising or minimizing symptoms so that others may not become aware of their diagnosis. For most of the participants in my study, there were few outward signs of their MS. This meant that their condition may be concealed if that was what they chose. The participants in my study were all selective in the disclosure of their diagnosis, with some choosing not to tell employer, and others choosing not to tell family members in the early stages.

The data from some of the participants in my study showed that they tried to distance their experience of MS from common perceptions of people with

MS. Such reluctance to be identified by others as a person with MS may help to understand the reluctance of some to disclose their diagnosis to others. One of the participants in my study did not tell her husband about her diagnosis, preferring to go to her hospital appointments alone and dealing with coming to terms with the diagnosis in her own time. Not disclosing the diagnosis to employers was fairly common as participants did not want to be discriminated against in the workplace.

A number of the participants had faced open discrimination due to their MS; one who had to wear an eye patch due to blurred vision was openly ridiculed in a meeting, and another had become socially isolated by friends stopping contact. By not disclosing the diagnosis, individuals are able to carry on with life as if MS was not a part of them, thus maintaining activities and relationships separate from the knowledge and interference of MS. This phenomenon was described by Bury (1991) as “bracketing” and is seen as a way of preserving the pre-illness narrative and holding on to the self. By trying to shut the condition out of the person’s life they effectively strive to minimise its impact on the self and relationships with others thus creating a “protective capsule” around the self (Grytten & Måseide, 2005). The data from my study suggest that stigma and the resultant reluctance to identify with MS through concealing the diagnosis is a factor which contributes to the liminal self as the person remains betwixt and between trying to maintain one identity when faced with the reality of MS.

The stigma of disability was a prevalent factor in my data, with most participants referring to a fear of being in a wheelchair as a result of MS. The resultant loss of independence was viewed as an insult to their self-concept as independence was seen as something which they valued and wished to maintain. In distancing herself from the possible reference points of people with MS who are profoundly disabled, Janice strived to maintain herself as different, and was clearly not comfortable linking her own identity with the identity of those who have severe disabling MS. For the participants in my study this became problematic when faced with others who had MS at the six week course for people who were newly diagnosed with MS. For some, the

shock of seeing others disabled by MS brought feelings of shock and guilt; as mentioned in Chapter Five, I likened this experience to the “ghost of Christmas yet to come” (Dickens, 1843), when the participants saw someone more disabled with MS as a possible future reality for their self.

In her autobiographical account of living with MS Toombs (1995), similarly described her experience of watching a video of a person with MS who lost his vitality, becoming wheelchair bound, and forced to sell his house. Toombs (1995) described this experience as being “shown a detailed blueprint of the future” (p5), confirming her worst fears of MS rather than focusing on how to live positively with MS. All of the participants in my study who had attended this course spoke of the experiences of seeing others, with the one lady who was disabled by MS finding the experience very distressing as she was able to see that the physical impact of her MS was much worse than the other participants. This finding raises questions about the provision of standardised courses on multiple sclerosis, which although informative, may serve to induce fear and shock.

The proposed conceptual framework of “*Threshold concepts and the liminal self in MS*” may help health care professionals to better understand the nature of support individuals in this transition period require, in order to provide interactions which will provide a more therapeutic environment. Until now the model of support appears to be focussed on becoming disabled or going away and living with MS until one becomes symptomatic through relapse. This is perhaps due to the dominance of the biomedical model in health care which does not fit well with the patient experience of MS (Kleinman, 1995). However the data from my study has highlighted that significant changes to the self are evident even if symptoms are not yet troublesome and this calls for a better understanding of the psychological and social needs of the person in the liminal phase of their transition to living with MS.

### **6.5.3 Impact on the family**

With the onset of MS usually being when people are in their 20s and 30s (MS Trust, 2005) many of those newly diagnosed are engaged in raising young families or in intimate relationships. Being diagnosed with MS therefore has the potential to affect the whole family unit as well as profoundly affecting the person with MS (Halper, 2007). In a discussion paper on the psychosocial effects of relapses of MS, Halper (2007) highlights the impact of MS relapses on the family unit as being like a “sudden jolt” which may cause shifts in roles and responsibilities. The data from my study concurred with this, as being able to maintain specific roles with the family was a prominent theme and seemed to be important to the participants’ sense of self. For the participants with MS, two main roles within the family were particularly prominent in the data: the role of mother and the role of partner. Of the participants with MS, four were mothers, but none of the male participants with MS were fathers.

#### **6.5.3.i Impact on the self as mother**

For the participants in my study who were mothers, their role as mother appeared strongly linked to their identity and they all mentioned their mothering role in relation to their experience of MS. The issues raised related to mainly to disclosing information about MS, and being unable to engaging in the usual activities they associated with mothering. These findings support the findings of earlier studies on the parenting or mothering role of people with chronic illness (Barlow, Cullen, Foster, Harrison, & Wade, 1999; Finlay, 2003; Grytten & Måseide, 2005, 2006). My study adds to the existing literature on the mothering role and the perception of the person with MS on their own role as parent, specifically the mother role. There are relatively few studies which focus on exploring the impact of chronic illness on the mothering or parental role of the person with the condition, with most studies focusing either on the experience of children with parents who are chronically ill, or parents of children who are chronically ill.

The data from my study demonstrated a strong protective instinct from the mothers to shield their children from the realities of MS. The participants engaged in shielding their children from MS in several ways: through actively minimising symptoms, providing reassurance that the condition was not terminal, or by concealing the diagnosis completely. The difficulty of balancing informing the children and maintaining the mother role was challenging for the participants in my study which was similar to the case study by Finlay (2003). Finlay's (2003) participant Ann, described a strong desire to "preserve her mummy role" (p164) from the threat of MS. For one participant in my study, preserving the "mummy role" meant not telling her children about the diagnosis enabling her to maintain a façade of "everything as normal", thus maintaining her sense of self as mother, and not placing the burden of worry on to her children. Although none of the participants in my study had child carers, the literature suggests that people with MS often try to minimise the impact of MS to others in the family in order to avoid well-intentioned involvement and 'gentleness' by family members as they try to maintain normative roles (Grytten and Måseide, 2005).

The findings of my study concur with Grytten and Måseide, (2006) whose qualitative study of people with MS touched upon the mothering role finding that mothers strive to protect their children by communicating to others such as teachers, that the child may have altered emotional needs as a consequence of the mother's illness. It can then be argued that the "protective capsule" individuals with MS create around the self also extends to their children as they try to shield them from the realities of the condition (Grytten & Måseide, 2005).

For the one participant in my study who was more disabled, and thus not able to maintain the activities she associated with her mothering role, such as trips to the cinema, this came with a sense of sense of guilt and sorrow as she found it difficult to accept her now limited role as mother. The impact of MS on the mothering role where previous taken-for-granted activities of the role became restricted or no longer possible negatively impacts on the person's sense of self, and as such may be understood as a loss of self

(Charmaz, 1983). My findings support the findings of earlier work of Barlow et al. (1999) who explored the perceptions of parents and grandparents with arthritis regarding their perception of their ability to fulfil their parenting role and found that perceived inability to perform the role led to feelings of guilt, anger and depression.

The data from my study suggest that new understandings of that it means to be a mother with MS need to be constructed in the liminal phase. Thorne's (1990) qualitative study of sixteen mothers with chronic illness supports my conceptualisation of the liminal self as related to the mothering role, as she found that mothers with chronic illness faced uncertainty of their role particularly in relation to concerns over physical ability, being available, increasing dependency and social activity. Thorne (1990) also highlighted that the concerns of women related to their mothering role were not recognised by the health care system and as such went ignored and unsupported. Again the dominance of the biomedical model can be seen to marginalise the issues that are important to people with chronic illness as they adjust to the impact this has on their lives and their sense of identity (Kleinman, 1995).

One of the limitations of my study was that there were no participants with MS who were fathers, therefore no claims can be made as to whether this finding would relate in the same way to fathers. However the findings from Barlow et al.'s (1999) study which included fathers with arthritis suggests that the issues may be similar and the liminal state of being a father with MS may well apply. The data from my study suggests that MS poses a threat to the mothering role and as such causes disruption to a mother's sense of identity as mother, supporting the concept of liminality of the self as mother.

There were three support persons in my study who were parents of the person with MS, all were mothers. Some of the support person participants mentioned age and possible disability, suggesting they viewed MS as a condition which brought on premature aging. All of the mothers of the participants with MS reported trying to do more to help their adult child.

However this also has a negative aspect to the person's sense of self as they begin to feel less empowered by needing assistance or being perceived as needing assistance. Similarly, Grytten & Måseide, (2005) found that over involvement by family members led to increased withdrawal from social activities as well intentioned protectionism and generosity of close family was found to be humiliating.

The self as mother was an important theme in my study and is perhaps underrepresented in the literature to date. My findings therefore add to the existing body of literature as there were a number of participants who were mothers in this study. My data suggests that being diagnosed with MS posed threat to the identity of self as mother, as this is bound by the individual's socially constructed notion of what it is to be a mother, thus contributing to and supporting the concept of a liminal self. Additionally, for those participants who were mothers of the participants with MS, their sense of self as mother was disrupted and became liminal due to the unbalancing of social norms related to the aging process.

### **6.5.3.ii Impact on couple relationships**

The impact of the diagnosis of MS on couple relationships was highlighted in the data from four of the couples in my study and was presented in Chapter Five in the sub-theme of "self as partner" (section 5.3.2.ii). Previous studies have identified couple relationships as important "social context within which the psychological aspects of chronic illness are managed" (Harrison et al., 2004, p267). Harrison et al.'s (2004) longitudinal study over six years explored the impact of MS-related disability on marital relationships. Their findings suggest that partner roles can be important in marriages, and when they are unexpectedly changed due to disability, the relationship may be threatened. Findings from my data suggest this was particularly so for the support persons prior to confirmation of the diagnosis, when symptoms such as fatigue interfered with the person with MS's usual daily life. The assumption being that the person was simply being lazy.

The data from my study also uncovered issues relating to how the diagnosis of MS impacted on the intimate relationship between the couple. Intimacy and sexual issues are not well researched from a psychosocial perspective in the literature, with most literature tending to focus on physical dysfunction and methods used to manage such. Additionally, much of the literature which has focussed on the impact of MS on the relationship tends to focus on participants with middle to advanced MS (Harrison et al., 2004; Esmail et al., 2010; O'Connor et al., 2008). The findings of my study therefore contribute understanding the impact of MS in intimate relationships on for those in the initial stages of their MS journey.

In one of the few qualitative studies on this topic, the participants in Esmail et al.'s (2010) study highlight the biographical impact of impaired sexual relationships in people with MS. The findings from their study suggest that individuals construct their own definition of sexuality, influenced by various social and cultural factors as well as personal experience. As a result, the individual's definitions of sexuality might change during different stages of their life processes. These changes affect established roles within relationships and subsequently, the construction of identity within the relationship. The narratives from the participants in my study concur as they illustrate the physical changes which made experiencing intimacy more difficult, as well as the emotional and psychological impact of living with MS to the "self as partner" providing a threshold for the relationship entering a liminal state.

The liminal state of the relationship became evident for some participants in my study as new insecurity developed within the relationship due to the meaning that they attributed to living with MS. One participant described her perception of herself as "not ideal" which suggests a feeling of being less attractive to her partner. Sexual relationships allow for the expression of attraction to a partner and as such become an important factor within any intimate relationship. Similar to the participants in my study, the participants in Esmail et al.'s (2010) study described feeling less attractive and therefore

less inclined to engage in sexual activity, however the need for intimacy was highlighted. Such insecurity may be attributed with the individual's readiness to accept MS as a part of their new identity within the bounds of the partner relationship and as such poses a challenge to their previous construction of the self within that relationship.

Physical symptoms of MS which impede sexual relationships are widely reported in the literature (Gruenwald et al., 2007; Tzortzis et al., 2008) but the impact on the person's sense of self is less so. Four of the participants in my study reported symptoms which affected sexual relations, with one woman describing loss of feeling so that when her partner touched her intimately she could no longer feel his touch, and one of the male participants described being unable to achieve erection. The data from the male participant in my study suggested a sense of shame in not being able to achieve erection which Esmail et al. (2010) identified as symbolising a loss of masculinity. When considered in the context of biographical disruption, the data from my study suggest that being able to fulfil the sexual partnership role is an important aspect of what it means to be a wife, husband, or partner, and being unable to fulfil this aspect of the relationship causes dissonance and a liminal experience of what it means to be a person with MS in the relationship. Previous studies have suggested that sexuality and sexual activity within coupled relationships are tied to cultural and psychological beliefs that affect identity (Esmail et al., 2010; Harrison et al., 2004). The data from my study support the earlier findings and this thesis argues for understanding this in the context of a liminal self, thus contributing to developing understanding.

Previous studies have noted gender differences within the couple relationship. Esmail et al.'s (2010) study highlighted the shame of not being able to perform the sexual act in male participants, compared to female participants who downplayed the impact of sexual dysfunction, instead preferring to focus on developing intimacy through cuddling and other means. Sanderson et al.'s (2011) study of couples affected by rheumatoid arthritis suggest such downplaying of the importance of the loss of intimacy is

reflective of “normalising” behaviour. One of the limitations of my study is that with the sample being small, no such generalisations may be made, however it is worth noting that the male and female participants in my study did convey such attitudes towards their altered sexual function. Similarly the female participants in Esmail et al.’s (2010) study reconstructed their sexual self by focussing on developing intimacy and downplaying the importance of sexual intercourse. This concurs with O’Connor et al.’s (2008) earlier findings from their quantitative study of people with neurological conditions including MS, which found that a high level of dissatisfaction with sexual relations caused relationship distress.

The data from my study suggest that sexual issues related to MS may affect the individual’s sense of self within their relationship and as such supports the notion of the relationship itself being in a liminal state. Such disruption to the couple relationship has the potential for wider consequences as the data highlighted the diagnosis being the impetus for a re-evaluation of the relationship itself. For one participant in my study this meant reconsidering the choice of partner, as marriage and having children suddenly became important. And for another, having MS left the participant feeling trapped in an unhappy marriage as she felt helpless and dependent. Dissatisfaction within relationships has been found to occur in between a quarter and a third of MS couples (Du Pont, 1996) with men being more likely to re-evaluate the relationship negatively (Esmail et al., 2010). Toombs (1995) attributes her MS as contributing to the marital breakdown and subsequent divorce from her first husband.

However the literature is not conclusive, as other studies suggest that being in a relationship may also have therapeutic effects for some people with MS. Harrison et al.’s (2004) longitudinal study of couples where one person has MS found that men with MS who were married showed a greater acceptance of MS related disability over time when compared to women. Excluding the data from my participants described above, most of the participants in my study reported that having the support of their partner was an important factor in helping them cope with the diagnosis.

As previously stated, much of the current literature is focussed on physical dysfunction and finding methods to address these with little regard to the psychological or emotional impact of such issues on the couple. Studies which focus on helping couples to deal with relationship issues raised by MS are rare, but one study which implemented an intervention consisting of twelve counselling sessions found that they significantly improved marital and sexual satisfaction compared to the control group (Foley, LaRocca, Sanders, & Zemon, 2001). None of the participants in my study spoke of having such support. Indeed some confessed to having never spoken of such intimate matters to anyone before being interviewed by me. I did note that this was a subject that I was perhaps less comfortable discussing in the research interviews although I did try not to convey this and the participants who did talk about the issue did so freely. Pringle's (2011) thesis on couples affected by stroke also highlighted the issue of sexual problems being rarely discussed, however Pringle also included the use of diaries as a data collection tool and participants who did not discuss sexual issues in the interview setting often used the diary to highlight them. This does suggest a level of embarrassment around discussing the subject and perhaps such levels of comfort are significant in determining whether researchers wish to focus on such sensitive issues.

The findings from my study suggest that the diagnosis of MS places significant strain on relationships between intimate partners. The data illustrate the emotional and/or psychological impact as well as the physical changes of MS, contribute experiencing intimacy more difficult as the relationship enters a liminal state. My findings support the notion of the individual's definition of sexuality being challenged with a subsequent impact on established roles within relationships and a reconstruction of identity within the relationship. This thesis makes the case for the conceptual framework of "*Threshold concepts and the liminal self in MS*" and within the context of the partner relationship offers health care professionals a framework to better understand the nature of support individuals in this

transition period require, in order to provide interactions which will better address their needs.

This section of the thesis has presented the discussion of the findings supported by the findings from the sub-theme of “self as partner” which was presented in Chapter Five. Here I have described the impact of the diagnosis on the individual’s sense of self within the intimate relationship. The discussion will now move on to discuss the sub-theme of the “anticipatory carer”.

#### **6.5.4 The Anticipatory Carer**

The term “anticipatory carer” was used to describe my interpretations of the experience of the support persons who participated in this study. The term captures the sense of anticipation of a change in the nature of the relationship between the support person and the person with MS, from partner or parent, to that of carer. All of the support persons in my study reported a slight change in the balance of their relationship since the diagnosis of MS had been confirmed. The data presented in section 5.3.2.iv. support the experience of biographical disruption as being equally applicable to the support persons, and also suggests that they enter a liminal way of being as they grapple with what the diagnosis of MS will mean for them as individuals, and for their relationship with the person with MS.

One of the participants in my study described the prospect of changing her role from partner to carer as requiring a “big mental shift” in how she thought about herself within the relationship. This experience was echoed by a number of the support person participants in my study but was also clouded by uncertainty as even though the support persons face the prospect of becoming a carer, the nature of MS does not allow for them to determine when this will happen, if at all. My conceptualisation of lived experience as the “anticipatory carer” helps to explain the liminal state of the support person, indicating their previous conceptualisations of their self within the relationship as no longer valid. The current self being “betwixt and between,”

thus supporting the liminal self within the conceptual framework, applies to the support persons of people with MS. The findings from an earlier study by Courts, Newton and McNeal (2005) found that the spouses of people with MS struggled to maintain their identity in the face of changes to their role within the relationship. To date there have been very few studies exploring the perception of chronic illness on the support person and their identity where the support person does not have a clear role as direct care giver.

In Chapter Two I identified that much of the literature relating to carer roles refers to carers with physical caring duties, such as providing personal care, and administration and monitoring of medications (Eriksson & Svedlund, 2006; Ferrell et al., 1993; Murray et al., 2002; Persson et al., 1998) and is related to older individuals where chronic illness is often interpreted as an inevitable consequence of the aging process (Adamson & Donovan, 2005; Ray, 2006). In relation to people with newly diagnosed MS, many do not yet have symptoms which require significant hands-on caring support, however three of the support persons in my study clearly identified themselves as carers at the time of the study. For some, this meant taking on additional chores or roles that had previously been the domain of the person with MS. This change in role signifies the beginning of the “anticipatory carer” identity which may precipitate additional lifestyle adjustments.

Toombs (1995) highlighted, in her autobiographical account of having MS, how not only her lifestyle had to change, but also how the diagnosis of MS made her question if her husband may also have to abandon his goals. Similarly, in a qualitative study of spousal carers of people with MS who had been diagnosed for at least five years and required at least one hour of hands-on care each day, Cheung and Hocking (2004) identified that spousal carers often have to face long term caring for their partner and this may involve giving up their own employment and income, lifestyle, independence and future goals. Whilst Cheung and Hocking’s (2004) study focussed on spousal carers with a clearly defined caring role, the data from the participants in my study suggest an early awareness and an anticipation of

their role changing to that of carer, thus causing a disruption to their pre-MS identity.

For the participants in my study there was a strong sense of isolation of the support person, as a number of those I interviewed stated that the interview itself had been therapeutic as they had no-one outside the relationship to talk to about how they felt about the experience of MS. Not wanting to be a burden to the person with MS, and “just wanting to speak to someone” were common phrases used by the support persons which further supported the interpretation of the anticipatory carer role as one which requires support which is currently not readily available. Carer burden is widely discussed in chronic illness literature but this mainly focussed on carers who are engaged in physical caring duties rather than in the early stages of learning to live with a chronic condition such as in my study (O’Connor et al., 2008; Pakenham, 2007; Pakenham, 1998). The findings from my study therefore add to the existing body of literature by highlighting the anticipatory carer as a liminal state of being in the world for the support persons of people with MS.

Feeling helpless was highlighted by a number of the support person participants in my study. This may well be due to their role being in a liminal state, not yet clearly defined by physical caring activities, and the future being uncertain. The support person is therefore unable to make a significant difference in practical terms to the person at this stage and is limited to providing emotional support in an uncertain existence where both parties are experiencing biographical disruption and are betwixt and between in the liminal state (Bury, 1982; Turner, 1964). A quantitative study by Pakenham (1998) focussed on the coping experiences of couples with MS using validated assessment tools and was based on Lazarus & Folkman’s (1984) stress and coping model. The findings suggest a correlation between psychological adjustment and distress levels and that in most cases these are similar between carer and care receiver. Problem focussed coping approaches were found to be linked with lower levels of distress than emotion coping strategies. From the findings, Pakenham (1998) calls for

patients and carers to receive psychological support to help them in their adjustment to living with MS.

This section of the thesis has presented a discussion of the findings within the context of the “liminal self in MS”. Here I have described the impact of the diagnosis on the individual’s sense of self as they begin to determine what it means to be diagnosed with MS, as well as what it means for the support person. The liminal self in MS refers to a stage where participants stand at a threshold between their previous way of structuring their identity, which has become invalid as the individual is faced with new characteristics to be incorporated into the self (Turner, 1964). The discussion will now move on to discuss the concept of the post-liminal self in MS. The data from the super-ordinate theme of “Learning to live with MS: an uncertain future” which was presented in Chapter Five will be used to support this discussion.

## **6.7 The Post-Liminal Self in MS**

The post-liminal phase of the conceptual framework proposed in this thesis is based on van Gennep’s (1960, cited in Bigger, 1962) classification in the seminal text “rites of passage”, with post-liminal being the “rites of reincorporation”. Within the context of my study, specifically in terms of the biographical disruption caused by the diagnosis of MS, the post-liminal phase relates to the individuals learning to live with MS, thus MS is incorporated into the new identity. The data presented in Chapter Five, under the super-ordinate theme “learning to live with MS: an uncertain future” explained how the participants experienced living day to day life with MS and how this became part of their new identity and way of being in the world, supporting an ontological shift in their sense of self. In the post-liminal phase, biographical reconstruction continues and is a process that evolves following the period of biographical instability which I suggest is conceptualised as “the liminal self in MS”. The data from my study, however, suggest that this may be a very fluid process as the participants’ biographical narratives are overshadowed by the uncertainty of the MS trajectory. This thesis argues for

the conceptualisation to the post-liminal experience within the context of biographical disruption as the participants reincorporate their identity as a self living with MS.

### **6.7.1 Living with MS**

The physical symptoms of MS impacted on the daily life of all the participants with MS, which meant having to make concessions to their usual daily routine. There was a sense that reassessing lifestyle choices may be an on-going process as the course of MS progressed. During the liminal phase, the participants in my study described how they felt they had to consider the possibility of a change in job role, or complete change of career, depending on what the future held for them living with MS. However once these initial anxieties subsided and living with MS was incorporated into their way of being, a more considered approach was evident, suggesting a post-liminal state had begun. Kralik (2002) identifies the post-liminal phase within the context of transitioning to living with chronic illness as the phase where the individual incorporates a new status into their life. Likewise Johnson (2003) identified the period of learning to live with MS as a transition phase and called for this to be “actively managed” (p87), with Kralik (2002) further suggesting that if health care professionals failed to understand the chronic illness within the context of the individual’s life this would lead to continued distress. Thus the transition to living with MS may be understood as a phase where the biographical narrative of the individual begins to stabilise with MS being part of the new identity and as such becomes a post-liminal state.

### **6.7.2 Living with uncertainty**

Living with uncertainty was a theme which was common across the all participants in this study, both those with MS and the support persons. In Chapter Five, section 5.4.2, I presented the data which suggested the participants’ experience of uncertainty was a subjective and socially constructed experience which was often uncomfortable and leading

individuals to develop coping strategies to minimise their discomfort in the uncertain state. For some, this meant categorising their MS as a “mild case,” suggesting the use of hope or minimisation as a strategy to cope with the uncertain trajectory of MS. Previous literature has identified hope as a coping strategy which helps individuals adapt to life with a chronic illness (Dysvik et al., 2005; Felton et al., 1984; Grytten & Måseide, 2005; Stanton & Snider, 1993; Stanton, Tennen, Affleck, & Mendola, 1992; Wiener & Dodd, 1993). The data from my study support these earlier findings and, when conceptualised within the context of the post-liminal self in MS, suggest hope is a strategy used as a way to cope with the uncertainty allowing a reincorporation of the self to a more stable state: the post-liminal state.

Uncertainty also appears to be a strand which transcended many of the theme categories, suggesting it is a subject of some importance in the lived experience of those affected by MS. The data from my study suggest the post-liminal self may be a fragile concept, where the developing biographical narrative is threatened by the uncertainty of the condition. The experience of uncertainty in relation to chronic illness has been well researched (Charmaz, 2002; Kralik et al., 2001; Mishel, 1988, 1990; Shaw, 1999) and has emerged as an important concept in the study of a number of chronic illnesses including MS (Antonak & Livneh, 1995; Crigger, 1996; Grytten & Måseide, 2005; Johnson, 2003; McNulty et al., 2004; Mozo-Dutton et al., 2012). In keeping with the findings from previous studies, the participants in my study also identified uncertainty as an on-going feature of the lived experience as they face the constant threat of relapse (Grytten & Måseide, 2005; Johnson, 2003; McNulty et al., 2004). The data from my study support earlier findings, and suggests that uncertainty is relevant to the newly diagnosed person and their support person even where the symptoms of MS may not be considered as particularly intrusive. This has implications for nursing and other health care professionals involved in supporting people affected by MS at this time. It is important to recognise the distress that the uncertainty may create regardless of symptoms.

A study by Ritz et al. (2000) explored the nature of nursing intervention to reduce uncertainty through the provision of information about the illness and treatment. The findings suggest that it is possible to reduce patient uncertainty with specialist nursing support and as such highlights the need for understanding of the experience of uncertainty in the person newly diagnosed with MS, regardless of symptom experience. A different approach by Pakenham & Samios (2012) suggests mindfulness therapy may have a role to helping individual and dyadic adjustment and acceptance of the diagnosis of MS and in shaping in couples coping with MS. By conceptualising the lived experience of MS in this thesis within the framework “*Threshold concepts and the liminal self in MS*” this helps to extend current understanding of the experience and with the post-liminal phase highlighting the need for on-going professional support.

The participants in my study all spoke of the professional sources of support available to them and these will now be discussed in the following section, negotiating health care.

### **6.7.3 Negotiating health care**

The previous sections of this thesis have mainly focussed on the social context of biographical disruption caused by MS. In this section I will discuss the context of the health care system and how individuals’ engagement in this context is linked to their emergent identity as a person with MS, or support person of someone with MS. Section 6.5.2 discussed how the participants in my study experienced engaging with others in the introductory course for newly diagnosed people with MS. This section will discuss the experiences of engagement with health care providers on a more individual basis. For the participants in my study, learning the how to negotiate their way through the health care system was almost like learning the rules of a game; the terms of engagement, and as such were important to understand (Kelly, 2010). Furthermore, once the diagnosis was confirmed, it opened up a range of supportive services, including health care and insurance claims, which participants had to learn to negotiate their way round.

The data from the participants in my study did indicate a strong preference to be seen by health care professionals who were specialist in the field, or in the case of GP consultations, that GPs knew the person and had knowledge of MS. This finding concurs with Thorne's (1993) earlier study of people with chronic illness which highlighted that the "calibre of health care professionals is central to the quality of health care and to the experience of living with MS" (p82). Furthermore, this does suggest that individuals were beginning to identify with the condition and have a sense of ownership of the diagnosis, thus supporting the conceptualisation of the post-liminal self in MS. Section 6.3.2 also highlighted the difficulties of negotiating health care in the pre-liminal phase where participants did not yet have the validity of the diagnosis. In contrast, there is a strong sense of self agency in the post-liminal phase, as individuals have the validity of the diagnosis to help them negotiate access to relevant services and sources of support.

Thorne (1993) highlights the balance of power being in favour of health care professionals who make judgements based on their own terms of reference, about the symptoms experienced by the person with MS. Within the context of my study this was important, as the time participants had with specialist MS services was relatively short. However some of the participants engaged in actively seeking information about MS in order to better prepare for their consultations. This suggests a sense of ownership, internalising the information about the diagnosis, being prepared and almost attempting to shift the balance of power to the individual being empowered.

NHS guidelines for MS suggest that, following diagnosis and while people remain well, individuals should be seen once every twelve months by an MS specialist service, but they also have the opportunity to self-refer (NHS Quality Improvement Scotland, 2009). The standards focus very much on relapse of symptoms, again suggesting a dominant biomedical model of care for people with MS (Kleinman, 1995). Although psychological care and mental health services are mentioned briefly, partly from the standardised MS courses which have already been discussed in this thesis as having

limitations, there appears to be little emphasis on helping people with MS in this early stage.

This section has highlighted the context of health care provision and the social structures that influence how people with MS interact and negotiate their way through the complex system.

## 6.8 A Conceptual Framework for MS

This thesis argues for understanding the lived experience of biographical disruption following a diagnosis of MS to be understood in the proposed conceptual framework of “*Threshold concepts and the liminal self in MS*”. The process of developing this framework demonstrates my active engagement within the circular interpretative activity of hermeneutic analysis as the findings of my study which were presented in Chapter Five are now consolidated within context of existing theory and empirical works. The development of the conceptual framework draws on a number of theories including biographical disruption (Bury, 1982; Charmaz, 1983), uncertainty theory (Mishel, 1988), transition theory (Schumacher & Meleis, 1994; Kralik 2002), rites of passage (van Gennep, 1960, cited in Bigger, 1964) and threshold concepts (Mayer & Land, 2003; Turner, 1964) which are outlined in Figure Three.

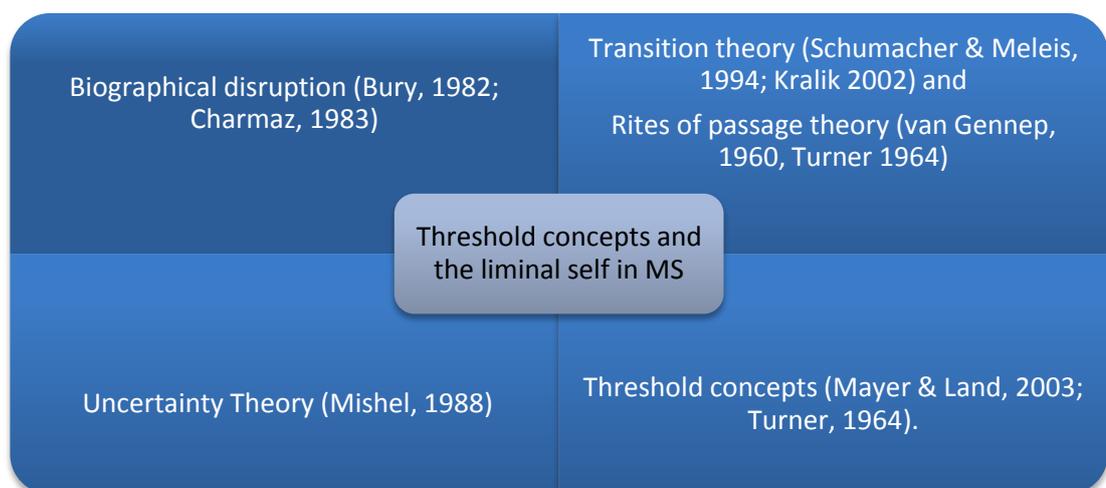


Figure Three: Relationship of key theories to conceptual framework, “Threshold concepts and the liminal self in MS”

This thesis has highlighted the lived experience of people with MS and their support person at a time when they are experiencing acute disruption to their taken-for-granted sense of self. This experience involved a number of processes and disruptions to daily life which impacted on the identities associated with the many roles individuals had in their lives. The findings from the data have captured the lived experience of being diagnosed with MS as close to the time of diagnosis as was possible within the constraints of the study. I argue that this has led to a nuanced description of the lived experience which has highlighted the concept of a liminal self in MS.

The data presented in this study highlight the impact of biographical disruption precipitated by the diagnosis of MS which has been conceptualised as the threshold concept, instigating a liminal state of being in the world characterised by uncertainty which overshadows the transition; and the new self, the post-liminal self, being overshadowed by the prospect of the effects of a relapse of MS. It is with this interpretation that I argue in this thesis for a new conceptualisation of the self in MS proposed in the conceptual framework “Threshold concepts and the liminal self in MS” (see Figure Four).

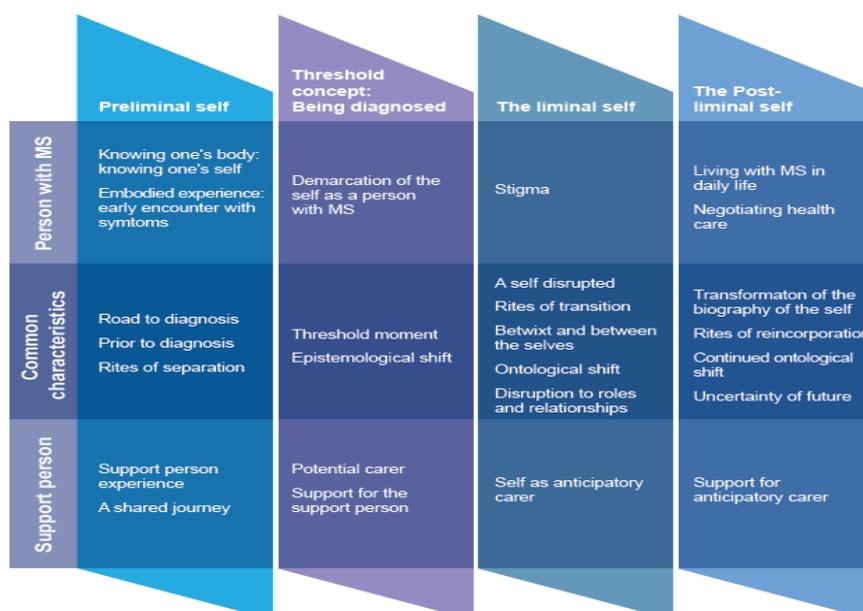


Figure Four: Threshold concepts and the liminal self in MS

**Preliminal self:** conceptualises the lived experience prior to diagnosis where symptoms of MS are experienced but the cause is not yet known.

**Threshold concept: being diagnosed:** conceptualises the experience of being diagnosed as a pivotal moment in the transition from person with symptoms to person with MS, or partner to potential carer.

**Liminal self in MS:** conceptualises the lived experience of biographical disruption where the person's sense of self is in transition, betwixt and between the old self and new self.

**Post-liminal self in MS:** conceptualises the reincorporation of the sense of self transforming the self as a person with MS or support person of someone with MS. This experience is subject to on-going uncertainty and as such is never quite stable.

The following section will present a reflective account of the research process, highlighting the limitations of this study as well as identifying its strengths.

## **6.9 Reflection on the research design**

The purpose of this study was to explore the lived experience of the person newly diagnosed with MS and their support person in order to develop an understanding of that lived experience, and in particular the impact being diagnosed with MS had on the individual's sense of self. The phenomenological approach taken allowed for the study participants to reflect upon their lived experience as they constructed narratives around that experience, narratives which helped to communicate the meaning of their experience of being diagnosed with MS and how this related to their sense of self. By using an interpretative phenomenological approach to explore the

lived experience of the participants, the interpreted meaning that has been presented in this thesis may not have been achieved if another approach had been used. The interpreted meaning presented is a result of active engagement in the hermeneutic circle, from developing an intersubjective connectedness when interviewing between myself the researcher, and the participant (Finlay, 2009) to analysing the data and discussing the findings in the context of existing literature. Each step has involved hermeneutic reflection which has resulted in a co-construction of meaning from the data. My position as researcher was one of active engagement in dialogue with the data and as such must be viewed as subjective. Pezalla et al. (2012), describe the phenomenological researcher's position as an "instrument of the research" (p167), with the research interview being viewed as a social interaction. With this in mind, I have attempted to adopt a "meta-reflexive voice" throughout this thesis highlighting areas where my position has been particularly important (Finlay, 2002). In this section, I will present a reflective account of the research process, highlighting the limitations of this study as well as identifying its strengths and critiquing my own development as a researcher.

### **6.9.1 Reflective account**

My position as a researcher was outlined in Chapter One, where I provided an overview of my professional nursing background, which I identified as having the potential to bring an element of bias to the study through my own experiences and assumptions. I have attempted to limit this bias through adopting a phenomenological position of openness, setting aside judgements about the participants' accounts (Finlay, 2009). My ontological stance as a phenomenological researcher has also influenced my interpretation of the data. In engaging with my participants in the interview setting, I approached this on the basis of my underpinning epistemological understanding of social constructionism. This knowledge privileges the position of the construction of meaning by the participants as being reflective of their social context.

Throughout the study I have kept reflexive notes which have helped me to explore my experiences and understandings in more depth. Sometimes, my writing was very descriptive, particularly in the early stages of data collection, however later, when I became absorbed in analysing the data, these notes became much more detailed. I consider that using IPA helped to deepen my skills of analysis as the approach encourages free associations to develop creativity in the early stages of analysis (Smith, Flowers & Larkin, 2009) and I found this to be particularly liberating.

By using semi-structured interviews, this allowed me to construct a guide of interview topics which could be used loosely to guide the interview whilst being flexible to the participant's course of conversation (Smith & Osborn, 2008). I found my previous experience as a nurse communicating with people in distressing circumstances of particular value here but there is no doubt that my skill in interviewing developed throughout the course of this study. In reviewing transcripts of the interviews, I can see clearly in the earlier interviews how the guide, guided me slightly more rigidly than I would have wanted, and where I missed cues in the conversation that could have yielded more information. As I became more confident in the interviewing process I relied much less on the guide which I believe became less intrusive. Nevertheless, the data from the early interviews remained rich in detail. I had been aware of the potential for the interviews to be therapeutic (Holloway & Freshwater, 2007; Hyden, 1997; Morris, 2001) and I came to realise that the participants appreciated me listening to them tell their story, as some told me they found the experience to be beneficial.

### **6.9.2 Limitations and considerations**

Although many of the limitations have been considered throughout this thesis, a summary of the main limitations of the study is provided in order to allow the reader to consider the findings in within the context of the limitations. In Chapter Three I outlined the methodological considerations of the study and highlighted the change in influence of the methodology from a Gadamerian hermeneutic approach, to IPA. A change of methodology during

a study may be seen as a significant limitation. I described this blending of methodologies as “methodological bricolage” (Kincheloe, 2001). A ‘blended’ rather than ‘pure’ approach could be critiqued as a limitation. Smith (2007) and Shinebourne (2011) assert that there is a “close connection” with the hermeneutic circle being central to IPA. I would therefore argue that the original approach is in keeping with the origins and philosophical stance of IPA, in that the active engagement with the hermeneutic approach is central to both methodologies. This assures the congruency between the methodology and method of analysis in my study.

Given that the introduction of IPA occurred as I was beginning to analyse the data, it could be argued that IPA was adopted as a method of analysis rather than informing the methodological approach to the study from the outset. This influenced some of the earlier decisions such as sample size which otherwise would have been much smaller, allowing for more depth to the interpretative analysis, had I started out with IPA as the methodological approach. The findings of my study have been drawn from a sample of 19 participants (10 PWMS and 9 carers) from one neurology centre in Scotland. This sample size is larger than is recommended for IPA studies, which are suggested to be around a total of 3 to 6 participants (Smith, Flowers & Larkin, 2009). The rationale given for such a small number is the idiographic analysis that is required for IPA for it to achieve in depth interpretative critical analysis. The decision to recruit a larger sample was informed by an anxiety to recruit enough people to ensure good data. This is perhaps a limitation of my own experience and confidence as a researcher, when the focus should have been on quality of data rather than quantity. From my experience of conducting this study, and coming to understand the perspective of an IPA researcher, I would approach this issue with greater confidence in future.

With the limitations of sample size in mind, the findings of my study should be understood as emergent and themes may require further interpretation to achieve the level of depth in a true IPA study. It could be argued that due to the volume of the data I was handling the subsequent level of analysis is quite descriptive in places but this early analysis has laid firm foundation for

the developing conceptual framework which offers new insights into understanding the lived experience of a new diagnosis of MS. I look forward to working with this data, and deepening the analysis in the preparation of papers from this thesis for publication in relevant peer reviewed journals.

In Chapter Four I highlighted the issues relating to the boundaries between researcher and participant as I was very conscious of the narrative around power imbalances in researcher and participant relationships (Holloway & Wheeler, 2002; Parahoo, 2006). I was keen to ensure my participants felt empowered throughout their participation in my study. This perhaps reflects some sympathies I have with the feminist researcher perspective (Oakley, 1981). Although my study was not focussed solely on women, I wanted to reduce the hierarchical relationship in the research setting. With this in mind, I allowed my participants to choose the setting of the interview, and whether they were interviewed separately, or in pairs.

All the participants chose to be interviewed in their own homes. Once again, I reflected that as I was a visitor in their homes, I could not ask someone to leave their own sitting room in order for me, the researcher to conduct the research interviews. I felt this helped reduce potential power imbalances between myself, the researcher, and the participants. To this end, the interviews in my study are not of a homogenous type but a mix of individual and paired interviews. For IPA studies the preference is for an idiographic approach from a homogenous participant group (Smith, Flowers & Larkin, 2009). Therefore an IPA study would have either focussed on the experiences of the person with MS or the support person. In considering this aspect of the study, I contend that the data from each participant has been subject to analysis at an individual level, as the themes were identified using the idiographic approach before looking for connections between them (Smith, Flowers & Larkin, 2009).

Elliot, Fischer and Rennie (1999) suggest that multiple perspectives in qualitative research help to provide additional credibility checks as well as providing a more complete picture of the lived experience. The lived

experience of MS provided the foundation for the shared experience in this study which may be perceived in a different way by each participant but also provided credibility checks as the data were triangulated.

The limitation of using two different approaches to interviewing has the potential to affect the quality of the data as there were clear differences in the dynamics of the different interviews. In the paired interviews, the participants were able to remind each other about facts and events that the other had forgotten. In some cases one participant, usually the support person, would probe the other participant to reveal more information about the impact of MS than they had been disclosing in the interview to that point. Whilst the paired interviews had some benefits in encouraging further information, in the individual interviews some of the participants stated that they had disclosed more to me in the interview, particularly in relation to their relationship, than they would have if their partner had been with them. Both interview types therefore had their limitation but equally they had key strengths. The limitation of the different types of interview may have been reduced due to the benefit of having the different perspectives from both the person with MS and the support person, thus offering triangulation of data.

An additional strength of using the two interview approaches was for the development of me as a researcher. Doing individual and joint interviews in the same study has been a hugely beneficial experience. I can read about the strengths and limitations of interviewing separately or together, and there are arguments for and against either approach, but to have been able to conduct both and experience both, has actually given me the lived experience of the different types of research interview. These approaches to data collection have yielded rich and insightful data.

I interviewed the participants in my study at two time points, the first within one to six months post-diagnosis, and the second within six to twelve months following the first interview. I had initially hoped to interview all participants within one month of diagnosis and again at six months but the recruitment issues outlined in section 4.4.3 and a period of suspended studies for

maternity leave prevented this. The follow up interviews offered a greater opportunity for disclosure and allowed me to pick up on key issues from the initial interviews (Flowers, 2009). Despite this I found that there was not a significant number of new themes arising from follow up interviews. Given the varied and often prolonged trajectory of MS, a more longitudinal study may have yielded more differences in the data.

Whilst my study has captured the experience of the preliminal and liminal self in MS for all participants, because each participant moves through the process at different times and experiences MS differently, the full extent of post-liminal experience in MS cannot be captured in this study. Kralik, Visentin and van Loon (2006) suggest longitudinal studies are required to capture the full biographical transition experience. With this in mind a longer period of follow up may have brought more richness to the development of the post-liminal experience and perhaps also captured the experience of an MS relapse. This would have allowed for further development of the conceptual framework, however this was not possible within the timescale of the study.

Despite the limitations of the study outlined above, the steps I have taken to minimise the impact of the limitations and the decision trail presented throughout this thesis allows the reader to have confidence that this study has been conducted in a rigorous manner. The findings presented in this thesis offer a new way of understanding the lived experience of being diagnosed with MS and as such offers key recommendations for clinical practice.

### **6.9.3 Strengths**

This research study set out with the aim of providing an understanding of the biographical impact of newly diagnosed MS on the individual and their support person(s) and how this impacts on how the person manages the transition to living with MS. I believe I have met the aim of this study through

my in depth phenomenological exploration of the lived experiences of people affected by a new diagnosis of MS.

The rigorous process of research supervision, and yearly progress reviews has provided a supportive environment for collegiate critique and scrutiny, which has supported my development as a researcher, and ensured that my study has been conducted in accordance with the University guidelines and ethical principles.

Using interviews as the basis for the data collection in this study allowed the participants to tell their story and as such, helped to “give voice” to their lived experiences of MS (Koch, 1998; Larkin et al., 2006). Involving people with MS and their support person has allowed for triangulation of the data which has enhanced the credibility of the participant accounts in this study (Elliott et al., 1999). Furthermore, the follow up interviews offered the opportunity to confirm emerging issues from the initial interviews, and allow for further exploration of the lived experience. At the time of writing, there has been no other study with both the person with MS and their support person being interviewed in the same study in the time shortly after diagnosis.

The timescale of my doctoral study allowed for one follow up interview with each participant at six to twelve months after the initial interview. This provided some longitudinal data which highlighted early impact of the diagnosis of MS on the sense of self for the person with MS and their support person. Kralik, Visentin and van Loon (2006) suggest longitudinal studies are required to capture the full biographical transition experience. A longer timescale may have allowed for deeper exploration and understanding of the biographical impact as it is possible that the post-liminal self will be subject to further threshold moments due to relapses of MS. This study was conducted within the time constraints of the doctoral degree.

The process of analysis using IPA has provided an in-depth and rigorous approach to the analysis (Smith, Flowers & Larkin, 2009). Providing an annotated transcript in Appendix Ten aims to add to the rigour of this study

by laying the analysis process open for scrutiny. I have attempted to follow the guidance for good practice outlined by Elliot, Fischer & Rennie (1999) and described this in detail in Chapter Four. This has provided a detailed audit trail of the decisions made in my study which the reader can use to judge the quality of the research presented in this thesis.

Drawing on theories from nursing, psychology and sociology has added depth to the interpretative process, bringing a different lens through which to view the experience of being diagnosed with MS. My active engagement in reflexive thought and the hermeneutic process has brought those perspectives together towards a “fusion of horizons” (Gadamer, 1976) informing the development of the conceptual framework presented in section 6.8 of this chapter.

As the study was set in central Scotland, this adds a unique perspective from participants within the Scottish context. As such the findings are not intended to be generalisable beyond this setting however they may have relevance to others in similar settings.

A key strength of this study is that this thesis has contributed to current knowledge by proposing a new conceptual framework “*Threshold concepts and the liminal self in MS*” which seeks to explain the experience of biographical disruption in people affected by a new diagnosis of MS.

## **6.10 Chapter summary**

To summarise, this chapter has presented a thorough discussion of the findings from my study by situating them within the context of the wider literature. The conceptual framework proposed in this thesis has been developed through in depth analysis of the study data, contextualised within existing theoretical perspectives and as such makes an original contribution to knowledge and understanding of the lived experience of biographical

disruption for people affected by a new diagnosis of MS in Scotland. The conceptual framework for understanding the experience of biographical disruption in people affected by a new diagnosis of MS, "*Threshold concepts and the liminal self in MS*" offers a new way of understanding the lived experience and calls for a move away from the dominate biomedical approach which mainly focusses on the experience of physical symptoms. The conceptual framework does require further refinement and evaluation.

The findings from this study provide a meaningful insight into the experience of people living with the early consequences of being diagnosed with MS, suggesting that biographical disruption is relevant even where there is no significant physical impairment from their MS. The conceptualisation of being diagnosed as a threshold concept and the subsequent disruption to the self as the liminal self, offers a new way of understanding the early impact of the diagnosis on the individual's sense of self. The study has in particular highlighted the concept of the "anticipatory carer" as relevant to the biographical disruption of the support person, which is a phenomenon not previously described in the literature. In relation to the extant literature, the discussion clearly argues for the development and contribution to knowledge in relation to our understanding of biographical disruption in those affected by a new diagnosis of MS.

I have also provided a reflective analysis of the research process, identifying the strengths and addressing the limitations of the study. The chapter concludes with some personal reflections on the PhD process and my plans for the dissemination of the findings. The implications for nursing practice, research and education will be highlighted in the following chapter.

## **Chapter Seven: Conclusions and recommendations**

### **7.1 Introduction**

In Chapter Five I presented the findings from my study and in the following chapter discussed them in light of the existing body of literature. Through rigorous analysis using the IPA approach I have developed a conceptualisation of the lived experience of people affected by a new diagnosis of MS in a conceptual framework “*Threshold concepts and the liminal self in MS*”. This framework is grounded in the data from this study and is contextualised within existing theoretical understandings. As such the framework provides a new way of understanding the lived experience of those affected by a new diagnosis of MS and as such makes an original contribution to knowledge. In this final chapter I will summarise the main arguments of the thesis and highlight my recommendations for clinical practice, education and future research. Finally I will outline my plans for disseminating the findings of my study.

### **7.2 Main arguments of the thesis**

This thesis has explored the experiences of the person newly diagnosed with MS and their support person in order to develop an understanding of the lived experience and in particular the impact on the individual’s sense of self and how individuals affected manage the transition to living with MS. My main argument is that in order for health care professionals to understand how to support people at the time around diagnosis, a critical understanding of the lived experience for the individual self is required in order to fully appreciate the meaning of the experience. Only by understanding what this means to the person at an individual level will the health care professional be able to support and advise the person effectively.

The articulation of a preliminal self in this study drew attention to the experiences of the participants prior to their diagnosis. This is significant as for some this was a prolonged period highlighted by an embodied experience

of symptoms which indicated that something was wrong. This early warning sign initiated the early disruption to the sense of self as “something is wrong with me”, brought attention to the potential impact on the self.

Being given the diagnosis of MS was conceptualised as the “threshold concept” the moment when the individual transitioned from a person with symptoms to a person with MS or the support person of someone with symptoms to the support person of someone with MS. This threshold moment became the pivotal moment in the MS journey and initiated the start of the liminal self in MS. The participant sense of self was no longer assured, rather it was in a state of flux, transition or “betwixt and between” as they sought to make sense of what living with MS might mean for them.

The liminal self was a period of transition of the self, where the sense of self was not in a stable state, participants often sought to move back and forth between the old self narrative and new self narrative, as they sought to construct meaning in different social settings. Social context is key to understanding the experience of the liminal self, as the social roles people play, and sense of self associated with those roles are all affected by the diagnosis.

The post-liminal self illustrates how the individual’s biographical narrative changes to include a self with MS. However, the nature of MS is such that uncertainty of the condition pervades all the stages, and the post-liminal self is subject to further re-conceptualisation. This study allowed for limited longitudinal exploration of this stage, but it is possible that the post-liminal self will be subject to further threshold moments due to relapses of the MS, with further changes to the embodied self which impact the continued changing biographical narrative.

This study has highlighted the relevance of biographical disruption for the support person also through identifying the concept of the “anticipatory carer” as the support person constructs meaning around what the diagnosis might mean for the relationship which may change to a carer relationship. My study

has highlighted this phenomenon as relevant, even when the support person is not in a physical caring role. This suggests support for the support person may also be required.

This thesis makes a contribution to current knowledge by proposing a new conceptual framework "*Threshold concepts and the liminal self in MS*" which seeks to explain the experience of biographical disruption in people affected by a new diagnosis of MS. The development of the conceptual framework is grounded in the data from this study and has been informed by drawing on theories from nursing, health psychology and sociology. This places the contribution of knowledge in this thesis as relevant to those disciplines, as well as medicine and health care practice.

## **7.3 Recommendations**

On the basis of the findings presented in this thesis I have proposed a number of recommendations outlined in this section. These serve as suggestions for clinical practice and future research and are made in the spirit of care enhancement.

### **7.3.1 Clinical practice**

Health care professionals should consider the psycho-social impact of being diagnosed with MS and spend time to individualise the support offered to people newly diagnosed with MS. The current system focusses on a biomedical model of care which privileges the experience of physical symptoms over the psycho-social impact of MS.

Health care professionals involved in neurological clinics where the diagnosis of MS is usually given should consider highlighting in appointment letters that the person may wish to bring a support person with them to the consultation. This will help people with MS consider if they wish to have someone to support them at the clinic setting.

Consideration needs to be given to how the diagnosis is communicated. Wherever possible this should not be given over the telephone unless previously agreed with the person.

Consideration should be given to the nature and amount of information that is given to people when early symptoms present which may indicate MS is present. Communication and consultation with the person are paramount in determining if they wish to have fuller explanation of the possible causes for their symptoms.

Specialist services should consider the complement of participants in the programmes for newly diagnosed people e.g. *Getting to Grips* courses. Wherever possible participants should be attending with people who are experiencing similar levels of physical impairment.

Health care professionals should consider providing a greater focus on living well with MS rather than waiting for symptoms. This may well be a perception of the participants in this study.

Psychological support should be readily available for people who are newly diagnosed and express a wish for support, regardless of physical symptom profile.

Health care professionals need to consider the wider impact of MS for the support person, and consider their role in providing support, or being able to refer to additional sources of support.

### **7.3.2 Further research**

The proposed conceptual framework requires further exploration and refinement. In particular, a more longitudinal study may help to further illustrate the post-liminal experience.

The concept of the anticipatory carer which was relevant to the support persons in this study would benefit from further research to add further depth of understanding into this lived experience.

A similar study focussing on the experience of biographical disruption in fathers would be useful and would allow comparison with the experience of mothers in this study.

An evaluation study to explore the usefulness of the framework for health care professionals involved in the care of people with MS should be undertaken.

## **7.4 Dissemination strategy**

The findings of this study will be disseminated in a number of formats. Throughout the study I have presented both oral and poster presentations, both locally and internationally. I hope to present my findings at the MS Society conference to reach the specialist audience. Details of these presentations are given in Appendix Thirteen. I also plan to publish a number of papers from this study in peer reviewed journals. Such publications include: the literature review of the biographical disruption in MS, a paper discussing the use of paired interviews in IPA and one presenting the main thematic findings from the study.

In addition, the participants of the study will all receive a summary of the findings and note of thanks to express my appreciation of their participation. I also plan to prepare a lay summary of the study for the MS charity literature and through my own blog site. In addition I plan to present to a lay audience through the Ragged University. By engaging in audiences wider than the usual professional audience and traditional formats, I hope the findings of my research will be of benefit to the wider community.

## **7.5 Final summary**

In summary, this thesis has presented a robust analysis of the research approach and methods used to explore the lived experience of biographical disruption in people newly diagnosed with MS and their support person. The experience of using the phenomenological approach of IPA has provided a rich and detailed analysis of the experience.. The experience has also enriched my personal intellectual journey as a researcher. My reflexive commentary throughout the thesis, and reflections in Chapter Six have highlighted the decision trail and my personal intellectual journey.

This thesis has contributed to the existing body of knowledge of the lived experience of biographical disruption in people affect by a new diagnosis of MS by exploring the experiences of the person with MS and their support person at a time following a recent diagnosis. The thesis has proposed a new conceptual framework which has offered an articulation of the lived experience within the context of the liminal self. The conceptual framework is underpinned by key theories from existing literature on chronic illness, and from other disciplines. I believe this has added depth to previous understandings and as such is presented as my original contribution to knowledge.

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## Appendices

### Appendix 1: Table of literature reviewed

Author & date	Country of origin	Aim	Sample & Size	Methods	Findings
Antonak & Livneh 1995	USA	Review of literature relating to psychosocial adaptation to disability among persons with multiple sclerosis	review	Narrative review	This review provides a general discussion of the concept of psychosocial adaptation to disability, reaction phases that the adaptation process is thought to comprise, instruments to measure adaptation. Calls for more research and need to construct a theoretical model for the process.
Barret, J. 1995	UK	to explore the meaning of the diagnosis of a disabling disease for a young woman	12 participants who knew PWMS well	Rites of passage (van Gennep) as theoretical framework Narrative from Jill (PWMS) Interviews with friends and	Phased approach to living with MS based on rites of passage and liminality.

				relatives utilises both autobiography and biography	
Bogosian, Moss- Morris & Yardley 2009	UK	to explore and describe the experiences of partners of people who are in the relatively early stages of multiple sclerosis.	15 partners of people with MS	Qualitative study using telephone interviews	Loss of control, partner worry, psychological distress, Social isolation, relationship changes, lifestyle changes
Brooks & Matson 1987	USA	To explore the relationship of coping strategies to self concept	174 PWMS	Quantitative study collecting demographic, health related & adjustment variables using validated tools including a self- concept instrument,	Differing coping strategies were associated with differing self- concept scores. Four adjustment stages emerged: denial, resistance, affirmation, & integration.
Cahill et al. 2010	Ireland	To explore the explored the occupational adaptation of women with MS	7 women with MS were recruited from the MS Society of Ireland	Mixed methods but more focussed on quantitative measures using validated tools. Modified Interest Checklist (Kielhofner and Neville 1983), the Role Checklist (Oakley et al.1985) & Occupational Questionnaire (Smith et al.1986). Qualitative data were also collected, using the Occupational Performance History Interview—II (Kielhofner et al.2004).	Three main themes emerged: the impact of MS on (i) performance capacity, (ii) roles and (iii) interests. The findings highlight the importance of having an understanding of the impact of different types of MS on the adaptation process. Study conducted from the perspective of occupational therapists and their role in enabling people with MS to adapt to their condition by engaging in meaningful occupations.
Cheung & Hocking 2004	Australia	to explicate the meaning of caring from the perspective of spousal carers for people with multiple sclerosis	10 carers of PWMS	interpretive phenomenologi cal approach IPA was used to describe spousal carers' experiences of caring for their partner.  Data were collected through unstructured indepth interviews and	Key themes: Worrying about their partner and their relationship Worry about their partner's well- being Worry about their relationship Worrying about the future Worry about their own health Worry about institutional care Worry about

				analysed by the method of hermeneutic analysis.	requesting support
Courts et al. 2005	UK	To explore the experience of husbands and wives whose partners have MS	12 people – 8 man and 4 women	Qualitative focus groups	Highlighted relationship changes, spouses of people with MS struggled to maintain their identity in the face of changes to their role. lack of resources and the need for information and support
Crigger 1996	UK	Explored adaptation to the uncertainty of multiple sclerosis using a causal model	90 women with MS aged 25–65yrs	Quantitative study using several validated tools to measure uncertainty, spirituality, social support, self-esteem, mastery and severity of MS.	The results indicate the importance of relationships among family, friend. Spiritual well being appeared to play a significant role in adaptation to uncertainty. Life stressors had a significant impact on women's sense of mastery. Authors recommend that nurses should focus on the management of uncertainty and help patients with MS to achieve a better sense of self-esteem and a greater sense of control over their lives.
Dilorenzo et al. 2008	USA	to identify themes that influence adaptation in older PWMS	13 PWMS aged 60 or over. recruited from an MS Comprehensive Care Centre and local chapters of the National Multiple Sclerosis Society	Claims to be qualitative but appears to be influenced by quantitative methods. Used Perceptions of Aging Interview which was based on the literature on adaptation in MS, and Life Strengths, which was adapted from Kivnick's Life Strengths Inventory Interviewed by telephone.	Authors found the majority of participants reported to having adapted to MS and aging. Themes identified: Social comparisons, mobility/independence, integration of MS into self-identity, acceptance, pacing and planning, finding meaning/cognitive reframing, social support, religion/spirituality.

Esmail et al. 2010	Canada	Aimed to explore the impact of MS on the sexual relationship of heterosexual couples where men had MS	4 couples Men with MS and their partners	Phenomenological approach Semi-structured interviews	Themes: Communication salvaged the relationship Sexual function was affected therefore the relationship had to be re-evaluated Traditional roles changes after the diagnosis of MS Partner acceptance was a major source of support  Mens lack of sexual function affected their sense of self
Finlay, L 2003 & 2006	UK	To explore the existential impact of MS	Case study of one person with MS	Merleau-Ponty theory of embodiment as theoretical framework Phenomenological study	Embodiment; shock alienation, out of control Shock at diagnosis, fear Identity and project; compartmentalised and derailed Wanting to conceal diagnosis Shielding family from her emotional turmoil so they don't feel helpless Preserving her daily activities esp her mothering role Relationships with others; threat contamination & shame Reluctant identity – not wanting to meet others with MS Not wanting to build relationships based on pity Living uncertainty: disrupted time Sense of urgency to do "fun" things due to a worry of not being able in the future and not being able to predict when that might be
Forbes et al. 2007	UK	Survey to identify needs to PWMS	714 PWMS Varying stages	Survey Postal questionnaire Response rate 42%	Seven categories were identified: medical treatment (29%, n = 126); socio-

				(445 responses)	environmental support and adaptation (19%, n = 81); enhanced care provision (18%, n = 79); information provision (9%, n = 38); rehabilitation therapies (7%, n = 29); non-professional care (6%, n = 28); psychological support (3%, n = 15). Socio-environmental support, rehabilitation and non-professional care were more frequently identified by those with greater disease impact. Authors call for a needs assessment tool to be used in patient consultations
Fournier et al. 2002	Netherlands	To investigate the impact of optimistic beliefs on coping and adaptation over 6 and 12 mo of chronic illness (Type I diabetes, RA, MS)	Three chronic conditions with differing controllability : type I diabetes (n=105), RA (n=95) MS (n=98).	Quantitative using validated tools to assess psychological wellbeing Path modelling used as theoretical framework	Results suggest coping well contributes to the stability of the condition which, in turn, contribute to psychological wellbeing by using more task oriented and less emotion oriented coping.
Gagliardi 2003	USA	To explore the experience of sexuality among people living with multiple sclerosis (MS).	5 women & 3 men with MS Interviewed 3x over 1yr	Described as a qualitative, naturalistic case study method. Used telephone interviews. Uses Roy Adaptation Model as theoretical framework	3 main themes. "How I Feel About My Appearance", reflected elements of the Roy model physiological, self-concept, role function and interdependence modes. "I Have Feelings About My Sexuality", reflected the self-concept and interdependence modes. "Sexuality For Me Has Both Negative and Positive Emotions", reflected the self-concept and interdependence

					<p>modes. The small sample size precludes generalization of the results to all individuals living with MS. Suggests the need to nurses and other health care professionals need to recognize sexuality as an important issue for individuals with MS. Called for further research to explore this.</p>
Gagliardi et al. 2003	USA	To explore how people make sense of the experience of living with MS.	18 PWMS were interviewed 3x over 1yr	Qualitative study using interviews to explore how participants made sense of living with MS. Roy's adaptation model used a theoretical framework	5 recurring themes identified that reflect the Roy model adaptive modes: we're not completely the same (physiological mode), how I view my future (self-concept mode), let me tell you about my feelings (self-concept mode), how I see work (role function mode), and let me tell you about my life (interdependence mode)
Grytten, & Måseide, 2005	Norway	To explore the experience of stigma in PWMS and their relatives	14 participants 8 PWMS in mid to late stages of condition 6 relatives Age 33-60	Qualitative Interviews with PWMS and their relative	coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis. Participants concealed diagnosis in social situations in order not to be judged
Halper 2007	USA	Review article to review the effects of relapse on a variety of important psychosocial domains: social involvement, partnership and family roles, and employment/productivity.	Highlights Social role, partnership role as at risk from RR MS Social role – fatigue and visible disability force withdrawal from social contact and events Partnership role- helplessness of partner, may need to become carer and if that has permanency it poses a threat to the relationship, partners also need support, Sexual problems arise due to physical and psychological impact of MS, often lead to tensions in relationship Family role – due to age of onset parenting role is most under threat, where parents may not be able to continue as before Children having to forego activities		
Harrison et	USA	to investigate the	PWMS	Longitudinal	The findings

al. 2004		relationship between the quality and stability of the marriage and the person's ability to accept disability over time		study using validated quantitative measures to assess the relationship between the quality and stability of the marriage and the person's ability to accept disability over time	indicate that acceptance of disability and perceived impairment increase significantly over time for men and women. The study suggested some gender differences in that for men, being married was associated with a greater acceptance of disability and less perceived impairment. Men were more concerned than the women about how MS affected their sexual relationships.
Heesen et al. 2003	Germany	To explore the perceptions of the information given about diagnosis and treatment of MS from the perspective of both PWMS and neurologists	434 PWMS and 80 neurologists	Survey	Findings suggest a mismatch between PWMS and neurologist views on information at time of diagnosis. Neurologists were reluctant to give prospective information about MS where diagnosis not confirmed but PWMS wanted this information. 50% of PWMS reported to not getting any information on treatment at time of diagnosis and asserted the desire to have more information. We assessed the current status of diagnostic and therapeutic information on MS from the point of view of patients and neurologists.
Hepworth, Harrison and James 2002	UK	To explore the information needs of PWMS	103 PWMS took part in FG 2030 returned questionnaires	Mixed methods 11 focus groups across the UK Postal questionnaires	Information needs had improved in recent years but inconsistency of information provision still apparent. Differences in information requirement at diagnosis and for

					on-going MS and recommended that HCP recognise the differences. Information at diagnosis to include info on treatment, living well with MS and access to MS nurse
Johnson 2003	UK	Not clear in this paper but seems to be on what the support needs are around the time of diagnosis	12 participants (6/6)	Part of wider study of MS nurses Semi structured interviews	Emotional reaction to Dx- shock and images of wheelchairs Suspicions of Ms prior to Dx
Koopman & Schweizer 1999	Canada	to explore the individual's experience of having symptoms for a period of time and then to be told they have MS  more fully what this prediagnostic experience is like for them	5 participants with RR MS  time from symptom onset to diagnosis spanned a range of 6 months to 22 years	phenomenological qualitative research method	Four major themes emerged: Whispered Beginnings, Echoes of Silence, The Spoken Words, and Recreating Voice Journey to MS through a labyrinth of voices  Worry if it was cancer Prediagnosis phase often viewed by HCP as insignificant due to vague and mild nature of symptoms Not uncommon to see many drs before diagnosis  Anxiety and uncertainty key factors of lived experience
Lexwell et al. 2011	Sweden	to gain an enhanced understanding of how people with multiple sclerosis experience their occupational adaptation.	10 PWMS	Qualitative interviews using constant comparative method was used to analyse the data.	Findings suggest participants occupational adaptation was experienced as a constant struggle and non-linear, and served as the means of achieving either a desired self or a desired family life. The findings showed that the participants often selected occupational adaptations to meet their family needs over their own.

McCabe et al. 2004	Australia	To explore the coping and psychological adjustment of PWMS, compared to general population	381 PWMS 291 gen pop	Quantitative study using validated assessment tools – Ways of coping tool, Profile of mood states and WHO QoL tool	Women more likely to seek social support for MS and focus on positive than men Women more likely to experience fatigue More likely to adopt detached styles of coping More likely than gen pop to experience depression, confusion, tension and fatigue Linked wishful thinking to poor psychological adjustment Maintaining engagement of daily activities was linked to less incidences of depressive symptoms
McNulty et al. 2004	USA	To examine the role of spiritual well-being as a mediator and moderator between perceived uncertainty and psychosocial adaptation to living with MS.	50 PWMS 40F 10M	Quantitative validated assessment tools – illness uncertainty, spiritual (religious and existential) well-being, and psychosocial adjustment to illness	Both uncertainty and spiritual well-being independently predicted psychosocial adjustment to MS. . Spiritual well-being demonstrated a mediator effect but, mostly, failed to show a moderator effect.
Mozo-Dutton et al. 2012	UK	an in-depth exploration of personal perceptions of self and the perceived impact of MS on them	12 participants age 34-71 Time spent living with symptoms ranged from six to 28 years, with approximately four to 14 years of those without a formal diagnosis	Interpretative phenomenological analysis (IPA) semi-structured interview	1. <i>'My body didn't belong to me'</i> : The changing relationship to body. 2. <i>'I miss the way I feel about myself'</i> : The changing relationship to self. 3. <i>'Let's just try and live with it'</i> : incorporating MS within self. 4. stigma & social apathy but not discussed
O'Connor et al. 2008	Australia	To explore the impact of neurological illness on marital relationship satisfaction.	423 patients 335 carers Inc: MND, HD, Parkinson's & MS	Quantitative. Validated assessment tool used to assess relationship	The results suggested that for patients with MS and MND, social support was an indicator of marital

		Inc: MND, HD, Parkinson's & MS		satisfaction, sex life satisfaction, social support and severity of illness. Open questions to invite qualitative comments	relationship satisfaction, and for Parkinson's patients, social support and sex life satisfaction predicted marital relationship satisfaction.
Pakenham 1998	Australia	To examine relationship between couple coping strategies and psychological adjustment to living with MS	45 patient and carer dyads	Mixed methods including interviews and self-administered questionnaires at Time 1 and 12 months later	Findings suggest that congruence between coping styles and levels of coping ability were related to psychological adjustment and satisfaction with relationship.
Pakenham 1999	Australia	To explore the use of a stress and coping model of psychological adjustment to MS	122 PWMS	Mixed methods including interviews and self-administered questionnaires at Time 1 and 12 months later, Time 2 (n = 96).	Results indicated that psychological adjustment was related to less disability, greater reliance on problem-focussed coping, and less reliance on emotion-focussed coping. There was limited support for the stress buffering effects of coping and social support. Findings offer some support for the use of a stress and coping model of adaptation to MS
Pakenham 2001	Australia	To explore the usefulness of a stress and coping model of adjustment to caregiving in carers of PWMS.	51 carers of PWMS Age 16-76	Quantitative study Demographic data including illness characteristics, and problems associated with MS, cognitive status and neurological assessments. Functional disability, psychological distress, appraisal (threat, control, and challenge),	The results indicate that almost one third of the CGs reported clinically significant levels of psychological distress. Further, data indicate that adjustment to the carer role was related to less disability and distress in the PWMS, and higher levels of social support, lower threat appraisals, and less reliance on emotion- and problem-focussed coping. The findings support

				social support, coping strategies, global distress, depression, and caregiving impact data were collected	the utility of a stress and coping model of adaptation to caregiving in MS.
Pakenham & Saimios 2012	Australia	Explore the use of mindfulness and acceptance on adjustment in couples coping with MS	145 PWMS 91 partners	Quantitative intervention study of mindfulness, using validated measurement tools	Mindfulness reduces distress, particularly in patients but does not impact on adjustment
Pakenham Stewart & Rogers 1997	Australia	to evaluate the role of appraisal and coping strategies in the adjustment to illness-related stressors in PWMS	134 PWMS & their carers	Mixed methods interviews and self-administered questionnaires  Stress & coping theory	Adjustment outcomes included depression, global distress, social adjustment, and global health status. Findings indicated that illness variables were related to depression and social adjustment. Number of MS problems, appraisal and coping were related to most adjustment measures.
Pollock & Sands 1997	USA	To explore the meaning of suffering in PWMS	20 PWMS	Qualitative study using semi structured interviews as data collection method. The adaptation to suffering model used as conceptual framework.	Findings suggest PWMS responses to suffering follow a hierarchical progression from shock and denial through acceptance and understanding to finding meaning in their suffering. Findings provided support for the theoretical model and the importance of assisting PWMS to find meaning in their suffering experiences.
Pollock et al.1990	USA	To explore relationship between psychological and physiological adaptation to living with MS	211 participants, not exc MS also RA, hypertension	Mixed methods interviews and questionnaires (mental health index, health-related	Finding suggest psychological and physiological adaptation are not related for all participant groups nor were they related for any diagnostic group.

				hardiness scale, & Margin in Life Scale)  Adaptation Nursing Model provided the theoretical framework	The hardiness character was the only major variable that related to both physiological and psychological adaptation suggesting personality type more influential.
Porter & Keenan 2003	UK	article describes a diagnostic model that facilitates accurate timely diagnosis of MS and the role of the MS nurse in providing expert clinical assessment, guidance, support and education	N/A	Narrative article	Main arguments: PWMS need support, information, education and guidance in order to adapt effectively to the impact of the condition. The time around diagnosis is influential in supporting adaptation process as the information given and received may impact on the person with MS for the rest of his/her life. This article describes a diagnostic model that facilitates accurate timely diagnosis of MS and the role of the MS nurse in providing expert clinical assessment, guidance, support and education in order to help the person adjust to the living with MS.
Russell et al.2006	USA	To explore the beliefs regarding the cause and timing of MS and attempts to make meaning of the experience of living with the condition.	PWMS	Qualitative interviews	The process of making meaning is distinguished from the content of beliefs and is related to perceived quality of life. Implications for the stress and adaptation literature, family therapy, and information science are discussed
Starks et al. 2010	UK	To examine how couples adapt to the challenges of living with MS and to identify possible risk factors for	8 couples	Qualitative, using semi-structured interviews to explore how couples	Authors identified two patterns of adaptation to MS and conceptualised these as being 'in-

		relational stress		defined and identified the strengths and challenges in their relationship, negotiated the role changes brought on by MS and received external support.	sync' or 'out-of-sync'. Being in-sync was related to those with relapsing-remitting MS, and allowed both partners to maintain their social roles and identity, and a collaborative problem solving style. The out-of-sync pattern was related to those with rapid progressive MS, loss of employment before retirement age, differences in personal styles that shifted from being complementary to oppositional in the face of increased demands and struggles with parenting adolescent children. Authors suggest relational strain in couples with MS needs to be identified in couples who may benefit from referrals to family therapy or other relational support.
Toombs 1995	USA	To provide a qualitative insight into living with MS	1 PWMS	Autobiographical account of living with MS	Highlights biographical disruption, reflections on being newly diagnoses, embodiment, stigma, living with MS disability
Tzortzis et al. 2008	Greece	The aim was to evaluate female sexuality in women who were newly diagnosed with MS.	63 women with MS compared to 61 healthy women volunteers	Quantitative Using validated assessment tools	Findings highlighted sexual dysfunction higher in MS group; 22 (34.9%) compared to 13 (21.31%) in healthy group
Wineman 1988	USA	To explore the usefulness of two theoretical models in depicting the process of psychological	38 men and 80 women with MS aged 22-67yrs 51 RR MS 67 progressive	PhD thesis Mixed methods semi-structured interview: All	Results of the two models indicated that the parsimonious model was a satisfactory fit for

		adaptation to living with MS and related coping strategies.	MS	but four interviews were conducted within six weeks of the clinic visit. Validated tools: the Intolerance of Ambiguity Scale, the Mishel Uncertainty in Illness Scale, the Appraisal Questionnaire, the Ways of Coping Checklist (revised), the Purpose-in-Life Test, the Incapacity Scale, the Beck Depression Inventory, and the Social Support Questionnaire.	the data. This model was subsequently modified and found to be a better fit for the data for women alone, rather than for both sexes. The more complex model, which included constructs related to the unpredictable nature of MS, did not fit the data well.  In general, a positive-cognitive appraisal of one's situation with MS explained the largest portion of the variance in active forms of coping, whereas a negative-cognitive appraisal accounted for the largest portion of the variance in passive-cognitive coping behaviours.
Wineman 1990	USA	To explore the usefulness of a path model which identifies the relationship between social support, functional disability, perceived uncertainty, and psychosocial adaptation in PWMS	38 men and 80 women with MS aged 22-67yrs	Mixed methods standardized instruments and a semi-structured interview	Findings suggest the perceived supportiveness of interactions was directly related to a feeling of having a purpose in life but not to depression. Both the direct path between the perceived unsupportiveness of interactions and adaptation and the indirect one through perceived uncertainty were related to depression and to purpose in life. Physical disability had a direct effect on psychological adaptation.

## **Appendix 2: Participant information leaflets (nurses)**

### **Nurse Information Sheet**

#### About the study.

Within the health service there is a need to ensure that the service provided meets the needs of the people it serves. It is therefore important to seek the views of people who use the service to find out if their expectations and experiences are adequately met. This helps to provide information on which to develop and guide the services of the future. To do this I propose to interview a small number of people newly diagnosed with MS and their support person to seek their views on what they expect their support needs to be and then to follow this up to find out if the support they received adequately met the needs they had.

Currently within Scotland, not all patients with MS have access to a specialist MS nurse. Where this is the case general neurology nurses usually assume the role the specialist nurse has.

A number of MS nurses and neurology nurses in Scotland will be interviewed using focus groups to explore what they define as their support role. This will provide information to seek to establish the context in which they work and allow the opportunity for these nurses to articulate their role.

#### If I took part, what will it involve?

You would take part in one of two focus group interviews with your peers. It is anticipated that each focus group will last about 1 hour. It is likely that the focus groups will take place at one of the Scottish MS Nurse Network meetings.

The purpose of the focus groups is to explore what interventions are used by specialist MS nurses and neurology nurses when providing support to patients newly diagnosed with MS. With your consent, focus groups will be tape recorded and then transcribed verbatim. You will have the opportunity to read through the transcription to make sure it is accurate.

#### What are the possible benefits?

It is anticipated that the results of this study will be used to inform and develop the service provided by specialist MS nurses and neurology nurses in Scotland. This should help to improve and develop the service for people with MS in the future. It may also provide information to develop the specialist MS nurse role.

#### What are the possible risks?

It is recognised that this topic may appear a little threatening. It is not, however, the purpose of the research to scrutinise the individual care that each nurse delivers. Rather it is intended to highlight the support role of the MS nurse for patients following diagnosis.

#### Do I have to take part?

You are not compelled to take part, however by doing so you will have the opportunity to make your role in the provision of care to people with MS clear.

#### How will the information I provide be kept confidential?

It is important that you feel able to discuss your views freely. Therefore it is assured that your decision to take part will not be revealed to anyone but the researcher and a secretary who will be transcribing the tapes. Ground rules of confidentiality will also be negotiated within the focus group. Written consent forms and tapes will be stored in a locked cupboard at all times. Typed interviews will be made anonymous as will any extracts from the interviews in subsequent reports and publications.

#### What to do now?

If you are interested in taking part in one of the focus groups or wish to discuss the study further, please contact me at the address on the front of the information sheet. Alternatively you may complete the reply slip attached and return it to me in the pre-paid envelope. If you decide not to participate you need not take any action.

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

A full report of this study will be submitted to Napier University for assessment for the award of Doctor of Philosophy. Abridged versions of these results will be submitted for publication in peer reviewed journals. Participants will not be identifiable in any of these reports.

### Who has reviewed this study?

This study has been reviewed by Napier University Research Ethics Committee and has been granted ethical approval. Ethical approval was not considered to be required by the Main Research Ethics Committee (Scotland A). Approval has been granted from the local R&D offices. A steering group comprising both professional and patient representatives have also reviewed this study.

### Who can I contact for further information?

You may contact myself, the Principal Researcher:

Karen Lockhart, Napier University, 0131 455 5680, [k.lockhart@napier.ac.uk](mailto:k.lockhart@napier.ac.uk)

Or one of the academic supervisors:

Dr Catriona Kennedy, Napier University, 0131 455 5620,  
[c.kennedy@napier.ac.uk](mailto:c.kennedy@napier.ac.uk)

Or an independent advisor:

Dr Dorothy Horsburgh, Napier University, 0131 455 5628  
[d.horsburgh@napier.ac.uk](mailto:d.horsburgh@napier.ac.uk)

This copy of the information sheet is yours to keep. If you do decide to take part in the study you will also be given a copy of the signed consent form.

Thank you for reading this.

Reply Slip

I am happy to be contacted to participate in the research study:

People with newly diagnosed Multiple Sclerosis (MS): experiences of nursing intervention and support.

Please complete the contact details below:

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Telephone: (Home) \_\_\_\_\_  
(Work) \_\_\_\_\_  
(Mobile) \_\_\_\_\_

E-Mail: \_\_\_\_\_

Preferred means of contact: \_\_\_\_\_

**N.B. This form is not a consent form and does not compel you into taking part in the study.**

# Appendix 3: PowerPoint from neurology unit

## Transition to living with MS: a study of people affected by a new diagnosis

Karen Lockhart  
PhD study  
Supervisors: Dr Catriona Kennedy,  
Dr Allison Worth, Professor Diana Woodward

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## The need for this research:

Empirical and theoretic influences;

- No previous comparable studies of nursing intervention and support for people newly diagnosed and their support persons,
  - One significant study by Johnson et al (2001)
  - One systematic review by Forbes et al (2003)
- Previous research has highlighted the significant impact of chronic illness on the person's sense of self;
  - Bury (1982), Charmaz (1983), Krallik, Brown & Koch (2001)

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## Aim of the study:

- The aim of this study is to provide an understanding of the biographical impact of newly diagnosed MS on the individual and how this impacts on how they and their support person(s) manage the transition to living with MS.

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## Research Questions

1. What impact does a new diagnosis of MS have on how a person views the 'self'?
2. How has the onset of MS affected how the person goes about their daily life?
3. How has MS affected close relationships?
4. How have those affected by MS managed the physical and emotional changes during the transition to living with a confirmed diagnosis?
5. What support have people found helpful / lacking?
6. What are the experiences of MS nursing from people with MS and their support person(s)?

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## Ethical approval

Ethical approval:

- granted by Napier University Ethics Committee,
- application made to MREC but study not deemed to require formal approval by Chair of committee.

Local R&D approval gained from NHS Lothian and Borders

Honorary Research Contract granted.

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## Inclusion / Exclusion Criteria

### Inclusion criteria

- Aged 18 or over
- Male or female
- Newly diagnosed with MS
- Able to give informed consent
- Able to be interviewed by the researcher
- Willing to have interviews taped

### Exclusion criteria

- Pregnancy or childbirth in past year
- Confirmed cognitive impairment
- Co-existing chronic illness
- Previous diagnosis of cancer
- Inability to give informed consent

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## Recruitment

- Patients recruited from neurology clinics in Lothian and Borders.
- Where possible the researcher would like to attend clinic to be available to answer queries about the study.
- Details of potential participants who are willing to discuss study further may be forwarded to me.
- Patients will nominate their own support person(s)

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## Methods:

Three phases of data collection:

1. Focus group interview with MS nurses,
2. Participant-led interviews with people with MS and their support person soon after diagnosis,
3. Participant-led interviews with people with MS and their support person six months following diagnosis

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**Anticipated outcomes of the study:**

- An understanding of the impact of a new diagnosis of MS on those affected and how they manage to incorporate this into their lives
- An understanding of how specialist nurses and other services contribute to supporting this transitional period
- Recommendations for practice and future research will be made in light of the findings

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# Appendix 4: Poster for recruitment

INFORMATION FOR HEALTH PROFESSIONALS: NOT TO BE GIVEN TO PATIENTS



## Transition to living with Multiple Sclerosis: A study of people affected by a new diagnosis.

Researcher: Karen Lockhart

### Aim of the study

The aim of this study is to provide an understanding of the biographical impact of newly diagnosed MS on the individual and how this impacts on how they and their support person(s) manage the transition to living with MS.

### What is your role in this study?

I would be grateful if you could help with recruitment of potential participants for this study. To do this I am asking you to ask people to participate in this study who have been newly diagnosed (within one week of a confirmed diagnosis) and who meet the following inclusion and exclusion criteria:

Inclusion criteria:	Exclusion criteria:
<ul style="list-style-type: none"><li>• Aged 18 and over</li><li>• Male or female</li><li>• Newly diagnosed with MS</li><li>• Able to give informed consent</li><li>• Able to be interviewed by researcher</li><li>• Willing to have interviews taped</li></ul>	<ul style="list-style-type: none"><li>• Pregnancy or childbirth within past year</li><li>• Confirmed cognitive impairment</li><li>• Co-existing adult onset chronic illness such as diabetes, epilepsy, Motor Neurone Disease</li><li>• Previous diagnosis of cancer</li><li>• Inability to give informed consent</li></ul>

### What will be asked of people who take part?

The person newly diagnosed with MS and their support person (nominated by the person with MS) would be asked to take part in two interviews. The first interview will be soon after diagnosis, and the second six months later. Each interview will last no longer than 1 hour. The interviews will take place at a time and place that is convenient to the participants. This may be in their own home, or at the hospital. They may wish to be interviewed together or separately, it is entirely their choice.

### How do you refer potential participants?

Please give all potentially eligible participants an information pack and ask if I may contact them to discuss participation. Please email, fax or phone me (details below) with contact details of potential participants and I will then get in touch with them to discuss their potential participation. Potential participants will be free to decline to take part and withdraw from the study without giving a reason at any time.

**Contact details:**  
Karen Lockhart, School of Nursing, Midwifery & Social Care, Napier University,  
Canaan Lane Campus, 74 Canaan Lane, Edinburgh, EH9 2TB.  
Tel: 0131 455 5880, Fax: 0131 455 5831, Email: [k.lockhart@napier.ac.uk](mailto:k.lockhart@napier.ac.uk)

Thank you very much for your help

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## **Appendix 5: Participant information sheet (PWMS)**

### **PARTICIPANT INFORMATION SHEET (PWMS)**

#### About the study.

Being told you have Multiple Sclerosis (MS) can be a very difficult time for people. I would like to interview people who have been recently diagnosed with MS and their main support person, (normally a spouse, partner, parent, sibling or close friend) to find out what effect this has had and how people manage the condition. Six months later I will talk to you and your support person again to find out about your experiences.

#### Why have I been chosen?

You have been chosen to take part in this study as you have recently been diagnosed with MS. Your views are important in helping us to understand your needs. About 10 people with MS and their support person in East Central Scotland will be invited to take part.

#### If I took part, what will it involve?

You will take part in two interviews. The first interview will be soon after diagnosis, and the second six months later. Each interview will last no longer than 1 hour. The interviews will take place at a time and place that is convenient to you. This may be in your own home or at the hospital. You may wish to be interviewed with your support person present or on your own, it is entirely your choice.

At the first interview you will be asked how MS has affected your life; what, if anything, has changed, and what has stayed the same. At the second interview you will be asked to talk about you have managed to live with MS. You will be asked about what sources of support you have used and what has been helpful or unhelpful. If you agree, each interview will be tape recorded and then typed. If you wish you can read through the typed interview to make sure it is accurate.

#### What are the possible benefits?

I hope that the results of this study will be used to inform and develop MS services in Scotland. This should help to improve the service for people with MS in the future.

What are the possible risks?

I know that this may be a stressful time for you. It is possible that by discussing your needs and experiences you may become upset. If this happens I will offer to stop the interview immediately. I will offer to provide additional support to you at this time either by talking things through with you or by contacting someone you feel comfortable with. This may be your GP, community nurse, specialist MS nurse or neurologist.

Will my decision to take part or to decline have any effect on the care I receive?

Your decision to take part or to decline will not affect the standard of care you receive in any way. If you agree to take part now, you can withdraw from the study at any time without explanation.

How will the information I provide be kept confidential?

It is important that you feel able to discuss your views freely. The content of your interview will not be revealed to anyone but the researcher and a secretary who will be transcribing the tapes. Written consent forms and tapes will be stored in a locked cupboard at all times. Your name will be removed from interviews in any reports and publications. No-one will be able to identify you. As a courtesy, your GP will be informed that you are taking part in this research study by letter. This letter will be filed in your medical notes.

What will happen to the results of the study?

A full report of this study will be submitted to Napier University for assessment for the award of Doctor of Philosophy. Some results will be submitted for publication in professional journals and presented at conferences. Participants will not be identifiable in any of these reports.

### Who has reviewed this study?

This study has been reviewed by Napier University Research Ethics Committee and has been granted ethical approval. Ethical approval was not considered to be required by the Main Research Ethics Committee (Scotland A). Approval has been granted by the local R&D office. A steering group comprising both professional and patient representatives have also reviewed this study.

### Who can I contact for further information?

You may contact myself, the Principal Researcher:

Karen Lockhart, Napier University, 0131 455 5680, [k.lockhart@napier.ac.uk](mailto:k.lockhart@napier.ac.uk)

Or one of the academic supervisors:

Dr Catriona Kennedy, Napier University, 0131 455 5620,

[c.kennedy@napier.ac.uk](mailto:c.kennedy@napier.ac.uk)

Or an independent advisor:

Dr Dorothy Horsburgh, Napier University, 0131 455 5628

[d.horsburgh@napier.ac.uk](mailto:d.horsburgh@napier.ac.uk)

This copy of the information sheet is yours to keep. If you do decide to take part in the study you will also be given a copy of the signed consent form.

Thank you for reading this.

## Appendix 6: Consent form (nurses)



### CONSENT FORM (NURSES)

Title: People with newly diagnosed Multiple Sclerosis (MS):  
experiences of nursing intervention and support.

Researcher: Karen Lockhart

	Yes	No
I confirm I have read and understood the information sheet.		
I confirm I have had the opportunity to ask questions and discuss the study before taking part.		
I confirm that my participation is voluntary and that I am aware I may withdraw from the study at any point, without explanation.		
I agree to focus groups being tape recorded.		
I agree to take part in the above study.		

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Researcher's signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix 7: Consent form PWMS



### CONSENT FORM (People with MS)

**Title: A study of the transition to living with a diagnosis of MS.**

Researcher: Karen Lockhart

	Yes	No
I confirm I have read and understood the information sheet.		
I confirm I have had the opportunity to ask questions and discuss the study before taking part.		
I confirm that my participation is voluntary and that I am aware I may withdraw from the study at any point, without explanation and with no adverse affect to the care I receive.		
I agree to interviews being tape recorded.		
I agree to take part in the above study.		

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Researcher's signature: \_\_\_\_\_

Date: \_\_\_\_\_

## **Appendix 8: Topic guide for focus group with MS nurses**

Research study: People with newly diagnosed Multiple Sclerosis (MS): experiences of nursing intervention and support.

Preamble: Thank you all for agreeing to participate in this focus group. As this study seeks to find out the process people go through following a diagnosis of MS and what their experiences of nursing support are during this time, your views are important. There are no right or wrong answers, it is your perceptions and experiences that are important here.

To begin with I'd like to ask you a bit about your role around the time people are diagnosed.

In your area, where and how are people normally given their diagnosis?

Who is normally present when they are given the diagnosis?

What happens immediately after this event?

What things stick out for you during this time as prominent?

How would you describe your role at the time of diagnosis being given?

If you are not present, how are people referred to you?

Generally how soon after diagnosis do you make contact with the person?

With regard to having MS, what are the main concerns for people at this time?

How would you describe your role in addressing these concerns?

What do you consider are the main support needs for people?

Who or what are the main sources of support at this time?

In what ways do you offer to support people at this time?

Does the reality of the support you provide for people newly diagnosed meet with what you aspire to deliver?

If no, what challenges?

What would enable you to achieve this?

How would you like to see the MS nurse's role develop?  
Further comments?

## **Appendix 9: Interview guide for people with MS**

### Interview guide (I) (PWMS)

#### **Research study: A study of the transition to living with a diagnosis of MS.**

Preamble: You have been asked to take part in this study as you have been diagnosed with MS. For this study I would like to find out how MS has affected people and how they are learning to live with it, your views are important. I would also like to learn whether the support of an MS nurse has helped so we will talk about this during the interview as well. There are no right or wrong answers, it is your experiences that are important here.

To begin with I'd like to learn a bit about your journey to being diagnosed with MS.

What things stick in your mind about the time leading up to diagnosis?

Did anyone mention that it might be MS?

What did you know about MS at this time? / What did you think having MS would be like?

Can you tell me about the time you were given the actual diagnosis? How did you feel / react?

Did you talk it over with anyone? Who... why etc...

How has MS affected you personally? Self, daily life, work, social, relationships....

Have you had to make any changes as a result of your illness? If yes, how do you feel about this?

Were you given any information regarding who to contact for support or further information?

With regard to having MS, what are your main concerns at this time?

What support do you think the main concerns will be in the coming six months?

Who do you think is your main source of support at this time?

If you have access to a MS nurse what support would you expect of him/her?

Do you have any further comments you would like to add?

## Appendix 10: Annotated transcript

<p>Recognition this is serious</p> <p>Fear of what symptoms may indicate</p> <p>Acting on symptoms</p> <p>Being kept in the dark</p>	<p>gone up both sides of my legs and I had <u>uhm</u> stiffness in my knees. I thought this is really odd, what could this be and then Sunday a <u>numbness started going up the side of my face and I thought 'oh my God I'm going to have a stroke or something.'</u> So <u>uhm</u> leading up to that point I'd felt absolutely great, I mean I felt as well some time... I was doing exercise and things were pretty good as far as my anatomy was concerned, as far as I knew.</p> <p><u>I really</u> started to panic, so I phoned up NHS24, that was the Sunday, so it would have been the last Sunday in October or first Sunday in November, or whatever, and... no it was the first Sunday in November, it was maybe the 4<sup>th</sup> or something like that. And the person that I spoke to said 'look, someone will phone you to give you details of what you've got to do'. <u>And I got a phone call right away</u> saying 'look you know we'd quite like you to come up to the Western can you come up right away. So this was like seven o'clock, I phoned, and get in for eight o'clock.</p> <p>I went yes, sure <u>sure</u>. I went up, myself and SP8F went up and they checked things like ... <u>they didn't tell me what it was right away, they just said that they were checking for something called is it Neon Barry [Guillain-Barre]?</u></p> <p>F1: Guillain-Barre.</p>	<p>plea to God, plea for help Fear of symptoms and what they may indicate, linking to serious condition</p> <p>Symptoms were cause for concern and "panic"</p> <p>Emphasis in timeline here indicating the immediacy of acting on symptoms and the sense of urgency and perhaps panic she felt at the time. Very precise recall of the events also, indicating they were very significant to her</p> <p>Not being told what they were investigating, and using terminology she was unfamiliar with adds to the sense of bewilderment at this time</p>
<p>Who I am - professional me</p>	<p>F2: <u>Guillain-Barre, so they looked in my eyes, took a urine sample, checked my reflexes and said no, it's not that. Still don't know what it is, I never looked to see what that was.</u></p> <p><u>She says well you know if the symptoms persist, go and see your doctor tomorrow. So I went to see my GP but I normally just see whoever is there, it was a locum who was on, Dr Xxxx. And she said, oh I don't know it sounds like it's a nerve thing.</u></p> <p><u>So she contacted the Western General - no no she put me on relaxants, some sort of relaxants and said take a week off work, maybe it's just stress, take a week off work and see how you go.</u></p> <p><u>So by the time it came to the end of the week, I'd taken a week off and nothing had improved. The knee thing had got worse, it felt like I had a really tight elastic bands around my knee caps, I was finding them really stiff.</u></p> <p><u>Just because of my job and I'm teaching I leave the house at half seven in the morning and I'm not home till... this is pretty early for me, I'm normally home between half five and six o'clock. So getting a call during the day is quite difficult.</u></p>	<p>Phrasing almost gives a sense of this happening to someone else and not her, then her admitting that she didn't look to see what the cause was and the unsaid part may be that she felt she should have known</p> <p>Does the fact she makes ref to GP being a locum call to question who she feels she was treated as opposed to if she had been seen by her own GP Terminology used here hints at not being taken seriously</p> <p>Missed diagnosis – putting symptoms down to stress</p> <p>Repetition of symptoms getting worse gives impression of her feeling like she is not being listened to</p> <p>Identity of herself as a busy professional is important to her and this situation as it posed difficulties getting access to relevant people and for them to get in touch with her. Need for understanding of people's lives and taking this into consideration at this time in the trajectory</p>

<p>Diagnostic event</p> <p>Impact of diagnosis – shock</p>	<p>So eventually <u>I got a phone call and it was late February this time and it was during the evening because we had [Friend] around for dinner and er he called me and he said 'oh I'm glad we've contacted you at last.' And he said 'you know we thought initially it was just an episode of some sort of neuralgia, but actually you've got MS.' I'm like [I've got what! I just... I said 'I'm sorry I'll have to get you in to speak to you'. And I was just like blown away. Just... that was it, that phone call - what!!! You know.</u></p> <p>So then - sorry - so then we went to, myself and SP8F we went to see him and up to that point, <u>between the phone call and going to see him I think it was the first week in March or</u></p>	<p>Diagnosis was given over the phone with little apparent consideration for what was happening in her life at that moment (my judgement). The diagnosis was giving when she was in the middle of a sociable evening with her partner and friend.</p> <p>Impact of this call is evident from her description of the event, Use of language suggests disbelief and total shock. The tone of her voice (from audio) Stresses this shock also. The metaphor of being blown away suggests the impact of losing her footing and feeling out of control when realising the seriousness of the condition she had. This had further implications I think for how she then handled telling her family who lived at a distance Time lag from being told and appointment again</p>
<p>Images of MS</p> <p>What does this mean for me?</p> <p>Being in control</p> <p>Need for control</p> <p>Access to information</p>	<p><u>somewhere in between, um I went and did some research because the images in my head was just of being crippled and not being able to function at all, being totally disabled and blah blah blah.</u></p> <p><u>And so I had a wee look and I think it reassured me really - well from the point of view that I didn't realise there was so many different types of MS that you could have. At this point I didn't know which one I had. And so I did a bit of research on the multiple sclerosis website and got a lot of good knowledge for myself and then opened up questions which I made sure I prepared before I went to see him.</u></p> <p><u>So I went to the hospital we saw him, sat down and the first thing I says is 'well are you sure?' he goes 'well yes', he goes well your scans, and I goes 'can I see them?' and he goes 'well no I don't have those' so he was talking about the white rash things that he could see. And he went through things that I was asking about like concerned for my twin and things like that and of course [SP8F] and myself and what was going to happen. So he kind of went through that with me.</u></p> <p><u>And then he said I'm going to have to make you an appointment with Dr [Neurologist], so that happened in June. I went to see Dr [Neurologist] and I got introduced to [MS Nurse</u></p>	<p>suggest her feeling as though she was left a bit Visual representation of PWMS as disabled, did this link to a sense of her thinking that this would be her future reality? It was not her lived reality to that point and she may not have known that there are many unseen MS symptoms</p> <p>Describes process of learning about MS to equip herself for her consultation. Information helped her contextualise her own experience within the range of experiences of MS and what this might mean for her even though at that stage she did not know which type she had perhaps the knowledge of different types helped to give her hope which made her more positive. Implications for practice – when giving diagnosis give some limited information also so that folk are not left in despair.</p> <p>Priority of confirming diagnosis, not wanting it to be true.</p> <p>Externalising her cause for concern as concern for her twin which although may be true legitimised her probing questions to get information on behalf of another but in doing so access information for herself</p>

<p>Impact of seeing other with MS disability</p> <p>Like me but not like me</p>	<p>1] who's one of the nurses and that's basically it.</p> <p>And she says well look you know, we'll just have to see every year to find out how you're getting on, and she gave me an appointment with the secretary on the way out, so I did, I got an appointment for next year and the only thing I've done up till then was there's workshops that have been on for the last couple of Thursdays. I couldn't make last Thursday because I had meetings on after school, but went to the one before and I was just surprised at how many people were there first of all, and also was surprised how many of the people that were there had actually gotten really quite ill over a short period of time.</p> <p>So I kind of thought well <u>shit</u>, is this a good place for me to be, because then these started putting all these kind of images, you know it just started to play havoc with my mind. This could happen to me now, <u>this is real</u> and... So I think last week although my meeting finished at half six and the meeting started at seven o'clock, I was more [laughs], I think it was more <u>counterproductive</u> rather than... although it was nice to kind of see that you weren't on your own, well actually you know <u>these were people like myself who had just been recently diagnosed and they were in different states from what I was and it brought it home</u> to me I suppose - <u>a hammer</u></p>	<p>Despite having researched the different types of MS she was surprised when confronted with others with more severe physical symptoms than herself at the newly diagnosed course</p> <p>Shit – expressing shock at seeing others</p> <p>Vivid description of how seeing others impacted on her facing up to having MS and considering the possibilities for her own future. Until then she had been able to suppress this in the knowledge that she had a different type of MS</p> <p>Comparing her own experience of MS to that of others worse affected. Recognising they all had the same condition but that their symptoms etc were profoundly different. This had a negative impact on her rather than a positive experience as it forced her to face up to what MS may be like in</p>
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## Appendix 11: Table of themes

<i>In vivo</i> themes (free coding)	Intermediate theme	Superordinate theme		
Relief at diagnosis Knowing why Stress of not having a reason for symptoms Comfort in knowing <i>Looking for an answer</i>	Being diagnosed: crossing a threshold	Road to diagnosis		
Information seeking Horrified at prospect of MS Arousing suspicions Pre-warning of diagnostic consultation Validation that something is causing symptoms Re-evaluating what is important to one's self <i>This is something serious</i>	Shared journey (themes common to PWMS & SP)			
Uncertainty Fear of the unknown Validation of symptoms Not all in the mind Less of a stigma than mental health issues				
Knowing the self/ knowing own body Experiencing symptoms – something is wrong Disembodiment Need for support			Knowing one's body, knowing one's self	
Living in the shadows Hidden self Emotional impact of diagnosis Feeling of not coping Facing mortality Re-evaluating what is important to one's self			A self disrupted	Liminal self
Self as mother <ul style="list-style-type: none"> <li>• Threat to mothering role</li> <li>• To tell the children or not</li> </ul>	Disruption to roles and relationships			
Self as partner <ul style="list-style-type: none"> <li>• Changes to established roles</li> <li>• Changes to intimacy</li> </ul>				
Self at work <ul style="list-style-type: none"> <li>• Changing work patterns</li> <li>• Limited disclosure</li> <li>• Reactions of colleagues</li> </ul>				
Anticipatory carer Stigma of diagnosis Realisation of fears Fear of disability Spectre of MS	Self and others with MS			
Being let down by NHS Familiarising with medical world Negotiating health care system Rules of engagement Knowing how to navigate through the services	Negotiating health care		Learning to live with MS (postliminal self)	
Getting on with things Threat to control Symptom monitoring – hyper vigilance Ways of coping Threat of disability I'm always going to have this	Impact of MS on daily life			
Remaining positive Spectre of MS Difficulty planning future events Moving forward		Living with uncertainty		

## Appendix 12: Relationship of focus group themes to interview guide

Research Questions	Themes from focus group	Questions from interview guide related to address research questions
<ol style="list-style-type: none"> <li>1. What impact does a new diagnosis of MS have on how a person views the 'self'?</li> <li>2. How has the onset of MS affected how the person goes about their daily life?</li> <li>3. How has MS affect close relationships?</li> <li>4. How have those affected by MS managed the physical and emotional changes during the transition to living with a confirmed diagnosis?</li> <li>5. What support have people found helpful? Lacking?</li> <li>6. What are the experiences of people with MS and their support person(s) of MS nursing?</li> </ol>	<p><b>Diagnosis event</b></p> <p>Most diagnosis made in clinic setting, with occasional GP. MS nurse not usually present and needs a referral from neurologist or other medical staff Patients not routinely told to bring a relative with them at diagnosis</p> <p><b>Role of nurse</b></p> <p>Support, emotional and informational support Follow up and monitoring symptoms management advice on practical issues such as work, driving and insurance Liaison between hospital and primary care Difficulty in providing support due to uncertainty of condition Provision of support for family and main carer</p> <p><b>Readiness of the individual</b></p> <p>Being a reminder of MS Tentative introduction to support groups</p> <p><b>Lack of resources</b></p> <p>Lack of referral resources e.g. OT physio psychologist MS seen as poor relation to cancer services</p>	<p><b>Preamble:</b></p> <p>To begin with I'd like to learn a bit about your journey to being diagnosed with MS. Can you tell me about the events leading to your diagnosis?</p> <p>What did you know about MS at this time? / What did you think having MS would be like?</p> <p>Can you tell me about the time you were given the actual diagnosis? How did you feel / react? (Note: opportunity to explore who gave the diagnosis, setting and offer of additional support.)</p> <p>Did you talk it over with anyone? Who... why etc... What sort of things did you feel you wanted to talk about? (Note: opportunity to explore the person's preferred support person.)</p> <p>RQ1: How has MS affected you personally? (global question to explore impact on self).</p> <p>RQ1: Has having MS made you think differently about yourself? If yes, Can you tell me what has changed? Can you describe yourself before having MS and now? (Note: opportunity to explore biographical impact in depth.)</p> <p>RQ3: Have there been any changes in the relationships you have with those close to you? For example your partner, children, friends? If so, can you tell me about these?</p> <p>RQ2/4: Have you changed your life in any way as a result of having MS? If yes, can you tell me about what changed? Was this a change in the way you think, feel or a change in the way you go about your daily activities (change in behaviour/work/roles)?</p> <p>RQ5: With regard to having MS, what are your main concerns at this time? (Note: opportunity to explore support issues / needs)</p> <p>RQ5: Where / who do you turn to, to help with your concerns?</p> <p>RQ5: Have you sought any support or help and found it particularly helpful / lacking?</p> <p>RQ6: Who do you think is your main source of support at this time? (Note: opportunity to explore lay support, primary care etc)</p> <p>RQ6: If you have access to a MS nurse has that person done anything that has been particularly helpful to you and your family?</p>

		<p>RQ6: Is there anything else you think you would like from the MS nurse?</p> <p>Do you have any further comments you would like to add?</p>
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## **Appendix 13: List of presentations**

### **Oral presentations**

**2008** 'Issues and tissues: interviewing participants at a vulnerable time.'  
Edinburgh Napier University, School of Nursing Midwifery and Social Care,  
Research Seminar

**2007** 'Transition to living with MS: a study of people affected by a new  
diagnosis.' Neurology Unit Seminar, Western General Hospital, Edinburgh

**2006** 'People with newly diagnosed Multiple Sclerosis (MS): expectations and  
experiences of nursing intervention and support.' European Doctoral Nursing  
Science Conference, Berlin

**2006** 'People with newly diagnosed Multiple Sclerosis (MS): expectations and  
experiences of nursing intervention and support.' Edinburgh Napier  
University, Faculty of Health Life and Social Sciences, PhD Student  
Conference – Prize for best oral presentation

### **Poster presentations**

**2012** 'A phenomenological exploration of the transition to living with a  
diagnosis of Multiple Sclerosis: the experiences of individuals and their  
support person.' Edinburgh Napier University, Faculty of Health Life and  
Social Sciences, PhD Student Conference – Prize for best poster  
presentation (3<sup>rd</sup> place)



