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**“TAMING THE BEAST”: EXPLORING THE
LIVED EXPERIENCE OF RELAPSING
REMITTING MULTIPLE SCLEROSIS USING A
LIFE HISTORY APPROACH.**

Therese Burke

A thesis submitted in partial requirement for the degree of
Doctor of Philosophy

School of Nursing
The University of Notre Dame Australia

2019

DECLARATION OF AUTHORSHIP

This thesis is the candidate's own work and contains no material which has been accepted for the award of any degree or diploma in any other institution.

To the best of the candidate's knowledge, the thesis contains no materials previously published or written by another person, except where due reference is made in the text of the thesis.

Therese Burke
Candidate's name

18th February 2019
Date

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LIST OF ABBREVIATIONS

ABS	Australian Bureau of Statistics
APA	American Psychological Association
CAQDAS	Computer assisted qualitative data analysis software
CCSVI	chronic cerebrospinal venous insufficiency
CIS	clinically isolated syndrome
CNS	central nervous system
CSF	cerebrospinal fluid
DMT/DMTs	disease modifying therapy/therapies
DSM-V	Diagnostic and Statistical Manual of Mental Health Disorders 5 Th edition
EDSS	Expanded Disability Status Scale
GAP	Global Adherence Project
GT	grounded theory
HCP/HCPs	Health Care Professional/Professionals
HLA	Human Leukocyte Antigen
HREC	Human Research Ethics Committee
HSCT	Haematopoietic Stem Cell Transplant

IOMSN	International Organisation of MS Nurses
IPA	interpretive phenomenological analysis
JCV	John Cunningham virus
LP	lumbar puncture
MND	motor neuron disease
MRI	magnetic resonance imaging
MS	Multiple Sclerosis
MSA	Multiple Sclerosis Australia
MSL	Multiple Sclerosis Limited
MSNA	Multiple Sclerosis Nurses Australasia
MSRA	Multiple Sclerosis Research Australia
MSS	Multiple Sclerosis Society
NHMRC	National Health and Medical Research Council
SLE	Systemic Lupus Erhythematosus/ Lupus
PBS	Pharmaceutical Benefits Scheme
PICF	Patient Information and Consent Form
PML	progressive multifocal leukoencephalopathy

PPMS	Primary Progressive Multiple Sclerosis
PTSD	post traumatic stress disorder
PwMS	people/person with Multiple Sclerosis
PwPPMS	people/person with Primary Progressive Multiple Sclerosis
PwRRMS	people/person with Relapsing Remitting Multiple Sclerosis
PwSPMS	people/person with Secondary Progressive Multiple Sclerosis
QOL	quality of life
RRMS	Relapsing Remitting Multiple Sclerosis
SPMS	Secondary Progressive Multiple Sclerosis
TB	Therese Burke, the author
WHO	World Health Organisation

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ABSTRACT

Multiple Sclerosis (MS) is a complex neurological disease affecting the central nervous system and is driven by a complex autoimmune cascade. The peak age of onset is between the ages of 20 and 40 years and shows a female preponderance of 3:1. The most common form of the disease affecting 85% of people living with the illness is called relapsing remitting MS (RRMS), and is characterised by unpredictable relapses or exacerbations which usually last a few weeks before returning to baseline function. There is the possibility of disease progression and non-reversible disability after many years. RRMS is also characterised by a complicated array of symptoms which may affect sensory function, motor function, vision, gait, cognition, mood, bladder, bowel and sexual function. There is currently no curative treatment for RRMS, although recently there have been major advances in more efficacious treatments called disease modifying therapies (DMTs) to control relapses and possibly future disability.

The aim of this study was to gain insights and understanding into the lived experience of RRMS in order to inform patient-centred nursing care. Although there is an abundance of literature dealing with various aspects of the MS experience, there is a paucity of literature specifically exploring the general life experience of living with the disease and considering a broader understanding. Life history methodology, a form of focused ethnography, was used to explore the illness experience across the lifespan of 13 study participants living with RRMS. Semi-structured interviews were used to gather data and later transcribed by the researcher, before undergoing data analysis. Braun and Clarke's (2006) method of thematic data analysis ensured a systematic and robust exploration of the lived experience and revealed eight key themes, 30 subthemes and 44 sub-subthemes, providing clarity and insight into the experience of living with RRMS.

Several novel findings were revealed by the thematic analysis including an appreciation of the importance of early life events prior to the onset of RRMS and their potential impact on later coping, adjustment and resilience after diagnosis. A

key study finding was of people living with RRMS experiencing “Surplus Suffering”, a form of suffering over and above that caused by the disease itself and inflicted most often by health care professionals and significant others. Other themes explored concepts of “Piecing together the Puzzle” of RRMS at the beginning of the journey, “(Re)defining self” in the wake of an RRMS diagnosis, “Battling the Demons” that RRMS uncovers, dealing with invisible symptoms of the disease, managing the DMTs necessary to control the disease and their side effects, and ultimately “Taming the Beast” that is RRMS and “Holding Hands with Hope”.

The life history approach revealed these themes to be reflective of the ebbs and flows of life, intertwining with each other and changing positions of importance according to life events, whether directly related to RRMS or indirectly related. Numerous recommendations for clinical practice in MS care have been developed from the study findings which are anticipated to improve clinical care and to enhance the quality of life for people living with RRMS, along the life trajectory.

CHAPTER 1: INTRODUCTION

Introduction

Life history, a form of focused ethnography, was employed in this study to explore the experiences of people living with a specific type of Multiple Sclerosis (MS) called Relapsing Remitting Multiple Sclerosis (RRMS). The study uncovered participants' personal meaning and understanding as they learned to live with a chronic neurological illness that followed an unpredictable and uncertain disease course. Participants discussed and described the impact of RRMS on themselves, on their aspirations, their family, their friends, their work and their social and community lives. Interactions with various health care professionals (HCPs) formed the basis of many of their experiences related to living with RRMS and were highlighted as being both satisfying and challenging. Study participants were frank and open about their life experiences, drawing the researcher into their world and providing powerful and impactful knowledge to provide a truly meaningful understanding of what it feels like to live with RRMS.

This chapter introduces key concepts about RRMS, providing a baseline understanding of the condition which will be fully explored throughout chapters 2 and 3. Thereafter follows a discussion of the research question and specific aims of the study and the significance of the research, in the context of nursing research and in the context of knowledge about the disease. A short discussion regarding nuances of the terminology that will be used throughout the thesis will help provide consistency and clarity to the following chapters. Finally, an outline of the structure of the entire thesis will be presented.

Background

MS is one of the world's most common neurologic disorders, with 2.3 million people diagnosed with the disease and the rate steadily increasing (Browne et al., 2014). The most common form of MS at diagnosis is RRMS, affecting 85% of people living with the disease (Compston & Coles, 2008). The remainder of MS cases are characterised as Primary Progressive Multiple Sclerosis (PPMS), which has a

different prognosis and different characteristics to RRMS (Compston & Coles, 2008). RRMS is characterised by unpredictable relapses (also called exacerbations, attacks or flare-ups) which usually last several weeks before the individual returns to baseline functioning (Lublin et al., 2014). Although there may appear to be a return to function after a relapse, it has been reported that there is a measurable and sustained effect on disability (Lublin, Baier, & Cutter, 2003). The degree of disease progression and disability is unpredictable at the outset of RRMS and may lead to the sequale of Secondary Progressive Multiple Sclerosis (SPMS) in later years where people with an initial relapsing course develop irreversible disability without a relapse, although relapses are still possible (Lorscheider et al., 2016). RRMS is also characterised by a complicated array of symptoms, which may affect sensory function, motor function, vision, gait, cognition, mood, bladder, bowel and sexual function amongst other many other signs and symptoms (Ben-Zacharia, 2011). There is currently no curative treatment for RRMS, although recently there have been major advances in more efficacious treatments called disease modifying therapies (DMTs) to minimise relapses and possibly prevent future disability (Stüve & Racke, 2016).

Although there exists an abundance of literature examining the many different aspects of MS and MS symptoms, there is a paucity of literature which explores the whole life experience of living with MS and more specifically, RRMS. Several seminal studies in the 1990's and 2000's started to explore the lived experience of people living with MS, but some did not disclose the specific type of MS included in the study (Hainsworth, 1994., Clair, 2003; Courts, Buchanan, & Werstlein, 2004) or else used groups of mixed MS types with varying levels of disability (Koopman & Scheitzer, 1999; Barker-Collo, Cartwright, & Read, 2006) making it challenging to be able to assess transferability of findings to the individual's circumstance. It has become more important in the last two decades to differentiate between the types of MS, as DMTs are only available to treat RRMS; although there have been some advances recently for treating progressive types of MS. Miller (1997) was one of the first to explore the lived experience of people living with RRMS as 10 participants were interviewed as they attended MS clinics in the United States. Interpretative phenomenological analysis was used to present a story of the interplay of social networks in RRMS, coping skills, issues with control and conflict, unpredictability

and loss, fear and relief, getting to know RRMS and of the relationships of revealing and concealing the diagnosis (Miller, 1997). This seminal study is the most closely linked to the current study question, aims and goals, however it is important to note that this study took place before medications were available to treat relapses, unlike the current study. There is an absolute dearth of literature exploring the lived experience of people living with RRMS (PwRRMS) since this time and this concept will be explored further in the literature review in Chapter 3.

Aims of the study

The purpose of this research study was to gain insights and understanding into the lived experience of RRMS. More than just listening, describing and appreciating, this study aimed to produce a rich, thick account of how it *feels* for people to live with this disease, what is felt and how it is felt, the entire experience along the life trajectory. By gaining such insights, MS Nurses may have a deeper understanding of their patients' experience and be able to plan and adjust their nursing care accordingly. The ultimate aim of the study is for the findings to have the capacity and diversity to improve nursing care and the quality of life for people living with RRMS at all stages of their life path and illness trajectory.

The research question

To address these specific aims, the study seeks to answer the research question:

“What is the experience of living with Relapsing Remitting Multiple Sclerosis?”

Methodology

Qualitative research focuses on the way people make sense of their experiences (Holloway & Wheeler, 2013) and attempts to make the world visible (Denzin & Lincoln, 2000). The very nature of the research question immediately informed the choice of methodology. Using a qualitative approach to understand the lived experience would ensure the person living with RRMS is firmly at the centre of the

research process and their lived experience the focus of the research. The sampling method was purposive. Data was collected by conducting 13 semi-structured interviews with adults living with a diagnosis of RRMS. A life history approach explored the entire life lived to date; with and without RRMS. Thematic analysis using the recommendations of Braun and Clarke (2006, 2013) provided a systematic and robust method for data analysis, uncovering eight primary themes and over 70 subthemes and sub-subthemes to further clarify and explain the data and to offer meaning and understanding of the lived experience of RRMS.

Significance of the study

Through sharing stories people come to understand their experiences, legitimise their behaviour and share their emotional experience with others in holistic form (Holloway & Freshwater, 2007a). Stories of illness and disability are often not heard, and as the paucity of lived experience literature in the field of RRMS suggests, it is time for that to change. By understanding the patient experience, MS Nurses and other HCPs can realise that there are more realities beyond the beliefs and perspectives they hold in their practice. The seminal work of Miller (1997) in RRMS was performed prior to the introduction of medications and modern treatments for RRMS, therefore it is critical that further research into the contemporary experience explores if and how things have changed for the patient and if subsequently the role of the MS Nurse needs to change. Miller's (1997) seminal recommendations for MS nursing practice may need to be reviewed and updated to reflect modern practice.

As a qualitative nurse researcher, my aim in conducting the research was to follow Munhall's (2012) recommendations to add the following to the knowledge base of nursing: description, understanding, discovery, meaning, interpretation and explanation; all within and amongst genders, regions and cultures. By approaching the research question in a qualitative way, I searched for meaning that was different from the statistical, from the survey-reported general information often described in the literature. I searched for deeper meaning that could ultimately help with improving the quality of life for PwRRMS, and to make MS care more humane, safer and equalitarian (Munhall, 2012). A major personal goal was to develop recommendations for clinical practice based on patient focused nursing care. I

strongly believed this would allow MS Nurses to truly understand what PwRRMS experience on their life journey and ultimately allow MS Nurses to be in a position to make this journey happier, healthier and more rewarding.

As the reporting of scientific and biomedical knowledge in MS has dramatically increased in recent years, there has been a shift in focus away from the patient experience and on to the next medication, the next molecule, the next blockbuster discovery. Instead, I argue that it is vital to go back to basics (to understand how patients feel and what they need) in order for any of these new discoveries to have their maximum impact. This then highlights what MS Nurses and HCPs can do in order to make each patient's life journey with RRMS the best it can possibly be.

Nuances of the thesis writing style and terminology

Throughout this thesis, there will be certain instances or situations that are specific to the context of living with RRMS. I will discuss these now to ensure clarity and consistency throughout the thesis.

Firstly, the term PwMS refers to “a person/people living with MS” and the term PwRRMS refers to “a person/people living with *“Relapsing Remitting MS”*”. Although this research study is primarily concerned with one type of MS, RRMS, often previous literature may just refer to MS in general with no distinction between different types of MS studied. This makes it difficult to know the degree of relevance to RRMS specifically. Literature in this category was mainly prior to the introduction of treatments for RRMS (after which delineation of RRMS became more necessary), but has also been seen in some more recent work referred to in the current study. In these cases the more generic term “PwMS” will be used, reflecting the author's reporting of the information. At other times, the idea or concept will be specific to RRMS or researched only in RRMS, and so the term “PwRRMS” will be used when this is certain. Each situation and use of the term will have been carefully assessed to ensure the correct terminology appropriate to the case.

The second area requiring clarification pertains to the terms “patient” and “participant”, which are both used extensively throughout this thesis. Where the

discussion refers to a current study participant taking part in the study, the term participant will be used, an accepted term in qualitative research (Holloway & Wheeler, 2013; Braun & Clarke, 2013). Where the discussion refers to a patient rather than a participant, this will be as a result of the specific term patient being used in the literature. In the case of the overview of MS in chapter 2 and the clinical recommendations in chapter 9, the term patient has been used. This is because it is appropriate to the more general context of patients and medicine/nursing concepts under discussion in those chapters.

Thirdly, as this is a nursing thesis being undertaken at the School of Nursing, University of Notre Dame, the primary audience of this thesis is likely to be an MS Nurse, therefore professional references are made to MS Nurse/s, unless a finding or comment relates specifically to another member of the health care team (where the role will be specified), or to HCPs in general. However, the study findings from this thesis and clinical recommendations are likely to universally apply to all MS HCPs, no matter what specialty they practice in.

Importantly, much of the qualitative literature referred to throughout the thesis, and particularly in chapter 4, is seminal work and as such, can date back decades. Unlike scientific and quantitative work which places great value on the most up to date information and references, qualitative research texts and terminology very often refers to this seminal work, usually as it is the most outstanding representation of the qualitative paradigm available. Where more recent explanations or supporting evidence is available, it will be used in this thesis. Traditional reporting of quantitative findings provides exact numbers, quantities and percentages (Polit & Beck, 2010). However, as recommended by Braun and Clarke (2013), findings of this qualitative study will use terms such as “some”, “several”, “many”, “most” and “all” to refer themes and subthemes generated by the data. This is because in qualitative research, just counting numbers misses the point (Pyett, 2003), whether something is insightful or important for shedding light on the research question is not determined by numbers (Buetow, 2010; Braun & Clarke, 2013). The goal of qualitative research is not to generalise, but to provide a rich, descriptive, contextualised understanding of some aspect of human experience (Polit & Beck, 2010).

The peak organisation in Australia providing assistance, education and support to PwMS has had several name changes over the years. In the state of New South Wales (NSW) where the current study was performed, the MS Society (MSS) later became MS Limited (MSL), and is now named MS Australia (MSA). Direct quotes from the participants will be unchanged, however all other references made will be to the current organisational name, MSA.

Medications have both generic and trade names. In this thesis, they will be referred to by their generic names in the more formal discussions. However, medication trade names will also be referred to where necessary to ensure clarity as, very often, the study participants referred to their medications by the trade name.

Overview of the thesis

This first chapter has provided a rudimentary overview of RRMS, providing context for the research study. The study aims and research question are stated and a clear justification for the study is argued.

Chapter 2 will provide a more comprehensive overview of the disease, outlining characteristics and features which have an impact on a life lived with RRMS. This chapter contextualises the work as one exploring a complex, dynamic and unpredictable disease.

Chapter 3 provides a critical review of the existing literature. It is argued that, although there has been much research conducted in specific areas of MS care, understanding the broader context of the lived experience is poorly understood. The significant gaps in the literature indicate that the lived experience in RRMS is under-researched. Rather than a traditional thesis layout of the literature review in its entirety, chapter 3 provides a basic overview of the important work related to the lived experience of MS and, if it is specifically referred to by the authors, RRMS. However, the study findings located in chapters 6, 7 and 8 will weave more specific areas of MS/RRMS knowledge throughout each of the themes to firmly position the study findings within the current understanding of these phenomena.

A description and justification of the methodology and method that were employed to meet the study aims and answer the research question are detailed in chapter 4, along with a discussion regarding data management, ethical considerations, study rigour and reflexivity.

The individual narratives for each study participant are presented in chapter 5. A short life story is presented to provide context to their unique lives. This introduces the reader to each participant and provides context for the study finding chapters that follow in chapters 6, 7 and 8. In these later chapters, direct quotes from the study participants will be used to provide evidence to justify the study themes.

The findings for the study are presented and integrated with the relevant literature in chapter 6 titled “Walking the Low Road” and Chapter 7 titled “Finding the High Road”, where a total of eight primary themes are revealed. The main focus of chapter 6 is the early journey with RRMS, putting together the little hints that something might be wrong, seeking help, being diagnosed with RRMS and living with the challenges the early days present, some of them serious and confronting; others a chance to (re)define self and make new discoveries. The main focus of Chapter 7 is finding a path to a brighter future and discovering the skills to live well with RRMS, skills critical to “Taming the Beast” and looking forward to life with positivity and hope.

Chapter 8 is called “The Life Journey - Ebbs and Flows of Living with RRMS” and weaves the study themes together with life history methodology, demonstrating the effectiveness of using this novel method in qualitative MS nursing research. This chapter provides meaning and understanding of the lived experience of RRMS and highlights how this methodology works with the long-term trajectory of a chronic illness.

Chapter 9 concludes the thesis by presenting a summary of the research process and the major study findings. Recommendations for clinical practice in MS nursing care are presented and are linked to the key themes identified in the study. Limitations of

the research are discussed, as well as suggested directions for future research in RRMS.

Conclusion

This study aimed to uncover deep and rich understanding of the experience of living with RRMS. Using a life history approach, semi-structured interviews and thematic data analysis, themes were developed which detail the stories of people living with RRMS as they go about the challenges and joys of their daily lives. Using the life history approach also enabled particular attention to each participant's life before RRMS in order to appreciate what came afterwards, with the diagnosis of RRMS and (re)defining of self. Chapter 2 provides an overview of the disease, outlining the specific challenges for individuals living with RRMS and the modern day treatment paradigm. This provides a context for understanding the complexities and intricacies of the disease, allowing an appreciation of what it means to be diagnosed with RRMS.

CHAPTER 2: OVERVIEW OF MULTIPLE SCLEROSIS

Following on from the brief introduction of MS in the previous chapter, chapter 2 will provide a more comprehensive overview of MS. This is primarily to support situating the context of the study as people living with an unpredictable and potentially serious threat to health and wellbeing but also to give an understanding of the many possible symptoms of RRMS and the specific issues that relate to living with the disease. RRMS has a great variability of possible presentations and disease courses, as well as being a complex disease to clinically diagnose and manage. Having an understanding of the overall picture of MS and more specifically RRMS will help the reader to appreciate the impact of the themes and sub-themes of the study findings and to realise the overall significance of the research in terms of potentially improving clinical care for PwRRMS in the future.

What is MS?

MS is a disease of the central nervous system (CNS) affecting the brain, spinal cord and optic nerves. MS is a progressive inflammatory disorder in which there is damage to key components of the nerve cells, namely myelin and axons (Compston & Coles, 2008). The pathological processes involved in MS are immune mediated and directed against the myelin sheath, the protective covering of the axons, termed *demyelination* (Calabresi, 2004). More recently it has become apparent that grey matter disease occurs early in the disease process, causing additional inflammation and neurodegeneration and possibly playing a role in physical and cognitive disability (Calabrese et al., 2015).

As a result of demyelination and the subsequent healing process, sclerotic plaques (scars) develop in multiple areas of the CNS. This pattern needs to occur more than once to fulfil the diagnosis of MS - *multiple* sclerotic lesions in *multiple* locations. However, over time, the disease becomes one of chronic neurodegeneration rather than acute inflammation, with progressive accumulation of disability due to nerve loss (Compston & Coles, 2008). The impaired nerve conduction, resulting from

demyelination and axonal loss, leads to many of the signs and symptoms of MS. The course of MS is highly variable and patients may develop irreversible disability, with MS remaining a major cause of disability in young adults (Brownlee et al., 2016). MS remains incurable, although recent breakthroughs in understanding MS and more targeted treatments are resulting in a brighter future for people recently diagnosed with the disease.

Clinically Isolated Syndrome (CIS)

Most cases of MS present with an acute *first* episode, known as the clinically isolated syndrome (CIS) (Compston & Coles, 2008). Until recently, a diagnosis of MS was not able to be made at the time of CIS, even if highly suspected, because there needed to be two clinical relapses more than 30 days apart to meet the diagnostic guidelines of a *multiple* relapsing MS course (Poser 1983; McDonald et al., 2001; Polman et al., 2005). This situation was often frightening for many patients after suffering a first relapse, with no clear answers and just a “wait and see” approach. In recent years, it has become possible with the revised diagnostic guidelines to diagnose MS after one CIS, if the magnetic resonance imaging (MRI) and other testing meets certain criteria to demonstrate multiple relapses (Polman et al., 2011; Thompson, Banwell, & Barkof, 2018). Internationally, the currently used criteria for diagnosing MS are known as the 2017 McDonald criteria (Thompson et al., 2018).

Once the McDonald criteria have been met and the diagnosis of MS has been confirmed, there are three clinical course descriptions (phenotypes) of MS that will categorise the disease and thereby guide future treatment, prognostication and management strategies (Lublin et al., 2014). These are relapsing remitting MS, secondary progressive MS and primary progressive MS. Educating patients and families about the differences between these phenotypes is essential, as they are very different disease courses each with different treatment options.

Relapsing Remitting MS (RRMS)

The majority of people diagnosed with MS (up to 85%) begin with a diagnosis of RRMS (Milo & Miller, 2014; Brownlee et al., 2016). A relapse is defined as “patient reported or objectively observed events typical of an acute inflammatory event in the

central nervous system (CNS), current or historical, with duration of at least 24 hours, in the absence of fever or infection” (Polman et al., 2011, p.293). Relapses are also referred to as “exacerbations”, “attacks” and “flare-ups” but the term relapse will be used throughout this thesis for clarity and consistency. New relapses occur erratically but seldom occur more than one to two times per year (Compston & Coles, 2008). Typically, people recover from a relapse and return to baseline (before the relapse) function over a period of four to eight weeks, but recovery can be uncertain, variable and incomplete (Sorensen, 2014). Additionally, although it may appear that physical function is returned following a relapse, there is still a measurable and sustained effect on disability from relapses (Lublin et al., 2003). Relapse symptoms are generally considered to resolve over time, even if not treated (Ross, Halper, & Harris, 2012). However, if the relapse symptoms are bothersome or affecting function, treatment may be considered to speed up the process of recovery, usually involving a short course of high dose corticosteroids to reduce the acute inflammation (Bevan & Gefland, 2015; Kalincik, 2015; Yamasaki et al., 2016). Relapses can be a significant physical, emotional and economic burden with the reduction of relapses by using disease modifying therapy (DMT) an important goal of treatment in order to reduce future neurological disability (Kalincik, 2015). The forms of DMT available to treat RRMS and their implications will be discussed later in this chapter.

At present there is no tool or test that can advise what the future clinical course of RRMS will be for an individual, adding to the uncertainty at the time of diagnosis (Bergamaschi et al., 2015) where no specific information on prognosis can be given. However, there are prognostic risk factors which can provide some guidance, including a better prognostic outlook for PwRRMS who are female, experiencing sensory rather than motor relapses and showing minimal burden of disease on imaging (Weinshenker, 1995). There are groups of people with RRMS who experience very few symptoms and little clinical activity and yet others have highly active clinical and radiological disease (Hum, Lapierre, Scott, Duquette, & Mayo, 2017). MS progression can be so variable that there was a time when it was thought that no common disease course existed and that each patient followed a unique path (Minderhoud, van der Hoeven, & Prange, 1988).

Secondary Progressive MS (SPMS)

Over time, recovery from relapses in RRMS is incomplete and accumulation of disability begins (Compston & Coles, 2008). SPMS is diagnosed retrospectively by a history of gradual worsening, after an initial relapsing course, with or without acute relapses during the progressive course (Lublin et al., 2014). There are no clear criteria to determine exactly when this transition occurs, it can be an unpredictable and uncertain period of time for PwRRMS (Bergamaschi et al., 2015) and also for their HCPs. The natural history data on the course of MS suggests that on average, SPMS occurs about 19 years after RRMS onset, with PwSPMS taking an average of 20 years to progress to using a walking stick and 30 years for wheelchair dependence (Vukusic & Confaveux, 2006). Reaching SPMS at a younger age and with only a short RRMS course has also been associated with a more rapid disease progression (Tremlett, Zhao & Devonshire, 2008).

Primary Progressive MS (PPMS)

PPMS is a separate clinical phenotype affecting 10-15% of people diagnosed with MS (Milo & Miller, 2014). PPMS is progressive in nature from disease onset with gradual worsening of neurological function and no relapses occurring (Compston & Coles, 2002). It has been hypothesised that PPMS represents a distinct, non-inflammatory form of MS (Lassmann, van Horssen, & Mahad, 2012), which may explain why the traditional DMTs (which are effective in RRMS) do not alter the disease course in PPMS. However, there has also been recent literature to suggest that in PPMS there may be some inflammatory activity, but it is different in nature to RRMS and SPMS and features axonal destruction and eventually brain atrophy (Mahad, Trapp, & Lassmann, 2015). Compared with RRMS, people with PPMS are older at onset and a higher proportion are men (Lassmann, van Horssen, & Mahad, 2012). There has recently been a breakthrough in a new treatment for PPMS with Ocrelizumab, a CD-20 monoclonal antibody, leading to depletion of B-cells and demonstrating effectiveness in PPMS by slowing disease progression (Hauser, 2015). Ocrelizumab has very recently been approved for use in Australia and internationally.

New classifications for MS

There has recently been a suggestion to reclassify the phenotypes of MS, taking into account disease activity; reclassifying PwMS as experiencing either a *relapsing* or *progressive* path and with either *active* or *inactive* disease and either *progression* or *non-progression* (Lublin et al., 2014). However, this has not universally been adopted at present, so reference to the original phenotypes outlined above will be used throughout this thesis.

Natural History of MS

Much is known about the natural history of MS, mainly because there were no treatments or disease modifying drugs until the 1990's (Jacobs et al., 1996). The natural history pattern is highly variable. The seminal natural history data from Weinshenker (1994) suggests that at 15 years from disease onset, 50% of patients are disabled to the point of needing a walking stick to ambulate. Additionally, an early age at onset, female sex, relapsing-remitting course at onset, optic neuritis or sensory symptoms and relatively few attacks in the first two years are associated with a more favourable course (Weinshenker, 1994). Conversely, patients with the greatest risk of disability are those with PPMS or RRMS patients who are older at onset, have pyramidal or cerebellar involvement, and who have frequent or prolonged attacks with incomplete recovery. The biological basis for the variation in the course of MS is poorly understood.

Epidemiology

In many countries MS is the leading cause of non-traumatic neurologic disability in young adults (Browne et al., 2014). The Australian Bureau of Statistics (ABS) estimate a total of 23,700 people in Australia to be living with MS (ABS, 2009). However, more recent data from Multiple Sclerosis Research Australia (MSRA) suggests this number may now be as high as 25,600, with an average of more than 10 people being diagnosed in Australia every week (MSRA, 2018). The increasing incidence and prevalence of MS over the last five decades (Pugliatti et al., 2006; Koch-Henricksen & Sorensen, 2010) is concerning and requires continued research

to better understand the potential environmental factors impacting on the development of the disease.

Interestingly, the prevalence of MS has a female preponderance with women almost three times more likely than men to develop the disease (Koch-Henriksen & Sorensen, 2010). RRMS can occur at any age, but the most common age for diagnosis is as a young adult between 18 and 40 years, with a mean age of 30 years (Compston & Coles, 2008). However, paediatric MS occurs in about 5% of cases with onset before the age of 18 years (Lulu, Graves, & Waubant, 2016) and is more prevalent in adolescents than younger children (Waldman et al., 2016).

Causes of MS

The cause of MS is unknown, however there are several clues about how MS begins (Spencer & Karceski, 2015). It is thought that MS is caused by a complex interplay between the immune system and environmental factors (Compston & Coles, 2008). It seems unlikely that MS results from a single causative event, but rather the disease develops in a genetically susceptible population as a result of environmental exposures (Ramagopalan & Sadovnick, 2011). Exposure to environmental risk factors in MS is thought to occur before the age of 15 years (Belbasis, Belbu, Evanelou, Ionnidis, & Tzoulaki, 2015). The risk factors thought to be associated with an increased risk of MS include Epstein-Barr and other viral and bacterial infections, vitamin D levels, geographical location/latitude gradient (the closer to the poles, the greater the prevalence of MS), cigarette smoke exposure, and certain human genotypes (Banwell, Bar-Or, Giovannoni, Dale, & Tardieu, 2011; Sellner et al., 2011) as well as obesity, gut microbiota and pregnancy exposures (Belbasis, Belbu, Evangelou, Ionnidis, & Tzoulaki, 2015). The infection exposure theory is currently thought to originate in childhood, where antibodies are formed against an infectious agent (an as yet identified virus or bacteria) and for reasons that are unknown, these antibodies attach to a protein in the myelin coating of the axons resulting in the body becoming confused and destroying the protective myelin (Spencer & Karceski, 2015).

MS has a familial recurrence rate of about 5% for siblings and about 2% for children and parents (Compston & Coles, 2008), suggesting genetic links but not heritability of the disease, with most PwMS having no affected relative (Coyle, 2016). Recent genetic research has accelerated the understanding of genetic MS theories with the identification of non-human leukocyte antigen (HLA) risk genes that are related to immune function (Waubant et al., 2016), opening exciting new areas of hope for answering questions about the causes of MS in the future.

Diagnosing MS

The diagnosis of MS is based on neurological signs and symptoms and is primarily a clinical diagnosis, assisted by specific investigations (Brownlee et al., 2016). Often there are significant delays before a person with symptoms suggestive of MS sees a neurologist and receives a diagnosis (Giovannoni et al., 2016). There are several reasons for this delay including lack of recognition of symptoms by the person, the family doctor not referring on, lack of available neurology care and appointments and symptoms being both vague and intermittent in nature.

In most PwRRMS, clinical manifestations (the symptoms) reflect the area of demyelination in the CNS and indicate the involvement of motor, sensory, visual, and autonomic systems, but many other symptoms and signs can occur (Compston & Coles, 2008). Adding to the difficulties with diagnosis, very few clinical features are disease-specific and there is no pathognomonic test for MS. Specifically, there is not one symptom, sign, or paraclinical result that provides an unfailingly accurate diagnosis of MS (Giesser, 2011). This can be a time of extreme frustration for patients as often the diagnosis involves many tests and investigations and can sometimes not be definitive, and in some cases, not definitive for many years.

Over the last four decades, certain criteria have been developed to help guide the diagnosis of MS, beginning with Poser et al. (1983) and followed by the “McDonald criteria” (McDonald et al., 2001), which incorporated the MRI scan for the first time. The McDonald criteria were updated in 2005 (Polman et al., 2005), again in 2010 (Polman et al., 2011) and more recently in 2017 (Thompson et al., 2018) to reflect changes in MS knowledge and practice. The most recent changes have made an

important impact, allowing for an earlier diagnosis of MS, leading to more rapid treatment initiation and reducing the risk of disease progression (Mantero, Abate, Balgera, La Mantia, & Salmaggi, 2018). This has led to an increase in MS cases being diagnosed but still requires careful assessment to prevent misdiagnosis and mistreatments (Mantero et al., 2018). However, this can also create significant emotional and coping issues as people can be diagnosed with RRMS in just one visit to the neurologist, and then also face difficult and complex treatment decisions simultaneously.

Investigations used to diagnose MS

In addition to neurological and clinical examinations, diagnosing MS often depends on excluding other disorders that can mimic MS (Filippi et al., 2016). Some of these investigations include the MRI scan, neurophysiological tests such as evoked potentials and extensive blood tests. A spinal tap or lumbar puncture (LP) can also be performed to obtain cerebrospinal fluid (CSF) for examination to assess for the evidence of oligoclonal bands, which can assist in confirming an MS diagnosis. Most of the investigations are not painful but can be uncomfortable at times (MRI, LP, blood tests), difficult (LP) or induce feelings of claustrophobia (MRI).

The Expanded Disability Status Scale

The Expanded Disability Status Scale (EDSS) is used to quantify the degree of MS related disability in individual patients (Kurtze, 1955; 1983). Many studies show that MS relapses can leave permanent neurological deficits and play a role in disability accumulation (Goodin et al., 2016). The EDSS aims to measure the neurological function and provide a score to reflect neurological deficits. A clinical examination of eight functional systems impacted by the CNS (pyramidal, cerebellar, brain stem, sensory, bowel/bladder, visual, cerebral and other) results in individual scores which are compiled together with ambulatory data to form a total score, the EDSS. The final score ranges between 0 and 10, with 0.5 measurements between each level. A score of 0 indicates no neurological impairment, a score of 1.0 indicates mild disability in a single area, a score of 4.0 indicates that a person is fully ambulatory

but accruing significant disability in several functional areas, a score of 6.0 indicates assistance required to ambulate with a unilateral walking assistance, 6.5 bilateral walking assistance or walker, a score of 7.0 indicates wheelchair dependence and a score of 9.0 indicates confinement to bed. An EDSS score of 10 relates to death from MS.

Common symptoms in MS

The initial presentation of MS varies according to both the location and size of lesions and the type of onset (relapsing or progressive onset) (Brownlee et al., 2016). Common symptoms in MS can greatly affect quality of life (QOL) and rarely occur in isolation (Crayton & Rossman, 2006; Newland, Thomas, Riley, Flick, & Fearing, 2012). These symptoms include fatigue, depression, anxiety, cognition issues, bladder and bowel dysfunction, sexual dysfunction, pain, spasticity, motor weakness, sensory dysfunction, visual disturbances, ataxia and gait disturbances. Symptoms usually result directly from nerve conduction issues secondary to demyelination, either in response to an acute relapse, or as long-term consequence of previous demyelination and axonal loss. Additionally, many of these symptoms are not immediately obvious to others and are described as “hidden” or “invisible” symptoms of MS, which can lead to possible stigmatisation or poor understanding by others who do not have the disease (Joachim & Acorn, 2000).

Symptom management in MS is an integral part of its care, with accurate assessment and management providing increased quality of life (Ben-Zacharia, 2011). It has been suggested that MS-related fatigue is different to normal fatigue due to its severity and the ability to significantly impact upon daily activities (Newton, Griffiths, & Soundy, 2016), being complex, multidimensional and poorly understood (Smith, Hale, Olson, Baxter, & Schneiders, 2013). There are two symptoms, not diagnostic of, but often peculiar to, demyelination in MS. These are L’hermittes sign, which is an electric shock-like feeling when flexing the neck forward and is caused by inflammation in the spinal cord (Al-Araji & Oger, 2005). The second is Uhthoff’s phenomena, MS symptoms which can be worsened or triggered by factors such as the menstrual period, exercise, infection, fever and stress and refers to symptoms

coming on paroxysmally and being reversible (Frohman et al., 2013). “Pseudo-relapses” can occur in RRMS and describe fatigue occurring in isolation or a transient fever-related worsening of MS symptoms (Polman et al., 2011).

Aside from the highly variable disease state and multitude of possible neurological symptoms, MS can also cause numerous secondary and tertiary effects. Issues may develop in highly personal areas of intimacy and sexuality, relationships and employment. MS often causes challenges for people coping with the disease and the associated changes in life (Rommer, Koenig, Suhnel, & Zettl, 2015).

MS and mental health issues

MS is often diagnosed at an exciting time of life, when young adults are graduating from school or university, getting married, starting a family or advancing a career, MS therefore has the potential to cause significant emotional stress in the lives of people diagnosed with the disease. As a result of the current shortened diagnostic workup, people with RRMS can be rapidly confronted with a disease of uncertain prognosis that requires complex treatment decisions (Solari et al., 2014). This can also be at a time of great vulnerability when PwRRMS could be ill-equipped to make these decisions due to recent high dose steroid treatments, feelings of stress and worry, other mental health issues, confusion over the meaning of the disease and the wealth and complexity of available information and resources. Anxiety and depression in particular have both been associated with less adherence to medication, increased risk of relapses, cognitive impairment, increased use of health resources, mortality, fatigue and pain in PwMS (de Jong & Uitdehaag, 2018). An additional area of concern is the rate of suicide in people living with MS, which is up to seven times greater than the general population (Pompili, 2012).

Anxiety

It is not surprising that the unpredictable nature of RRMS, specifically with respect to relapses and potential for disability, leads to anxiety (Morrow, 2018). Anxiety is a diagnosable mental health illness under the Diagnostic and Statistical Manual of Mental Disorders (DSM-V®) with a variety of criteria and specific anxiety disorders

(APA, 2013). Several studies exploring anxiety in MS have shown that anxiety is more prevalent in the MS population than in the general population (Feinstein, Magalhaes, Richard, Audet, & Moore, 2014) and may be as high as 36% in PwMS (Hoang, Laursen, Stenager, & Stenager, 2016). A large cohort study (n=5084) of MS patients matched with a control population, has reported that during both the pre and post diagnostic period, MS patients had an increased risk of anxiety and medication usage when compared to the general population (Hoang et al., 2016). In RRMS, anxiety may be severe and prolonged due to the uncertain nature of the disease, in terms of relapses, symptoms and disease progression (Janssens et al., 2004). Furthermore, anxiety has been strongly associated with lower QOL scores across all levels of illness severity, from mild impairment to severe (Ionescu et al., 2012). Anxiety is more prevalent in females than males in PwMS (Theaudin, Romero, & Feinstein, 2016) and needs regular assessment and evaluation. There is also a higher likelihood of alcohol use, substance abuse and smoking associated with anxiety in PwMS (Marrie et al., 2015).

Anxiety has also been identified as being significantly associated with low levels of disease acceptance and mindfulness in MS (Pakenham & Samios, 2013), which may have direct consequences on adherence to DMTs and to MS wellness prescriptions. Anxiety is most highly associated with depression, low self-efficacy, stress, emotion focused coping, pain, fatigue and QOL, factors that may be amenable to intervention if identified and actioned by MS HCPs (Butler, Matcham, & Chalder, 2016).

Depression

As with anxiety disorders, depressive disorders are a diagnosable mental health illness under the DSM-V® with listed criteria including depressed mood, loss of interest and enjoyment in usual activities, reduced energy, reduced self esteem and confidence, ideas of guilt and unworthiness, pessimistic thoughts, disturbed sleep and appetite and ideas of self harm (APA, 2013). For people with MS the lifetime prevalence rate of a depressive disorder has been reported as greater than 50% (Hoang et al., 2016) and is three times higher than the general population (Kessler et al., 2012; Patten, Beck, Williams, Barbui, & Metz, 2003). Depression in MS is still

undertreated and under-recognised and most importantly, depression can be fatal (Feinstein, 2011; Newsome et al., 2017)

A multitude of aetiologic factors contribute to depression in MS, including biological (lesion burden, location of lesions and brain atrophy) as well as the stresses, losses and threats that accompany living with an unpredictable and potentially disabling disease (Patten et al., 2003). Depression in MS is extremely complex and complicated by other factors such as fatigue, cognition and physical impairment, which can also mimic depression and prevent accurate diagnosis (Gunzler et al., 2015). Turner and Alschuler (2018) suggest that depressed mood and MS symptoms such as fatigue, cognition and pain have a bidirectional relationship, each causing the other to be worse. Depression in MS possibly has a different pathophysiology to the general population and has been described as chronic rather than episodic in nature (Koch et al., 2015). Additionally, depressive syndromes occur with significant frequency across the natural history of MS, including patients with very mild forms of MS, and do not correlate well with the severity of neurologic disability (Perez, Gonzales, & Lazaro, 2015).

Treatments for RRMS

Disease modifying treatments for MS

There have been many recent developments in treatments for RRMS, however a cure for the disease remains elusive. The immune dysregulation in the development of MS leads to a cascade of events resulting in inflammation and axonal degeneration in the CNS (Grigoriadis & van Pesch, 2015). The DMTs act to interrupt this cascade at varying points of the process. The goal of the DMT is to delay the accumulation of disability and to delay transition to the more progressive and disabling SPMS (Liu et al., 2016). The occurrence of a relapse on a DMT is usually considered an indication of breakthrough disease and suboptimal response (Liu et al., 2016) and often results in a “switch” of DMT to another therapy, usually to a more efficacious medication (Bevan & Gelfand, 2015). However, as no current DMT completely eradicates disease activity, there is much debate currently about what constitutes breakthrough

disease and what the primary aim of treatment is; as treatment goals move and monitoring of outcomes is more active (Giovannoni et al., 2015).

In the past 20 years RRMS has been transformed from a disease of relative hopelessness, with few, if any, treatment options to one of optimism and robust therapeutic promise (Ross & Thrower, 2010). The approval of immune modifying medications for RRMS is often cited as a major advance in our understanding, however many questions still remain unanswered (Stüve & Racke, 2016). Whilst the number of DMTs are rapidly increasing, there is still need to define which patients will respond to which drug and who is at higher risk of side effects (Stüve & Racke, 2016). The option of individualised optimal treatment is complicated because of the unpredictable natural behavior of the disease, the different phenotypes and stages, the diversity of different therapies, and the serious and sometimes life-threatening side-effects of some of the treatments (Rio, Comabella, & Montalban, 2011).

With advances in DMTs, survival in RRMS has increased and a slower accumulation of disability has resulted (Tremlett, Zhao, Rieckmann, & Hutchinson, 2010) with the natural history of the disease shown to be altered in randomized clinical trials (Wingerchuk & Carter, 2014). Treatment options for the disease are most effective during the relapsing remitting phase and are recommended to start early after diagnosis for the best clinical outcomes (Broadley et al., 2015; Kavaliunas et al., 2017). Australia is in a fortunate situation in terms of registered and government supported programs for DMTs to treat RRMS. There are set criteria to follow in order to gain Pharmaceutical Benefits Scheme (PBS) approval, but once these criteria are met, patients can be prescribed a range of DMTs, benefitting from an individualised approach to choose the DMT most appropriate for their level of disease activity and based on pathophysiology and illness patterns. The cost of these medications is high, but the DMTs are made available to patients in Australia at greatly subsidised rates. All available medications have been tested clinically for safety and efficacy in large, multicentre clinical trials in people with RRMS. Many other countries (currently such as Great Britain) have restrictions on which medications may be used at which stage of the disease or have regulations on which medications need to be used as first, second or third line therapy (Giovannoni et al.,

2016) or other countries (such as the United States) need to rely on approval from insurance companies to begin a certain DMT (Parise et al., 2013).

There are currently 12 DMTs approved to treat RRMS in Australia; the injectable medications which the patient learns to self-inject (four forms of interferon beta, two forms of glatiramer acetate) the oral medications (fingolimod, dimethyl fumarate and teriflunomide) and the intravenous monoclonal antibody medications (natalizumab, alemtuzumab and ocrelizumab). A current list of DMTs approved in Australia is listed in Table 1. The many options for treatment can be complex and challenging to negotiate, however there are suggested guidelines that can be followed to assist in choosing the most appropriate DMT for patients with RRMS (Broadley et al., 2014a; Finkelsztejn, 2014).

Table 1. *Currently approved and marketed DMTs for RRMS in Australia*

Generic name	Trade name	Mode of delivery	Frequency of dosing	Common side effects or serious side effects
Interferon beta-1b	Betaferon®	subcutaneous injection	every other day	influenza-like symptoms (fever, chills), injection site reactions, depression
Interferon beta -1a	Rebif®	subcutaneous injection	three times a week	as above
Interferon beta- 1a	Avonex®	Intramuscular injection	weekly	as above
Interferon beta- 1a-pegylated	Plegridy®	subcutaneous injection	fortnightly	as above
glatiramer acetate	Copaxone®	subcutaneous injection	daily or three times/week	injection site reactions, lipoatrophy “immediate post injection reaction”
Teriflunomide	Aubagio®	Oral	daily	liver enzyme elevations, hair thinning, nausea
Dimethyl fumarate	Tecfidera®	Oral	twice daily	gastrointestinal disturbances, flushing, rare PML
fingolimod	Gilenya®	Oral	daily	first-dose cardiac effects, infections, macular oedema, liver enzyme elevations, skin malignancies, rare PML
Natalizumab	Tysabri®	Intravenous infusion	Every 4 weeks	infusion related side effects, variable risk of PML
Alemtuzumab	Lemtrada®	Intravenous infusion cycle	Annually x 2 years	infusion related side effects, autoimmune side effects (thyroid, blood and renal)
Ocrelizumab	Ocrevus®	Intravenous infusion	6 monthly	infusion related side effects, ?malignancies

All of the DMTs have side effects associated with their use, some of which (such as injection site reactions and intermittent mild diarrhoea) can be easily managed. Some of the newer treatments (the monoclonal antibodies) are more efficacious than the injectable therapies, reducing relapse rates by 50-70% compared to approximately 30% for injectables (Kalincik et al., 2017). However, they do possess significant

additional safety concerns. The newer DMTs require specific monitoring for adverse events, some of which can be fatal if not recognised early (Finkelsztejn, 2014). The added pressures of greater efficacy balanced with an increased side effect profile can cause significant stress and emotional burden for PwRRMS. Additionally, factors such as cognition issues, tolerance for side effects, cost and fatigue play havoc with adherence to treatments (Kopke, Solari, Khan, Heeson, & Giordano, 2014).

Some of the more serious side effects related to DMTs came up frequently in the data collection for the current study. Progressive multifocal leukoencephalopathy (PML) is a brain infection caused by the John Cunningham virus (JCV) and has been associated with natalizumab treatment, and to a much lesser degree with the oral treatments fingolimod and dimethyl fumarate (Broadley et al., 2015; Clifford & Nath, 2010). The PML infection has been reported in over 750 cases of RRMS with a greater than 20% fatality rate and a substantial morbidity in survivors (Biogen, 2018). PML is difficult to differentiate in PwRRMS because the symptoms of the brain infection can mimic MS symptoms and can be missed. There are algorithms to help MS HCPs and PwRRMS determine specific risks dependant on individual levels of JCV antibodies (measured on a blood test), on the number of infusions administered and on previously prescribed MS treatments. Other serious DMT side effects are related to treatment with alemtuzumab, and include serious autoimmune thyroid issues, idiopathic thrombocytopenia purpura (a blood clotting disorder) and autoimmune renal disease (Coles et al., 2012). Ocrelizumab was not approved for use in Australia at time of data collection and did not feature in discussion in the participant interviews.

The current treatment landscape in Australia has a myriad of first line treatment choices for people diagnosed with RRMS, all with varying degrees of efficacy, risks and side effect profiles. Coupled with a rapidly expanding digital world with growing information of unknown quality and accuracy, it is no wonder that people diagnosed with MS face considerable stress coping with not just the disease and the decision making processes that go along with DMT treatment options, but also the uncertainty and unpredictability which are features of the disease. The lack of an accurate prognostication tool at the beginning of the disease trajectory can be both

frightening and frustrating for people diagnosed with MS and make it difficult to reach a comfortable decision on DMT choice (together with their MS HCP).

Controversial therapies

Even though there are many rigorously clinically proven DMTs to treat RRMS, patients can be so desperate for a cure that they will overlook the lack of carefully tested scientific evidence and consider unproven and potentially dangerous treatments (Bowman, Racke, Kissel, & Imitola, 2015). This is understandable as vulnerable patients search for answers to their illness, not just in the absence of a cure, but also in the setting of very serious effects from DMTs and the risk of disease progression, even when compliant with DMT.

One form of treatment which has been controversial in the past, but with continued research is becoming more accepted as a potential treatment in RRMS, is haematopoietic stem cell transplant (HSCT). This emerging therapy is being used for aggressive RRMS unresponsive to current DMTs, and is currently the subject of several international clinical trials (Dorr, 2016). Early results show great promise in improving neurological function and preventing new MS lesions (Atkins et al., 2016), however there is also a 5% mortality reported with the procedure and a general consensus on protocols and safety have not yet been established (Dorr, 2016). The evidence for using HSCT in certain individuals with RRMS is increasing and may be an effective treatment for specific situations, in the setting of careful patient selection and experienced staff (Alexander et al., 2018). However, outside of the clinical trials, some PwRRMS have resorted to “stem cell tourism” which a rising internet based industry that offers unproven procedures to people with incurable diseases, and in most cases involving travel overseas (Bowman et al., 2015). Once again, an understandable option to consider for people living with an unpredictable disease and uncertain future. It has been suggested that instead of seeing people who pursue unproven therapies as “desperate individuals duped by medical racketeers”, they could be seen as “empowered citizens who have taken an informed decision to pursue an experimental therapy” (Mazanderani, Kelly, & Ducey, 2018, p.232).

A controversial treatment that has been shown to be ineffective in MS, but is still sought out occasionally by PwMS, is liberation therapy. This type of angioplasty was

postulated to correct a possible cause of MS, chronic cerebrospinal venous insufficiency (CCSVI), but has been proven to be ineffective (Zivadinov & Weinstock-Guttman, 2018). Combating the spread of viral internet popularity for this therapy proved difficult, as the value of the MS neurologist and HCP expertise was largely ignored in favour of emotionally resonant blogs, despite reported mortality of the procedure (Green, Kamel, & Josephson, 2018). In a recent study of 168 participants all living with RRMS, Chacinska et al. (2017) found that in their search for a cure, PwRRMS were likely to accept very risky treatments, with 81% of participants accepting a 1:100 mortality for the *chance* of a cure.

New therapies

Besides HSCT clinical studies described above, there are many new therapies for MS currently in development, with over 20 phase two and three studies in progress (Shirani, Okuda, & Stüve, 2016). Several of the new biological molecules, such as amiselimod, have shown promise in efficacy with improved side effect profiles over the current DMTs (Kappos et al., 2016), leading to a great deal of hope about future treatments and their positive and safer impact on not just RRMS, but all forms of MS.

Neurorehabilitation

An important adjunct to DMTs, especially after a relapse, is neurorehabilitation and physical therapy (Davies et al., 2016). Various forms of exercise such as weight training, Pilates and yoga have also been found to be useful in alleviating symptoms of MS and in building strength (Feinstein, Freeman, & Lo; 2015). Rehabilitation in both physical and cognitive forms is a key treatment for all phenotypes of MS (Haselkorn et al., 2015; Khan et al., 2016; Mitolo, Venneri, Wilkinson, & Sharrack, 2015).

MS and Pregnancy

As RRMS predominately affects women, is on the rise in young women and has a mean onset of 30 years of age, many affected by RRMS will be in the childbearing

years of their lives (Coyle, 2016; Miller, 2016). Pregnancy does offer some protection against relapses (most effectively in the final trimester) although there is a return to baseline risk as soon as the baby is born (Miller, 2016). There has also been the suggestion that there are long-term benefits from pregnancy on progression of the disease (Masera et al., 2015; Ponsonby et al., 2012) and that there are no negative effects from pregnancy on MS prognosis (Coyle, 2016).

Many DMTs are not approved for pregnancy and need to be ceased prior to conception, which is often difficult to manage in a person with active disease who wishes to conceive and become pregnant (Coyle, 2016). Women with RRMS also often face decisional conflict regarding motherhood, although pregnancy has been found to be safe for mother and baby (Prunty, Sharpe, Butow, & Fulcher, 2008).

Contemporary Issues in MS

Although many people with RRMS continue to work and be independent, there are impacts on self esteem, relationships and friendships, community involvement and social activities that can be all-encompassing (Holland & Madonna, 2005). PwMS often have concerns that their disease will have negative economic and psychosocial effects for them and their family, impacts on childbearing and parenting and also burdening their partner with the disease (Alwan et al., 2013). There have been reports of an increased rate of broken relationships in PwMS particularly with the onset of other co-morbidities after the diagnosis of MS, suggested as relating to increased stress and demands placed on the relationship (Thormann et al., 2017). Perceptions by the PwMS and their partner of being “less able” can also lead to feelings of loss within a marriage and increased frustrations in maintaining relationships (Tabuleau-Harrison, Haslan, & Mewse, 2016).

There has been a focus on lifestyle matters for PwMS in the last few years, as awareness of the impact of positive lifestyle choices on MS has heightened. These include adopting a holistic approach to the management of MS and to the positive effects of exercise, smoking cessation, reduction of alcohol consumption, activities that improve cognitive reserve and a healthy diet (Giovannoni et al., 2016).

Support and resources for people living with MS in Australia

The number of MS groups and organisations worldwide has increased over recent years as demand for services and support has increased along with patient numbers diagnosed with MS (Browne et al., 2014). Support services are perhaps more important now than ever, as treatments evolve and patient management becomes more complex. In Australia, the growth of public and private based MS clinics over the last decade have increased dramatically to meet the needs of patients, to enable timely and efficacious treatments and to monitor disease activity and patient safety as the new DMTs become part of the complicated treatment paradigm.

It has been reported that coordinated, multidisciplinary care is of greater benefit than medical care alone in MS (Thompson, 2011). The goal of MS clinics is to offer specialized, targeted multidisciplinary care. Recently, patient engagement in their own healthcare has been described as “the blockbuster drug of the century” and vital for improving outcomes in people with MS (Rieckmann et al., 2015). Achieving patient engagement happens in the setting of education, confidence building, encouraging treatment adherence, valuing the importance of quality of life, empowering through responsibility and providing credible sources of information (Rieckmann et al., 2015) These are all important functions of MS clinics and MS organizations in Australia, involving an expansive and multidisciplinary approach. The importance of continuity of care and in particular communication between hospital and community, has never been more important and MS Neurologists, MS Nurses and MS organizations are integral in this regard.

MS Australia (MSA) is the national peak body for people living with MS in Australia; active in research, advocacy, disease awareness, communications, information and support for people affected by MS, their families and carers (MSA, 2018). Working alongside MSA is Multiple Sclerosis Research Australia (MSRA), dedicated to funding, co-ordinating and accelerating MS research, with the aim of ultimately finding a cure for MS (MSRA, 2018). Both organisations are integral for patients and MS HCPs alike, by providing considerable support, advocacy and information resources.

Modern communication technology and MS

Since the advent of the electronic and digital age, information and support is much more easily and freely available for people living with MS. The way people retrieve health information has changed due to an abundance of new media technologies and a remarkable growth in health information being available online (Haase, Schultheiss, Kempcke, Thomas, & Ziemssen, 2012). Websites from all of the major country MS societies and research groups are frequently accessed across the globe for information on all aspects of MS. Blogs and online support groups are also popular with patients and their families and also provide a means of communicating for people who may otherwise be isolated.

However, there are also negative aspects associated with these forms of electronic communication, including information overload, accessing inaccurate and outdated information, and misrepresentation of information. The rapidly growing production of healthcare information increasingly leads to a situation of information overload for all people involved in healthcare, patients, doctors and nurses (Klerings, Weinhandl, & Thaler, 2015). Having web-based information is an important and rich resource in healthcare to support practice and learning, but can also create conflicting evidence and security in the information (Bullock, 2014). The issues of technology and the digital age bring their known set of issues to living with MS and may impact greatly on patient care, in both a positive and a negative way.

The role of the MS Nurse

MS nursing has developed as a specialty after first being introduced in the United Kingdom on the early 1990's (Quinn, Leary, & Bowen, 2014). Evolution of the role has intensified over the last decade as new and more complicated therapies have been developed, greatly expanding the skillset and knowledge base of the MS Nurse as a specialist (Burke, Dishon, McEwan, & Smrcka, 2011). Most developed countries recognise this unique specialty, although some countries report no nurses with this specific expertise (Browne et al., 2014). Australia has a strong MS Nurse educational and resource organisation supporting MS Nurses in their practice, Multiple Sclerosis

Nurses Australasia (MSNA), which is a member of the International Organisation of MS Nurses (IOMSN).

The MS Nurse plays a critical role in assisting patients at the time of MS diagnosis and understanding options for disease treatment and management (Ross & Thrower, 2010). MS Nurses also play a central role in assisting patients with finding outside support to assist them in coping with their MS and in recognizing conversion to MS from CIS at an earlier stage (Kennedy, 2013). Additionally, fostering hope to combat feelings of hopelessness in MS is pivotal to the nursing role (Morgante, 2000).

In a survey of patients with MS, it was commonly felt that they had received insufficient support and education from healthcare providers in understanding and dealing with their diagnosis (Solari et al., 2007). Many people will have difficulty coming to terms with the diagnosis of MS and will worry about the possibility of becoming disabled and the future impact on employment, income, relationships, and activities of daily living (Ross & Thrower, 2010). Nurses, as integral members of the multidisciplinary healthcare team, play a major role in the education and support of the patient, and often at crucial times in living with MS.

Situating the current study in MS care

This overview of MS in general and the intricacies and complexities of RRMS in particular that have been presented in this chapter, have demonstrated that RRMS is a difficult and uncertain disease to live with. There are so many facets to MS care, so many possible symptomologies and so much unpredictability. Negotiating “normal” life alongside RRMS brings many challenges that need to be understood by MS Nurses and other HCPs in order to provide optimal clinical care to each individual. The following chapter will orientate previous research and knowledge of the lived experience of RRMS to the current research study in the form of a literature review. The significant gaps in the literature will also be discussed and the strengths of the current study in addressing these gaps will be presented.

CHAPTER 3: THE LITERATURE REVIEW

Format and scope of the literature review

There is a plethora of articles, studies and descriptive reviews reporting on the lived experience of MS. However, the great majority of this literature focuses on a certain *aspect* of living with the disease, whether it is a symptomatic aspect such as fatigue, bladder dysfunction or gait disturbance or a psychological aspect such as coping with diagnosis or change in symptoms. Others have reported on physical aspects such as falls, social aspects such as negotiating a changed world after diagnosis, or an adaptive aspect of MS, such as adapting to disability. This expansive array of literature also covers all phenotypes of the disease, CIS, RRMS, SPMS and PPMS, sometimes together and sometimes separately. Interestingly, however, there is a paucity of literature published on the overall, whole life experience of living with the phenotype of RRMS. In terms of life history research specifically, there is one article reporting on one particular symptom in MS, fatigue, but no in depth life history studies reported. The reasons for this could include the fact that the subject is so broad and heterogeneous that it is simply too vast a topic and needs to be broken down into smaller components; or it could be the time consuming nature of analysing qualitative work, especially when using the ethnographic life history approach.

This chapter, the literature review, will concentrate only on literature which addresses the experience of living with RRMS or MS in general, not reporting on specific characteristics or features of the disease, such as MS symptoms or disability. Later in the thesis, the findings and discussion chapters (6, 7 and 8) will integrate particular literature relating *specifically* to the study themes, reflecting on how the themes relate to what is already known. This approach has been recommended by others (Silverman 2010., Wolcott, 1994) as a process of conducting the bulk of the literature review in and around the specific data collection and data analysis rather than generally before the study commences. As supported by Silverman (2010), one of my study aims was to be innovative and creative in relating the literature to the study findings. *To develop*, rather than just present, ideas and concepts related to the themes advanced directly from the data. As Wolcott (1994) suggests, this calls for introducing related research towards the end of the study rather than at the beginning,

in an attempt to keep the literature more connected with the data analysis. Therefore, this traditional literature review in chapter 3 presents a critique and synthesis of the most significant research in the last three decades; research that is most akin to the current research study. In the subsequent chapters, I will present literature more directly connected with the study findings, some of which are presented in this chapter, but some literature the result of more specialised research in particular domains of MS.

The literature review in this chapter will be approached chronologically to show the progression of research and to demonstrate how new findings have built on what was already known. This approach also reflects how biomedical knowledge about MS developed and strengthened over time, allowing access to new and exciting areas of MS, supplementing the extensive quantitative and scientific work with qualitative, people-focused research.

Several search databases for academic literature were used in this literature review, in addition to medical, nursing and science search databases. These included CINAHL (nursing and allied health), PubMed (biomedical and life sciences), Scopus (scientific, medical, nursing and social sciences), PsycINFO (psychological), Embase (biomedical), Web of Life, Australian Bureau of Statistics, Libraries Australia, Joanna Briggs Institute, Cochrane library, Google Scholar, the Notre Dame University search engine “Summon” and Trove for dissertations/theses retrieval. Keywords used to search for the relevant literature were: life history, life experience, life story, lived experience, life journey, living with, battling, feelings in, meaning of, needs in, paediatric, aged, elderly, qualitative inquiry, qualitative methods, qualitative research, Multiple Sclerosis, Relapsing Remitting Multiple Sclerosis, Progressive Multiple Sclerosis, MS, RRMS, SPMS, PPMS, chronic illness, neurological disease, neurodegenerative disease, acquired disability and disability were used in a combination of ways to acquire the literature search.

The Literature Review

As already outlined in chapter 2, medications used to effectively treat RRMS did not become clinically available until just over twenty years ago, with the first treatment

for relapsing MS (Beta interferon-1b) approved by the American Food and Drug Administration in 1995 (Jacobs et al., 1996). Until that time, a considerable proportion of the qualitative MS literature was centred on coping and adjustment to the disease (Miller, 1997) with only a few descriptive reports, mostly centring on individual experiences living with MS (Robinson, 1990; Toombs 1988, 1990, 1992), but no studies offering explanations or latent meaning to the experiences.

Just under three decades ago, a study investigated the burden of disease and adaptation in 211 adults with rheumatoid arthritis (RA), hypertension and MS (Pollock, Christian, & Sands, 1990). Findings relevant to MS demonstrated that the MS group suffered more psychological stress than the other groups, even though the RA group were more physically burdened by disease than the MS participants (Pollock et al., 1990).

Moving forward through the early 1990's, a study by Hainsworth (1994) used a mixed methods approach to determine the presence of chronic sorrow in people living with MS; unfortunately the MS phenotypes were not disclosed nor levels of disability of the participants reported. Ten participants (nine female, one male) were interviewed individually and completed the Burke/NCRCS chronic sorrow questionnaire. The age of the study participants was 28-55 years and the length of time from diagnosis one to 22 years. Data was analysed using content analysis. Participants reported feelings of sadness, anger, frustration, fear and helplessness, with one participant describing their feelings when diagnosed with MS as "I felt a stabbing in my heart" and another as "it was a feeling of helplessness". The study also reported on strategies used by the participants to cope with chronic sorrow, including continuing to work, gaining support from family and friends, gathering information and thinking positively. Study participants also reported that empathic nursing support was helpful to them and an important part of their coping strategy. Even though the MS phenotypes were not disclosed, the presence of eight of the ten study participants reporting chronic sorrow as part of the MS journey possibly indicated the likelihood that many of the participants suffered from progressive forms of MS rather than RRMS, as this has not been a feature of the recent RRMS literature.

The first study using phenomenological methodology to examine the lived experience of people with RRMS was performed by Miller (1997) an MS Nurse in the United States, as part of her doctoral dissertation. This study is the most alike to the current study of all studies published in the literature in terms of the research question and the study sample. The significant difference however, is the data analysis method, which will be discussed in later chapters. The research question “What is it like for you living with MS?” was asked of 10 PwRRMS (seven female, three male) with an average age of 49 years and average duration of RRMS diagnosis of 20 years. Patients were recruited by convenience sampling to the study as they presented for neurological appointments at two MS clinics in New York over a period of about six months. To be eligible for the study participants needed to have an EDSS score of less than 3.5; indicating that they had mild-moderate physical impairment from MS and were able to mobilise independently. Semi-structured interviews were conducted on site, audio-taped, transcribed and analysed concurrently. Hermeneutic phenomenology was used to analyse the transcripts.

Miller (1997) abstracted a total of 12 themes from the study data. These themes covered many domains and included social networks (spouse, family, HCPs, can be both positive and negative), coping with the disease (changes to life because of MS, independence, resting to avoid fatigue), hope/hopelessness (initially “doom and gloom”, later hope after seeing the neurologist, hope for a brighter future), issues relating to control (difficulty with unpredictability, maintain independence) and conflict (conflict with HCPs, employers, family), uncertainty (unpredictable day-to-day), issues associated with loss (of independence, employment, relationships, abilities), fear (before diagnosis of brain tumour, relapses, losing support networks) and reveal/conceal issues (concealing from others who don’t understand, HCPs keeping MS suspicions to themselves, concealing from family to avoid too much concern). More positive themes centred on a feeling of relief with diagnosis (many feared a worse diagnosis) and gaining control getting to know MS (resources, observing others with MS). Importantly, the themes identified were supported with direct quotes from the participants to strengthen the theme development.

The themes from this study provided the first understanding of what it was like for people diagnosed with RRMS navigating the rapidly changing world around them,

with the first treatment for the disease on the horizon. The themes captured many aspects of life and living with illness, highlighting both the positives and the negatives. Miller (1997) did not find that chronic sorrow was a part of the experience in patients recruited for this study, as previous work had claimed (Hainsworth, 1994), this may have been a reflection of Miller's study focusing only on people with RRMS and possibly living with lower levels of disability than participants of Hainsworth's (1994) earlier study where the MS phenotype was not disclosed.

Miller (1997) identified that people with RRMS appeared to thrive on a sense of hope for, and control of, their MS and a strong drive to really know their disease. This was the first study to document these findings. Incredibly, until this time there had been arguments at length on whether clinicians should even inform patients of their MS diagnosis, due to the unpredictable course of disease, uncertainty of diagnosis, concern for stress triggering symptoms and potential emotional devastation (Sencer 1988). Miller (1997) argued the need for health care professionals (HCPs) to teach families to be supportive rather than stifling in their interactions, the role of independence and normalcy for people with RRMS, the need for nurses to explain the difference between relapsing and progressive forms of MS and the need for patients to be given information about the disease. To this day, these findings form the basis of many nursing interactions with newly diagnosed patients with RRMS and have influenced nursing practice in the specialty of MS considerably.

A major strength of this study was that Miller (1997) presented the themes back to patients in order to verify that the themes were congruent with their own experience. Additionally men with RRMS were also recruited and reflected the natural preponderance of MS incidence of 3:1/female:male (Compston & Coles, 2008), men had not been included in many of the qualitative studies up until this time. Limitations of the research primarily relate to the geographically limiting nature of a rural region in the USA and the fact that all patients interviewed were under the care of an MS clinic (and presumably receiving best practice care), potentially biasing the scope of the findings. There was also no reference to whether themes were saturated at this point, or if new themes were still emerging with the final participants enrolled in the study. However, this seminal study was one of the most important qualitative

studies in MS at this time, as the first phenomenological nursing study to examine the lived experience of RRMS. It is important to revisit the lived experience of RRMS in current times, with a completely different treatment paradigm, different management strategies, exciting biomedical and scientific MS discoveries. This will be discussed in further detail in chapter 8, after the current study findings have been reported.

Another seminal paper from Koopman and Schweitzer (1999) followed shortly after Miller's study (1997), and consisted of a qualitative project exploring the journey to MS of five participants, three females and two males with a mixture of disease courses of RRMS and PPMS. Participants were all diagnosed with MS within the previous 12 months, were aged 29-40 years and had experienced symptom onset with MS for between six months and 22 years. Although concentrating on the period up to and around diagnosis, the study aimed to discover the "essence of the lived experience". Individual semi-structured interviews were performed starting with the question "What was it like to have symptoms of an illness and then to be told you have MS?". Data analysis was not discussed in depth, but was reported as being performed using "common threads and patterns", one would imagine this being an early form of thematic analysis. Four major themes were identified from the data and were conceptualised as Whispered Beginnings (onset of symptoms, creating possible answers), Echoes of Silence (intermittent symptoms, come and go, worry and wait), The Spoken Words (unexpected diagnosis, pain, have to tell others, shock, numbness) and Recreating Voice (claiming the diagnosis, losses and gains, refocusing and changing life plans)

Koopman and Schweitzer (1999) concluded that the diagnosis of MS led to uncertainty and variability and participants needed to develop strategies to cope with the challenges of a disease with no cure. Although the themes provided new insights into understanding the experience, a deeper discussion about the methods of data analysis and separating the results for the different phenotypes of the participants would have led to readers being able to make informed decisions about generalisability to their particular situations and contexts. Similar to Miller (1997), this study identified worry, fear and feelings of loss in the participants as major themes living with MS.

A growing body of literature began to emerge exploring how people with MS were making sense of their world, their lived experience. Differences between MS as a “disease” and as an “illness” were seen as important to continuing the dialogue. Clair (2003) suggested that disease is seen as an objective measure of pathological change within the body and illness as the “human experience” of the disease. An exploratory study of 16 women diagnosed with MS (phenotypes not disclosed) initially used narrative data collection from focus group interviews with six participants, to generate an agenda of topics to explore during the second phase of the study with ten semi-structured interviews at a later date (Clair, 2003). Participants were recruited through a local New Zealand MS Society and purposive sampling was used to select women from a variety of settings and situations for the interviews. Data was analysed using a computer based software package to assist coding and analysis and symbolic interactionism was used to build a theoretical foundation for interpreting the illness. Symbolic interactionism has been described as looking for meaning by human beings, with the meaning derived from social interactions they encounter and subsequently process (Blumer, 1969).

Findings suggested that to live in a world of MS is to live in a world with uncertainty and little to no control. Essentially, two separate datasets were evident: women striving to identify the cause of their illness and find meaning, and women who transformed themselves and their illness, reclaiming control and finding peace and harmony (Clair, 2003). Intuitively, the women in the study engaged in story telling to make sense of their illness and regain control over their lives. Employing an in-depth interview method enabled the women to tell their stories, often for the first time, to convey their lived experience with MS. Clair (2003) surmised that MS can be seen in one of four ways, firstly MS as an aggressor (fight it head on, or let it run its course), or MS as a saviour (delivered to save the person from the person they were or were becoming), MS as a guest (but find ways to minimise the intrusiveness) or MS as an adversary (inspiring to overcome obstacles). These findings echoed some of the earlier findings from Miller (1997) and Koopman and Schweitzer (1999) in terms of seeing MS as an adversary and the feelings of participants losing control living with uncertainty. Coping with the disease, previously reported by Miller (1997) is aligned somewhat with Clair’s (2003) viewing of MS as an aggressor and fighting the

disease, or MS as a guest and finding ways to reduce the disease impact. However, the findings of MS as a saviour were novel and interesting to consider for HCPs caring for PwMS.

Limitations to the study were due to only women being included and that the participants interviewed were located in a regional area of New Zealand (NZ). Unfortunately the phenotypes of MS of the study participants were not disclosed, it would be interesting to know if the themes predominantly reflected a relapsing form of MS or if the participants were living with progressive MS. A major strength of the study included a purposive sampling method to obtain maximum variation in order to reach participants across a wide range of demographics. This improves generalisability of the study findings to others. It is also worth noting that although published in 2003, the study took place in 1996, before DMTs were available to people with MS living in NZ, rendering a replication of the study worthwhile.

The nature of invisible symptoms in MS and the uncertainty of what lies ahead when living with an unpredictable disease provided the inspiration for researchers to explore the lived experience of MS using separate focus groups for men (n=4) and women (n=6) (Courts et al., 2004). Again, unfortunately the MS phenotypes were not disclosed (Courts et al., 2004). The data was analysed by searching for themes, but no supporting information on how this was achieved was outlined in the article. Study findings identified four main themes; Nobody Listened (nobody takes symptoms seriously, a long time to diagnosis), Symptom Devastation (overwhelming symptoms, battle for normalcy, pain and anger), Picking and Choosing (making choices to regain control, using denial) and Fight Your Own Fight (self advocacy, taking charge). Once again, issues of control and conflict with HCPs, as reported by Miller (1997) were also a feature of these study findings. The theme of Fighting Your Own Fight by taking charge was somewhat seen previously in Miller's (1997) themes of getting to know MS and control, but the presentation of the other themes offered new approaches to understanding MS.

Participants in this study described creative solutions to the continual challenges and changes of MS interfering with goals in their lives. At times they described feeling depressed, dejected and desperate. Their most poignant need was for someone to

listen to them and teach them, as they identified knowledge as power (Courts et al., 2004). The authors suggested that nurses should utilise interventions to empower patients and also to teach self-management strategies.

The concept of the devastation experienced with symptom onset was reported by the researchers to be greatly helped by patient knowledge of their disease, which subsequently assists nurses in planning education sessions for patients and this finding is consistent with previous suggestions for practice (Miller, 1997). These themes again build on earlier work, as well as introducing new concepts for further research. The most notable being the importance of people with MS making their own decisions and practicing self-advocacy, which remain as major teaching elements in the MS Nurse repertoire to this day. By examining the lived experience, nurses are encouraged by the authors to build partnerships with patients, listen to patients, teach patients how to navigate the health care system, provide information and to teach self-advocacy and self-management.

Limitations to the study by Courts et al. (2004) included the study being confined to one small geographical area. A description of the data analysis phase of the study was overlooked in the report, which therefore limits readers being able to replicate the study in their own environment. Once again, no MS phenotypes were disclosed, it would have been interesting to note whether there were differences between relapsing or progressive courses. Strengths of the study centred on recruiting both men and women with MS to better represent both genders. Having the three investigators attend all focus groups together, and reaching a consensus on theme identification also strengthened the study results.

The life-world of one person with early onset RRMS was explored in great depth and richness during an unstructured interview at the end of the participant's first year of living with RRMS (Finlay, 2003). This dissertation used a case study method to focus on one individual's MS experience. Phenomenological methodology was used to access and describe life-world experience, however no meanings or abstractions were explained during the course of the research. The interview began with the general question "What is living with multiple sclerosis like for you?" and continued for a period of two hours, with prompts and requests for examples from the

researcher. Analysis of study results took place in two phases. Firstly, a narrative was created using verbatim quotes and secondly analytic methods suggested by Wertz (1983) involved repeated, systematic readings of the transcript, dwelling on the phenomenon through immersion and reflection, then describing the recurring themes that were present (Finlay, 2003).

The rich description of this lived experience illustrates the overwhelming impact of illness on the life-world and introduces the concept of embodiment in MS nursing research (Finlay, 2003). The lived experience in one persons' body is their own, personal experience. By focusing on the impact of physical illness, we are better able to understand that our embodied experiencing cannot be separated from the essence of who we are as a person and our place in the world (Finlay, 2003). It is just that – simply one person's lived experience.

The major limitation to this study is the focus on just this one individual. However, such a rich narrative may provide nurses with greater understanding, which can then be applied to others with MS, in ways deemed appropriate by the nurse to the context. The second possible limitation to this study is that the subject and researcher had been friends for 15 years prior to the study, possibly introducing some bias and assumed knowledge into the interview. However that may also be seen as a particular strength of the study; with strong rapport, trust and openness already existing between researcher and participant. This may have resulted in less censorship and more open responses.

Two years later, the life journey of one study participant with RRMS was also explored by Fawcett and Lucas (2006) exploring the journey from the first disease symptoms of a fit, active female subject aged in her early thirties who was a friend of one researcher. This study revealed the following key points; nurses play a pivotal role in MS care, the beginning of the journey is fraught with questions, GPs may not recognise symptoms as being MS, the impact of the diagnosis of MS should not be underestimated, uncertainty is a challenge, understanding and getting to know MS is an important step and that support from family and friends is valued by PwMS.

Similarly to Finlay's (2003) study, limitations to this work takes account that one researcher and the participant were friends before the study took place. However, as already mentioned, this could have strengthened the study findings based on the trust and rapport they already shared. Nevertheless, this in-depth case study adds to our insights and understanding of RRMS. Identifying the nurse as being in a pivotal role in the MS journey, the challenge of uncertainty, the under-recognition of MS symptoms in the community, the value of family and friend support and the need for resources to get to know MS further supports the previous research of others (Miller, 1997; Clair, 2003).

Barker-Collo et al. (2006) performed a qualitative study using semi-structured interviews to obtain narratives from 16 people, half living with RRMS and the other half with progressive MS. The age range for the study was 27-72 years with five males and 11 females. The primary aim of the study was to expand on the earlier work of Koopman and Schweitzer (1999) using a larger sample to explore the experience and subsequent journey at the time of MS diagnosis. The research was analysed using thematic analysis. The strength of this study was the separation and comparison of RRMS and progressive MS in the findings and discussion. A marked difference was found between PwRRMS and progressive MS. RRMS narratives tended to reflect variability and unpredictability for the patient and for their family "it's the not knowing". This contrasts with progressive MS where the prevailing theme was a sense of hopelessness in relation to the inevitability of disease related decline "you have this thing that will eventually make you a burden". Other themes in general, where RRMS and progressive MS results were reported together, included the impact of changes to life roles, the fear of impact from MS on others, the possibility of positive effects on relationships and on lifestyle and health, the potential for isolation from others, the need for appropriate MS related information and the central role of the MS nurse in patient care.

Once again, similar themes to previous work from Miller (1997) and others were identified, however the emphasis on the positive effects from living with MS were a welcome addition to our knowledge about living with MS. The concept that this devastating illness could bring fresh and new insights to PwMS and cause positive change to lifestyles and relationships was innovative information.

Malcomson, Lowe-Strong and Dunwoody (2008) aimed to explore the personal accounts of people living with MS in order to gain insights for HCPs and to identify effective self management strategies for patients. This study used focus groups to interview 13 individuals, nine females and four males, six participants lived with RRMS and the rest of the sample with progressive MS. Five study participants were no longer ambulant. The study results were analysed using thematic analysis, but again unfortunately, findings were not separated according to MS phenotype.

Themes identified included learning something was wrong (distress, uncertainty, fear), getting a name (the diagnosis, unhelpful feelings), getting help (lack of psychosocial support), consequences to lifestyle (interpersonal, changing employment circumstances, challenges), getting on with day to day life (proactivity, perspective and control), providing advice for others (peer support, self management) and providing advice for HCPs (personal needs, guidance and information, peer groups). The concept of patients providing advice for HCPs is particularly enlightening and nowadays is an important part of shared decision making in clinical care. One would imagine it was a surprising finding when it was first identified, before making its way into recommended MS care in recent times (Giovannoni et al, 2016).

A possible limitation to generalising the study to others with MS is that the study participants were invited into the study because they felt “able to cope” with MS and may have thus represented only part of the MS population. The method of focus groups rather than individual interviews may have also limited the information people were prepared to divulge in a group setting in front of strangers, especially in regards to sensitive topics such as sexuality and cognition. The findings however are useful as they provide an in-depth exploration of a very important time of the MS journey (up to, during and just after MS diagnosis) and also considers the insights of both males and females.

A more recent qualitative study used interpretative phenomenological analysis (IPA) to understand the experience of young adults living with RRMS, and was undertaken as part of a nursing dissertation (Beshears, 2010). The research question was “What

is the meaning of the experience of living with RRMS for the young adult?” with the purpose of understanding the lived experience in order to propose education and support for this specific MS population. The cross sectional study used convenience, purposive sampling to recruit six female participants between 20 and 40 years of age. Data collection involved three in depth interviews, which were transcribed, and data analysed using a Miles and Huberman approach and the Heideggerian method. This form of IPA uses the researcher as the data collection instrument, uncovering meanings in the narratives of the participants (Miles & Huberman, 1994). Specifically the study aimed to discover the meaning of changes occurring in the participant since their diagnosis of RRMS, to uncover how the participants made meaning of the expectations of others in their lives and how they learnt new ways of being during MS relapses.

Beshears (2010) presented many ideas from the data analysis, including the participants wishing for opportunities to talk to others about MS, living day by day, of MS being “scary”, the importance of planning ahead and the value of listening to one’s body. These findings led to the compilation of four broader themes; firstly participants realising that MS involves uncertainty, their discovery that RRMS is frustrating, concepts of being scared and fearful getting to know MS and that RRMS is always in the backdrop of life.

Beshears (2010) hoped to interview both sexes in the study, but no men volunteered, so unfortunately only women were included in this study, again potentially limiting the generalisability of results to men and extending the significant gap in the literature relating to RRMS in males. All participants in the study were married with the spouse being the household wage earner, thereby further hindering generalisability of the results to other social situations. Recruitment of participants was in a rural region of the US, with potential local influences biasing the data in unknown ways, for example local health care systems and the availability of neurology care in the rural area. A major strength of the study is the rich data in the six narratives and a strong focus on intimacy and relationships, which are important developmental milestones in adult development (Busch & Hofer, 2012).

The most recent study to explore the experience of living with MS comes from Jordan in the Middle East (Al-Sharman et al., 2018) and is from the speciality of rehabilitation. A total of 16 participants (equal numbers of male and female) with an average age of 36 years and average time since diagnosis of seven years, participated in a total of four focus groups directed by an interview guide. The study aimed to explore and describe the daily living experiences and challenges of PwMS. The study sample was a convenience sample representing two geographical areas in Jordan and was the first of its kind to be undertaken in the region. Unfortunately, no phenotype was disclosed for the study participants, however the average EDSS was 3.5, indicating mild-moderate disability for most of the participants with one participant having an EDSS of 6.0 (needing a unilateral walking stick to mobilise). The focus groups were split into one gender only to encourage open discussion, which may have been impacted in this region by cultural conditions inhibiting females from discussing important insights in front of males (Metcalf, 2008).

Two major themes were developed by the researchers: firstly, experiences related to the disease itself (physical decline, psychosocial withdrawal and fear of the future) and secondly, experiences related to the health care system (difficulty of diagnosis, poor communication and rapport with HCPs, lack of awareness about MS and MS rehabilitation)

The researchers recommended greater attention be given to MS in Jordan, with improved awareness of MS for both HCPs and for the general public. In addition, Al-Sharman et al. (2018) also recommended optimising and enhancing rehabilitation services for PwMS. The study is limited by the geographical region and cultural differences to the western world, however the study is strengthened considerably by the inclusion of eight males in the research, a demographic which until now had been greatly under-represented in qualitative MS research.

Life history research and RRMS

There is only one brief piece of research exploring the life of a PwMS using a life history approach (de Chesnay, Rassilyer-Bomers, Webb, & Peil, 2008). This was a

four page narrative presented in a book chapter discussion about performing life history studies where the purpose was to present an abbreviated story, told by the participant and interpreted by the researcher, to teach others about overcoming obstacles in chronic illness (de Chesnay et al., 2008). The author of this particular MS life history narrative within the combined chapter story (Webb) presented a single life history of a 46 year old female who successfully overcame her debilitating MS-related fatigue. The data is limited by the study purpose, dealing with only one aspect of her MS experience. The current study aims to explore all facets of living with RRMS and in many participants.

The lived experience in progressive forms of MS

As the current study focused solely on RRMS, only a very short literature review will be presented on progressive MS to provide some perspective of the overall situation. Several qualitative studies have concentrated on the lived experience of people living with progressive forms of MS (Edmonds, Vivat, Burman, Silber, & Higginson, 2007; Olsson, Skär, & Söderberg, 2010; Strupp et al., 2012). Although these phenotypes are distinctly different from the proposed study group, people living with SPMS did originally start their journey with RRMS, and may have important insights to offer when considering living with RRMS.

The most relevant of these studies to the current study, is a recent dissertation in the field of psychology (O'Loughlin, 2015). The investigator aimed to gain rich insight into the experiences of people with SPMS during the critical, but poorly understood, time of disease transition and change of labelled disease phenotype from RRMS to SPMS. A total of 16 people took part in the research, nine PwSPMS and seven HCPs involved in MS care. Thematic analysis was used to explore the experiences, coping strategies and needs of people during transition from RRMS to SPMS. Four themes were developed by O'Loughlin (2015) in exploring SPMS: is this really happening? (noticing decline, feeling "in limbo"), SPMS becoming a reality (shock, meaning, turning points), feelings of living a life of struggle ("it's all downhill now") and the concept of brushing oneself off and moving on (accepting, making the best in the circumstances).

Recommendations from this study included the need for HCPs to undergo education regarding the psychological impact of SPMS during the transition, the provision of peer support, and exploration of existing resources and coping strategies that PwSPMS may already have. A great strength to the study is the fact that participants were recruited within 12 months of their SPMS transition, possibly enhancing the accuracy of their recall of events.

As a university research Professor, Toombs (1988, 1990, 1992, 1995, 2001) began a series of phenomenological work exploring her own experience of living with MS, whilst navigating the world as a researcher. Toombs (1995, p.12) writes:

“For MS, like every other illness, is experienced not just as the breakdown of the body, but as the disruption of the life that is lived in that body. To live with MS is to experience a global sense of disorder; a disorder which incorporates a changed relation with one’s body, a transformation in the surrounding world, a threat to self, and a change in one’s relation to others”.

Such intimate and descriptive detail adds to the understanding of the individual’s lived experience with MS. Toombs (1988, 1990, 1992, 1995, 2001) provided reflections of her personal experience of living with progressive MS over many years to provide a phenomenological account of the human experience of disability. Particularly moving and striking in its simplicity, Toombs (1995) suggested that the loss of upright posture, as disability takes hold in MS, diminishes autonomy for the person and affects the way one is treated by others, disrupting social connections and leading to a loss of dignity. This insight from Toombs profoundly changed the way I viewed patients as I consulted in the MS clinic. In particular, it led to many changes in how I considered visits and appointments for patients, paying greater attention to positioning and clinic set-up to try and restore as much dignity as possible to the lives of PwMS visiting the clinic.

The lived experience of children and adolescents diagnosed with RRMS

Significantly fewer studies have focused on the lived experience of children and adolescents with MS, mainly due to the rarity of this condition in children younger than 18 years. An explorative qualitative study used a phenomenological approach to

explore experiences of children living with MS (Boyd & MacMillan, 2005). Patients from a children's hospital in Canada (n=12) were interviewed using a semi-structured format. A software package was utilised to sort data and then narrative analysis was used to generate themes and subthemes. The investigators found that the children described similar themes to their adult counterparts described earlier in this chapter; that is, worrying about burdens on families, fear of disclosure, hiding symptoms, dealing with uncertainty and fear of rejection from their peers (Boyd & MacMillan, 2005). A major difference was that the children and adolescents in this study reported conflict with their parents and lack of understanding from teachers, rather than the experience reported with adults who described this same conflict, but with the medical professionals (Miller, 1997). The great strength of the study is that it fills an enormous gap in knowledge regarding paediatric MS lived experiences and provides an excellent starting point for further research, possibly involving more centres and greater numbers.

A further research study in 2009 employed grounded theory to develop a theoretical model to understand psychosocial experiences of paediatrics with MS (Thannhauser, 2009). The study looked at the interplay between grief and peer relationships, which adds to the knowledge about paediatric MS, but not the lived experience. It has been suggested by others that there are significant gaps in qualitative literature in paediatric neurological conditions (Auduly, Packer, & Versnel, 2014).

Other aspects of MS and the lived experience

At the other end of the life trajectory, there is a paucity of research investigating the lived experience of the aged population with MS. Currently a quarter of people living with MS are aged over 65 years of age and experiencing a decreased health related quality of life (Buhse, 2015). This demographic of MS research demonstrates a significant gap in the literature and also needs immediate attention.

There have also been several studies investigating the lived experience of caregivers and partners of people with MS, but they have not been individually reviewed here as it is not aligned with the research question focused on people living themselves with RRMS (Aoun, McConigley, Abernethy, & Currow, 2010; Bjorgvinsdottir &

Halldorsdottir, 2014; Buhse, 2008; Buhse, Dela Ratta, Galiczewski, & Eckhardt, 2015; Cheung & Hocking, 2004; Corry & While, 2009; Pakenham & Samios, 2013; Strickland, Worth, & Kennedy, 2015).

The lived experience of other chronic illnesses

There are many illness states which have overlapping symptoms or share certain features with MS, which may also provide MS Nurses and HCPs with insights to help them understand what it is like to live with chronic illness. These lived experience studies include those in motor neuron disease (Brown & Addington-Hall, 2008; O'Brien, Whitehead, Jack & Mitchell, 2012), in stroke (Burton, 2000), in spinal cord injuries (Desanto-Madeya, 2006), in Parkinson's disease (Soundy, Stubbs, & Roskell, 2014), in medically unexplained symptoms (Nettleton, 2006), in fibromyalgia (Lempp, Hatch, Carville, & Choy, 2009), in the rare illness lymphangioliomyomatosis (Haylen, 2015) and in lupus (Mendelson, 2006; Beckerman, 2011). There are some commonalities in the findings between these chronic conditions and RRMS, most notably feelings of being unheard and voiceless (Nettleton, 2006) of uncertainty (Haylen, 2015) and of invisible symptoms (Beckerman, 2015).

The significant gaps in the literature

A significant amount of literature regarding MS has been published in the last decade, as important advances in earlier diagnosis of the disease and the advent of more efficacious drug treatments have transformed MS care. A search in Google Scholar reveals 210,000 articles in MS since 2011. However, the great majority of this research has been biological, scientific and medical in nature. Qualitative research in particular has been lacking in this specialty.

This literature review did not reveal any other studies using life history methodology to explore the experience of people living with MS (besides a short four page narrative). Why is this so? Using life history in researching chronic illness reflects the complexity of the human experience it is examining (de Chesnay, 2014),

presenting an ideal methodology to gain insights and understanding. However, there are many challenges inherent in using this methodology, including deeply personal narratives which may affect the researcher emotionally and the fact that the interviews and follow-up are time consuming and lengthy. Perhaps it is because life history is an under-recognised methodology in nursing. These aspects will be discussed further under methodology in the next chapter, together with the reasons why life history is an ideal approach to explore the entire life experience of living with RRMS.

From this literature review examining the experiences of people living with MS, three things are abundantly clear. Firstly, there is an enormous gap in recent literature surrounding what it is like to live with and experience RRMS. There were several pivotal studies in the early to mid 1990's, most likely they arose at this point because drug treatments were not yet available and major breakthroughs in genetics and understanding scientific aspects of the disease were still several years away. In this setting most of the nursing research centred on trying to understand the patient experience, in order to inform patient education and symptom management strategies. A seminal paper by Miller (1997) outlined the lived experience of people with RRMS using a phenomenological approach and was the first of its kind to examine how it felt to be the person at the centre of the MS experience (Miller, 1997). This informed health professionals to become aware of the patient experience, that patients wanted to learn more about their disease, to take control and to be in charge, to teach families to be supportive and not stifling in assisting with their loved one's care and for nurses to be at the forefront of educating patients about the different phenotypes of MS. Unbelievably, up until shortly before this time, it was still regularly debated in medicine whether patients should actually be told their diagnosis, for fear of causing emotional devastation in a disease with no available treatments (Elian & Dean, 1985; Sencer, 1988). Miller's (1997) findings set up important conceptual frameworks for MS nursing practice to understand the concerns of people living with MS.

Several studies in the last two decades have continued to explore the experiences of people living with RRMS, but recent studies are lacking. This gap in qualitative literature is of prime importance as the landscape of treatments for MS, the potential

side effect profiles of these pharmacological treatments and the emergence of even more new therapies continues to grow and become even more complicated for people with RRMS. How do patients feel? What is it like to be living with MS today? It is imperative that qualitative research answers these questions so that nursing practice and intervention reflects the needs of patients and that nursing theory and frameworks take these needs into consideration and develop as our understanding of the disease matures. Many of the studies presented above either did not discuss the phenotype of the participants, or only partly included PwRRMS in the research. Many of the themes identified in progressive MS research are vastly different to RRMS and therefore cannot be extrapolated. If study findings refer to both groups of participants, there should be a discussion (where possible) outlining any differences between the two groups.

The second area identified with significant gaps in the literature is research involving males living with RRMS. Many of the studies described here selectively, or coincidentally, recruited only or mainly women. Although the preponderance towards women developing RRMS at a rate of 3:1 is widely known, this still leaves a significant portion of men in the community whose experience living with RRMS is under-researched and unknown. Recruiting men into the current study is an attempt to ensure men are adequately represented and by doing so will enhance our understanding of the current experience of *both* genders living with RRMS.

The third areas of significant literature gap in this field involves research into the experience of both ends of the lifespan spectrum; children and adolescents, as well as the aged population living with MS. In regards to paediatrics and adolescents living with MS, this is an acknowledged area of deficit (Auduly et al., 2014). However, this will not be the focus of the research question in this proposal due to the specialty of the area and lack of experience and skills of the researcher in paediatrics, experience which would be essential to undertake such a study. The current study unfortunately did not see any PwRRMS over the age of 65 years volunteer to participate.

Summary

The current study aims to fill the significant gaps in the qualitative literature exploring the experience of adults living with RRMS. To achieve this goal, the study sample has targeted both males and females to add to the body of knowledge in the area of RRMS. A body of knowledge which is striking for its burgeoning scientific and biomedical research, but scarcity of contemporary lived experience literature. The findings and discussion following in chapters five to seven will bring into the conversation literature relevant to each theme and subtheme as they are explored, to provide further knowledge, background and linkage with previous research and theory.

There are no studies reported in the literature that have been performed using the same methodology and methods as the current study. In many ways, this was daunting at the beginning of the study, but as the study progressed and my faith in the methodology and methods strengthened with each interview, there was a quite confidence I developed in the operational framework of the study as the life histories from the participants were so strong with relevant data. These concepts will be discussed in the next chapter and will support how the life history methodology, underused in MS research (and illness research in general), provides a dynamic and useful tool to learn as much as possible about the experience of living with RRMS. The final chapter will connect the studies discussed in this chapter's literature review with the findings from the current study, with additional concentration on the research from Miller (1997), Clair (2003) Courts et al. (2004) and Beshears (2010) as the most alike to the current study, either in study aims or study sample. However, the data analysis for these studies used hermeneutic phenomenology, symbolic interactionism, searching for themes and interpretative phenomenological analysis respectively in their data analysis to uncover meaning rather than the current study method, which used thematic analysis (Braun & Clarke, 2006, 2013).

The following chapter, Methodology and Methods, will outline the ontological and epistemological viewpoints of the study, and the study process and procedures. Chapter 4 will also explain why the selection of the life history approach is an ideal methodology to answer the research question "What is the experience of living with

RRMS?" in a novel and insightful way, to add to the body of knowledge on the experience of living with RRMS. The current research approach differs from previous research in that it is contemporary, takes into consideration recent advances in MS care and provides a unique viewpoint looking at the whole life experience and incorporating previous life events into how RRMS is experienced.

CHAPTER 4: METHODOLOGY AND METHODS

The purpose of this chapter is to discuss and justify the qualitative research paradigm chosen for the current study, the ontological and epistemological frameworks employed to guide the study and the overall research design. This chapter will also present a clear justification of the methodology and methods implemented, including a discussion of how they link in with the overall ontology and epistemology of the current study. The roles of ethical considerations, study rigour and reflexivity in the current study will also be discussed.

The qualitative research paradigm

A paradigm may be viewed as a set of basic beliefs dealing with principles, a framework representing a worldview, defining the nature of the world and the individual's place in it (Guba & Lincoln, 1994). Qualitative research as a paradigm is a form of social inquiry that focuses on the way people make sense of their experiences and the world in which they live, with the goal of understanding, describing and interpreting phenomena as perceived by individuals and groups (Holloway & Wheeler, 2013). Strong advocates for qualitative research, Denzin & Lincoln (2000, p.3) have defined qualitative research as:

“A set of interpretative, material practices that make the world visible – these practices transform the world. They turn the world into a series of representations...qualitative research studies things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings that people bring to them.”

Several elements make up the qualitative research paradigm, and these elements are important points of difference from the number focused, hypothesis based, theory testing elements of quantitative research (Braun & Clarke, 2013). Holloway & Wheeler (2013) suggest the following characteristics as being integral to qualitative research; the data have primacy, the theoretical framework is not predetermined, but derives *directly* from the data, the data is context bound, the immersion of the researcher into the natural setting of the study participants, a focus on the “emic”

perspective (the views of the people being studied), the use of “thick” descriptions (dense and detailed [Denzin, 1989]), the presence of reflexivity, identifying the researcher as the main research tool and explicitly stating the position of the researcher in the study.

Choosing the qualitative paradigm

Central to the qualitative paradigm is a humanistic commitment to always study the world from the perspective of the study participant (Lincoln & Denzin, 1994). In the early phases of developing the research question and identifying the study aims, I felt that the qualitative paradigm, with its roots in gaining insights and deep understanding into the experiences of people, would suit the study aims very well. The research question required a methodology that would gain deep, rich insights and understanding of the experience of living with RRMS. Qualitative research retains complexities and nuances and respects the uniqueness of each individual, giving importance to the narratives and context of the participant’s stories (Ormston, Spencer, Barnard, & Snape, 2014).

In seeking to understand and interpret meaning within context, qualitative research also focuses on being inductive (developed directly from the data) and seeks patterns in data, but also has an appreciation for differences in data. I was adamant from the start of the study that I did not wish for the individual stories of study participants to “get lost”, I wanted to have their voices clearly heard because there is so little literature available which explores their world and considers the perspective of the PwRRMS. I therefore chose a purely qualitative approach early in the research design as the best “fit” to meet the goals of this research study.

Qualitative research involves much more than “simply reporting the facts”, it involves a great variety of interpretation (Miller & Dingwall, 1997). In general, qualitative research is a group of methods and ways of collecting and analysing data that are exploratory, interpretative and have a focus on meaning, with reality developed collaboratively by both the researcher and the study participant (Smith & Noble, 2014). The qualitative paradigm recognises the strength of bringing my own subjectivity as an expert MS nurse as a valuable tool to the research process

(Silverman, 2001). Constructing the research together with the study participants also greatly appealed to my epistemological outlook, which will be discussed in greater detail later in this chapter.

Qualitative research in health and nursing

Qualitative research has been conducted across many areas; education, business, sociology, psychology and health in particular. Especially relevant to the research question in this study, qualitative *health* research focuses more specifically on exploring health and illness as they are perceived by people themselves, focusing on their experiences, how they feel and maintaining patient centrality in the story (Morse, 2012). Over the last two decades, there has been an upsurge in collecting and valuing stories from patients, as Morse (2012, p. 27) observed, “illness was coming out from the closet, and as the door opened, it revealed all of its emotions and sensory secrets”. Finding individual meaning and understanding in stories from patients is fundamental to the caring and compassionate culture of nursing, and something nurses strive for in daily practice (Munhall, 2012). Nurses base their clinical practice on learning as much as possible about the people under their care, detecting commonalities and differences in order to ultimately individualise their care and management (Thorne, Ternulf Nyhlin, & Paterson, 2000). Traditionally, nurses are attracted to qualitative research as they value the richness of deep understanding and the perspective of the patient, and in doing so, nurses are able to develop culturally appropriate interventions and improve competence of care in diverse and vulnerable populations (Desantis & Ugarriza, 2000). PwRRMS are *both* diverse and vulnerable, and this will be explored and argued throughout this thesis, particularly in the later chapters discussing the study findings and themes.

Morse (2012) suggests that HCPs working in the clinical arena can be considered as “street smart”, that is, already having an understanding of the health system. HCPs are ideally positioned to conduct qualitative research, having working knowledge of the patient population, the ability to monitor patients during the process (for symptoms such as fatigue, distress) and being well placed to make clinical recommendations at the completion of the research (Morse, 2012). Munhall (2012) has proposed a range of elements that qualitative nurse researchers enrich their

practice with as a result of their research. These elements include caring for the individual, legitimization, understanding of experience, acceptance, change, emancipation, compassion, understanding of meaning, empathy, understanding needs of individuals and groups and critical needs for healthcare changes (Munhall, 2012); all of which are consistent with the personal aims I hoped would result from the current study.

As Munhall (2012) also suggests, nursing is a human science, and human sciences depend on a perspective from the inside to the outside. This contrasts with natural sciences, which investigate objects from outside to inside (Munhall, 2012). As an MS Nurse balancing both a clinical role consulting MS patients and a research role (in a mainly scientific and quantitative research environment) I often wondered how patients felt coming in for their treatments and appointments. I contemplated what was going through their minds, how they told their families about feelings and symptoms, what motivated them and how they coped with various aspects of the disease. Of course, I would find out some information as we chatted informally between tests, but I wanted to know more. I yearned to sit down for an uninterrupted hour and just talk, to know more about their motivation to give up their time for others, how they viewed their disease and how their life changed because of the disease. In the busy, biomedical focused world I worked in, there was insufficient time or opportunity to talk and share this vital, yet often overlooked information. As I could see that no change in the work environment was possible, it was time to explore how I could satisfy this curiosity through research.

Ontological and Epistemological Perspectives

In qualitative research appropriateness of the choice of methodology and method is paramount (Holloway & Todres, 2003) and the research design must clarify the contributions of epistemology, methodology and methods (Carter & Little, 2007). This required prolonged discussions and considerable thought as to how the research design could enable the best “fit” to answering the research question and in a way that was sensitive to the overarching ontology and epistemology I selected to provide the framework for this study.

Our own subjective world evolves from all of our previous experiences, those as a child, our relationships, the culture we live in, our age, our gender. Our subjective perspective is the result of these experiences, forming the context of where we are in the world at present, our “*situated context*” (Munhall, 2012). In constructing and defining the overarching ontology and epistemology for this study, I needed to evaluate where I sat presently in terms of “situated context”, how I felt about the world, what it was possible to know and how it could be known. Several key concepts characterizing qualitative research as suggested by Munhall (2012) drew me to the paradigm, and ultimately influenced the stance I took in this regard; these concepts included believing in a multiplicity of views in the world, perceptivity of phenomena, polyvocality of many voices, and the existence of multiple realities. I did not believe there was a singular reality or only one answer to the research question I posed.

I believed that my source of knowledge to answer the research question was not going to come from books and articles, but from the “knowers” (Munhall, 2012); the PwRRMS. I could begin to “know” by having conversations with people whose world I wanted to gain insights and understanding into. Talking to these informants allowed me to construct knowledge with them and learn about their lived world (Kvale & Brinkmann, 2007). I considered the PwRRMS as the experts in this situation (Windle, 2011). Thus began my allegiance with the qualitative ontology and epistemology, a strong belief in the co-construction of knowledge between the PwRRMS and myself.

Ontology

Ontology refers to the nature of reality and what there is to know about the world (Ormston et al., 2014). Essentially ontology is about how things really are and how they work (Guba & Lincoln, 1994). There are many variations along the spectrum in ontology, depending upon how the researcher views the relationship between the world and human interactions and practices within it (Braun & Clarke, 2013). The ontological beliefs I used to underpin this study were in line with *constructivism*, centred on the world being context specific, co-creating knowledge between the

researcher and study participant, being open to revision and possessing multiple realities.

Constructivism's hermeneutic/dialectic methodology is aimed at the reconstruction of previously held constructions, and is open to new interpretations as the sophistication of the information improves throughout the research process (Guba & Lincoln, 1994). This means that knowledge is ever changing, represents various interpretations and is context bound. Under the paradigm of constructivism, the concept of *relativism* also provided an excellent "fit" for the current study. Relativism explores the concept that all truth is "constructed" by humans and situated within an historical moment and social context and that multiple meanings of the same data may exist (Cresswell, 2008) and was particularly applicable to the values of the current study. Thus, an ontological foundation of constructivism and relativism was applied to the current study.

Epistemology

Epistemology has been defined as the nature of the relationship between the "knower" and what can be known (Guba & Lincoln, 1994). The essence of epistemology is the question of what is *possible* to know (Braun & Clarke, 2013) and how we come to know it. As with ontology, there are also many variations of epistemological stance dependant upon the views of the researcher; what they feel is possible to know, and the meaning of this knowledge (Braun & Clarke, 2013). *Constructivist* epistemologies state that there are *knowledges* existing, rather than singular knowledge, that knowledge is a product of how we come to understand it, and therefore how we construct it (Braun & Clarke, 2013). Knowledge construction involves the input of both the researcher and the study participant.

The epistemological base of **life history** is grounded in a pragmatic approach to knowledge, concerned with depicting the lived experience as actual members of the culture (in this study it is the PwRRMS) understand their experiences, but also understanding that this truth may not be universal (Faraday & Plummer, 1979). The constructivist epistemological stance for this research study involved the assumption by myself, as the researcher, that people living with RRMS had information to reveal

to me that MS Nurses and HCPs could benefit greatly in knowing. Believing that patient views are valuable and by asking questions of past experiences I could gain insights into understanding what it feels like to live with this disease. I viewed this as vitally important in order to better understand RRMS and its effect on people my colleagues and I were caring for. Understanding RRMS from a “lived experience” perspective would help MS Nurses and other HCPs make deeper connections with patients, enhance their understanding of the disease and promote patient adherence to both treatment and management strategies, improve quality of life, and provide truly empathetic and compassionate care. This is important to provide greater satisfaction and connection in work life for the MS Nurses and HCPs, and to ultimately improve quality of life for the patients, the PwRRMS.

Constructivist epistemology formed the basis of what I believed and ultimately influenced the selection of methodology and methods I selected in order to answer the research question in the best way possible. To guide the appropriate choice of methodology and methods for this study, it was necessary to gain this depth of understanding about my epistemological position and to keep the three elements of epistemology, methodology and methods consistent (Carter & Little, 2007).

The use of the first person in the study

A conscious choice was made to use the first person “I” in writing up and reporting this research study. The reason behind this was to use my subjective voice, as the co-creator of the findings (with the study participants) as recommended by Munhall (2012). The methodological and method choices were mine to make and to justify, and I needed to personalise those decisions. The use of the first person has commonly been recommended in qualitative research, especially in ethnographic work (Denzin, 1994; Richardson & Lockridge, 1998; Tierney & Lincoln, 1997; Tierney, 2000). Using the first person expresses greater vulnerability, keeps emotions in the process of knowledge production and promotes the researcher as central to the process, rather than being a disengaged observer (Tierney, 2000). These concepts were all central to my ontological and epistemological viewpoints, therefore the use of the first person was adopted to write the thesis.

Methodology

Methodology refers to the framework within which the research is conducted. It provides a theory of how the research should proceed and produce valid knowledge, while making sense of the research in terms of design and process (Braun & Clarke, 2013). Choosing a methodological approach that serves the inquiry under study is essential, as it acts as the initial guide to dictate the decisions made in a study to answer the research question in the best, and most thorough way possible (Holloway & Todres, 2003). Methodology also assumes what counts as research, how it is conducted and what methods (sample, data collection, analysis) are appropriate for the study (Braun & Clarke, 2013). Various forms of qualitative methodology were considered for this study, and a form of focused ethnography, **life history**, was chosen to answer the research question. Other forms of methodology that were considered for this study were grounded theory (and its many forms), interpretative phenomenological analysis and content analysis. The rationale for choosing the ethnographically based life history approach (and for rejecting the other qualitative forms of methodology) will be discussed in further detail in the data analysis procedures, where the procedural differences will be highlighted.

Ethnography as a research methodology

Ethnography is a research methodology which involves the process of learning *about* people by learning *from* them (Roper & Shapira, 2000) and has its historical roots embedded in social and cultural anthropology (Holloway & Todres 2003). Despite being popular at the beginning of last century, a long period of remission followed through the mid century, before a significant revival in popularity since the 1990's (Plummer, 2001). Ethnography involves key informants who represent the culture under study discussing their lives, so that others can better understand the culture (de Chesnay, 2014). Traditional ethnographic techniques involved long-term participant observation and interviewing, of researchers deeply engaging the socially organized settings they sought to describe and analyse (Miller & Dingwall, 1997). The goals of ethnography are to describe, interpret and understand characteristics of a particular social setting, taking into consideration the diversity and multiplicity of voices from key informants, the experts who have rich knowledge of the subject under research

(Holloway & Todres, 2003). Ethnography has a place in health research, particularly with its focus on the emic, or the patient perspective (Morse, 2012), being holistic, contextual and reflexive (Boyle, 1994). This ensured an excellent fit for the epistemological foundations and aligned with the broader goals of this study.

Ethnography takes on many forms and has been adapted for use in different settings, depending on the goals of the research. Early ethnographers spent long amounts of time in the field (“fieldwork”) getting to know the study participant/s and encouraging them to share their life stories, often forming personal relationships (de Chesnay, 2014). More currently, time constraints are considered to inhibit such long encounters between researchers and study participant/s, especially in the field of nursing. In keeping with the important aspects of traditional ethnography (insights, understanding and culture), focused ethnography developed, where researchers attempt to learn about certain conditions by asking about the experiences of those living with the condition (Cruz & Higginbottom, 2013; de Chesnay, 2014). Focused ethnography has become more popular in health research generally, as it is an effective method to gain information from a culture who may not necessarily have contact with one another (Morse, 2012). Exploring experiences in smaller sub-cultural units such as a shared illness, honors the ethnographic assumptions and is effective for eliciting information on a specific topic (Richards & Morse, 2007) and being less time consuming, is therefore more practical for most researchers.

Central to the way that ethnographers think about human social action is the idea that people construct the social world, through both their interpretation of it and through actions based on those interpretations (Atkinson, Okada, & Talmy; 2011). This is consistent with the epistemological framework for this study of constructivism. The version of the culture reported by the researcher is simply one version of the world, amongst many possible others.

Life history as a form of Ethnography

The life history is a “retrospective account by the individual of his or her life in whole or part, in written or oral form, that has been elicited or prompted by another person” (Watson & Watson-Franke, 1985, p.2). Life history is the story that a person

chooses to tell about the life he or she has lived, told as completely and honestly as possible (Atkinson, 1998). Immersing in accounts of people's stories about their lives, in their own words and in local context, the life history is a way to grasp meaning from a culture (Fetterman, 1998). The terms life history and life story are sometimes used interchangeably (Plummer, 2001). For the purposes of consistency and clarity in this study I defined life history as the story told by a person to me as a researcher (de Chesnay, 2014) and life story as the narrative analysis I created of the person's life from the life history they told me (Atkinson, 1998).

The history of life history as a method is interesting, as life history was used in psychology with Sigmund Freud's case studies, which later helped establish life history as a social science method (Connell, 2010). The genre of social science research was highlighted by important life histories earlier in the 20th century by Thomas and Znaniecki (1927), who explored the culture and society of immigrants. Connell (2010) suggested that this founding social research inspired new areas of life history research in gender exploring masculinity and sport (Messner 1992), life history studies in feminist sociology (Laslett & Thorne 1997), and race and racism in the context of people's lives (Blauner, 1989). Of course, important life history advances were made with Plummer's (1983, 2001) "Documents of Life" series comprehensively exploring and championing the use of social science life stories and providing important background to using the methodology. The value of life history is that the value of the participant's own perspective is highlighted in the research, as Connell (2010, p.67) so eloquently describes "the passages in an interview transcript that in traditional qualitative research are likely to be cherry-picked...in life history research become revealing details in a tapestry".

Life history in general is an underused methodology in nursing, but is perfectly suited to the profession, as nurses have always valued the stories and insights patients are able to provide to improve understanding of their world (de Chesnay 2014). Hagemaster (1992) has advocated the use of life history in nursing research, and although still developing, many more nurse researchers have used life history over the last two decades. Using life history in nursing research explores a person's microhistorical (personal) experiences within a macrohistorical (over time) framework, enabling the researcher to deeply analyse relationships, attitudes and

behaviours in a way that might not be possible using other methodologies (Hagemaster, 1992). Nursing studies using focused ethnography have been used to explore illness in homeless youth (Ensign & Bell, 2004), investigate health in immigrant adolescents (Garcia & Saewyc, 2007), report the experiences of community mental health nurses (Spiers & Wood, 2010) and to examine the experiences of a rare chronic health condition, lymphangiomyomatosis (Haylen & Fisher, 2014).

Given its ability to provide a comprehensive holistic examination of the subjective life experience, the life history method was chosen as the most appropriate design for this study, for the purpose of identifying important themes experienced by individual PwRRMS, which may also be experienced by their peers (Field & Morse, 1985). A great advantage of life history is that it retains the whole individual story and locates it in a wider social, cultural and historical moment (Plummer, 2001). Life history allows the exploration of experience over time in the context of the whole life, including both the individual social context and the broader historical context. Life history examines events and how they impact individuals and their life trajectory, revealing turning points, epiphanies and transformations that may occur over the course of the life living with disease (Haylen & Fisher, 2014). It also provides a way of understanding the meaning of illness and how this meaning might change over time.

Conceptualising life history in this study

The life history can be seen as a journey towards an inner quest for self, as part of a composed life or creation and allowing voices to be heard (Plummer, 2001). As suggested by de Chesnay and Fisher (2014), the purpose of the life history approach in the current study was to collect a focused history around a disease (RRMS), to document the story of each participant, but being careful not to frame this within a broader ethnography of all people living with RRMS. The life history methodology reflected the cultural and social contexts of each participant, allowed them to approach their life history in any way they chose, not necessarily in chronological order or centred only on their RRMS diagnosis. Interestingly, many participants

talked of other events in their lives being just as pivotal or more so, than their RRMS illness diagnosis.

In life history, the researcher and the participant come together as collaborators, composing and constructing a story (Atkinson, 1998), consistent with the ontology and epistemology of the study. A good relationship between the researcher and study participant is important and life history involves establishing a close relationship between the two (Plummer, 2001). Figure 1 is based primarily on the work of Plummer (2001, p.44), but also includes influences from Blumer (1969) and Tierney (1994). This illustration acts as a conceptual model to explain the relationships between the life history construction, the researcher and participant, what is unknown, what is knowable and the very important role of context. Contextual consideration is essential to enable readers of the research to assess for transparency, credibility, trustworthiness and transferability, by providing the detail required to ascertain how and why the research may be applicable to their own particular context or situation.

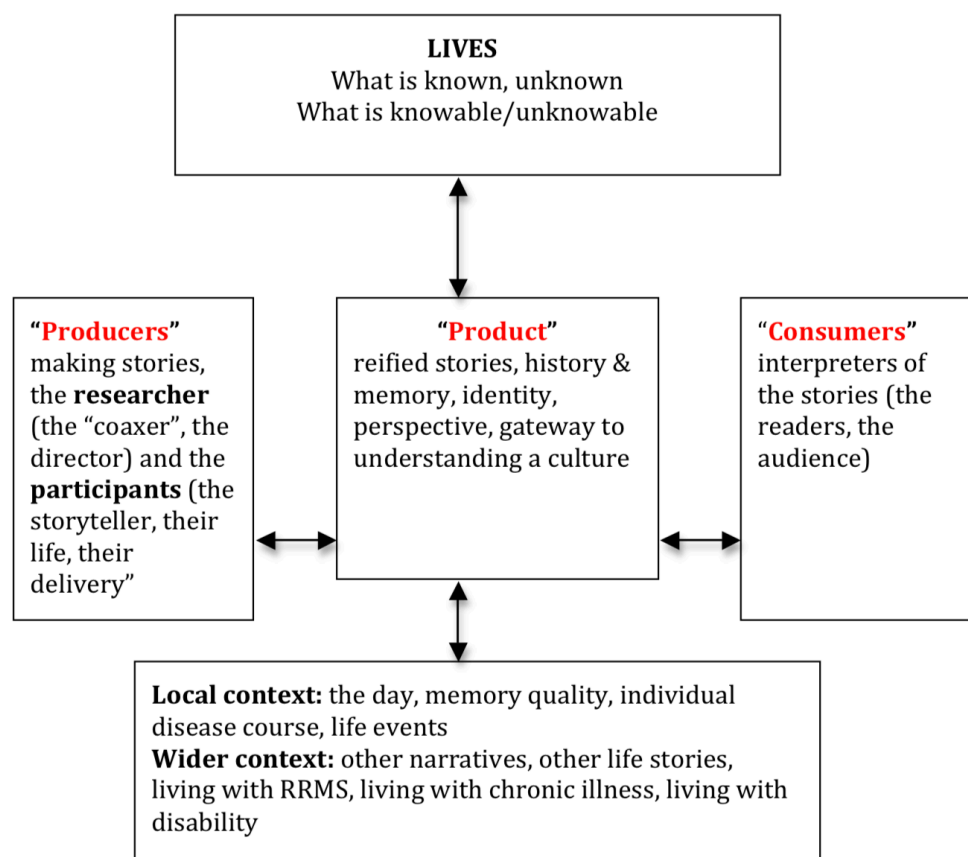


Figure 1. *Conceptual model highlighting the relationships between the life history construction, the researcher and participant, what is unknown, what is knowable and the role of context*

Motivations in life history

The purpose of using this methodology was to gain insights into the world of living with RRMS that could ultimately enhance knowledge in this area for MS Nurses and other HCPs, and thereby to potentially improve consultations, disease management and understanding. I was also clear that my motivation was part of the wider picture of gaining a higher degree in the process, although I was confident in myself that this was a secondary motivation. I ensured the study participants were provided with a clear discussion regarding my motivation in seeking out PwRRMS and the life history method in particular.

What motivated the study participants to be involved in the research? Allport (1942) suggests that there are many reasons why people volunteer to be the subject of a life history, and these include the factors already discussed, as well as self-justification, a desire for order, relief from tension, filling in one's life and as a form of confession. Others have reported the benefits of telling stories as being cathartic (Pennebaker, 2000) or to attribute praise or place blame (Holloway & Freshwater, 2007b). It has also been suggested that there could even be improvements in physical and mental health after emotions and experiences are made into stories; a result of helping the participant to feel visible (Pennebaker, 2000). I often wondered why the study participants agreed to be part of the research, to be interviewed, to think about their life and to give up their time to a stranger. Several participants openly disclosed their own motivations to volunteer for the research; these included wanting to help others (altruism), wanting to further research in MS specifically, as a form of therapeutic encounter and some participants simply wanted to talk to someone who was interested in their story. All study participants told me after the interviews that they had found the experience of telling their life history valuable, helpful and a positive experience.

Methods

“Everything has the potential to be data, but nothing becomes data without the intervention of a researcher that takes note - and often makes note - of some things at the exclusion of others”. Wolcott, 1994, p 3-4.

Methods in qualitative research are techniques and procedures used in collecting and interpreting data about social settings (Miller & Dingwall, 1997). Sometimes methods are recommended within a qualitative methodology as part as the intrinsic framework of that methodology (which is the case for both grounded theory and interpretative phenomenological analysis), with guidelines to follow for data collection and data analysis (Braun & Clarke, 2013). However, ethnography methodology allows for flexibility in method selection and it was up to me as the researcher, to design a framework for the methods that would meet the goals of the study and adequately answer the research question. To guide this process, I followed a conceptual model from Carter and Little (2007), which outlined the relationships

between methodology and method and the connection they both had to the epistemology of the study. It was a model where I had to consider if the epistemology of life history (as the methodology) would meet the study objectives, and thereby justify the methods chosen to produce knowledge. Having already identified the congruence between the study methodology and epistemology in the previous section, the influence of epistemology on the various study methods will also be discussed.

The current study utilised several different methods that were employed at separate stages of the research process and these are discussed as they occurred chronologically in the research design; firstly sampling and recruitment methods, followed by data collection methods, data management methods and the methods of data analysis.

Methods: Sampling

The sample

Purposive sampling guided recruitment for the current study, targeting people living with RRMS. Participants were deliberately selected to serve the task of a specific research intention (Morse, 2012). This approach was congruent with the epistemological position of the study, seeking to gain insights directly from people living with RRMS and co-construct knowledge.

The purposive sample was supported by inclusion criteria to ensure that potential study participants met a pre-defined measure to enable fair recruitment and that they were in a position to be able to answer the research question within the Human Research Ethics Committee (HREC) approval for the study.

Inclusion criteria:

- Diagnosed by a physician with RRMS
- Aged 18 years or over
- Able to speak and understand English
- Ambulant (be able to walk unassisted)

The criteria of being formally diagnosed with RRMS by a physician was to ensure authenticity of their life experience in terms of living with RRMS and not from another disease. The age of 18 years was in line with the HREC approval for adults in this particular study, and not for the paediatric (under 18 years) population. This was primarily because I wanted to explore the life history of living with RRMS over some years and I felt that the purposive sample inclusion criteria of being over 18 years would achieve this.

Reluctantly, I was only able to interview in the English language. I have respect for all cultures, and including people from a non-English speaking background would have added considerable depth to the study. As the interviews were conversation based and up to three hours in length, I simply did not have the financial support to allow for the considerable expense of interpreters or for translation services. This remains a goal for future research. The criterion to be ambulant was to capture the essence of RRMS. I felt that if a potential participant was wheelchair bound that there may be elements of SPMS from gradual progression of the disease and therefore a different diagnosis. Whilst I was mindful of the importance of life experiences for all PwMS, I wished to fully capture all of the other experiences of RRMS as much as possible and concentrate on one disease classification. Hopefully, exploring the life experiences of SPMS/PPMS may also be the subject of post graduate work.

Recruitment

People living with RRMS were recruited to take part in the study through the local state MS Australia (MSA) office, branch of NSW. A copy of the HREC approval for the study (Appendix 1) and flyers briefly explaining the study (Appendix 2) were provided to the State Manager of MSA. They were displayed in the Sydney offices where people living with RRMS were attending the gymnasium, and were also sent internally to regional staff of MSA by email for distribution locally.

A total of 14 expressions of interest were received over a period of ten months from March 2016 until January 2017. After making initial enquiries into exactly what the

study entailed, 13 PwRRMS agreed to be interviewed. One person making an enquiry about the study declined to take part after a brief telephone call and discussion, but did not provide a reason. Enquiries about the study filtered in slowly and consistently over this time, and I did not need to re-advertise again for volunteers. Most participants became aware of the study through the MSA network, but one participant was the result of the snow-balling technique (becoming aware of the study through someone else who had already taken part in the study), one participant heard of the study through a contact at the university I am studying at and four participants were alerted to the study by their MS HCP who directed them to the MSA flyer.

I was hopeful to attract participants with diverse characteristics to enhance my depth of understanding of the phenomena. I identified these characteristics as including both sexes, employed and unemployed, married/unmarried, parents/childless, rural/city based, newly diagnosed/long term diagnosed and also varying levels of disability. I was fortunate to be able to interview all volunteers and to be able to cover all of these characteristics comprehensively. This happened organically.

The study sample size was not initially stipulated in the study design, it was estimated that between 10 and 20 participants would be ideal. However, that number would depend on the amount and quality of data generated from the interviews, which was not known at the commencement of the study (this will be discussed in detail later in this chapter under study rigour). In conjunction with my study Supervisors, it was decided at each monthly meeting if interviews should continue. Once 13 participants had been enrolled, interviews performed and transcriptions completed, it was apparent that there was a considerable amount of data and it was felt that coding should commence before more participants were recruited and the situation reassessed again. However, further recruitment was deemed unnecessary after data coding due to the overwhelming amount of information and codes developed from the 13 interviews and transcripts. I felt that recruiting more participants would have lessened my ability to engage so deeply with the data and to understand the complexities of the data within the time frame of the study (Onwuegbuzie & Leech, 2005). The data was so detailed and plentiful that complete data analysis took just over a year working on the study as a full time student. I also

began to notice recurring themes across the study interviews from an early stage, increasing my confidence in the sample number being adequate.

Enrolled Sample

The demographics of the study participants (n=13) enrolled in the study are outlined in Table 2. The first person enrolled into the study was interviewed on the 14th of April 2016 and the last interview took place on the 31st of March 2017.

Table 1: *Study demographics for enrolled study participants.*

Study number	Pseudonym	M/F	Age at interview	Marital status	Years since RRMS diagnosis	Parent	Working
01	Piper	F	38	m	2	✓	p/t
02	Margot	F	57	m	16	✓	r
03	Kate	F	46	m	24	✓	u
04	Rudi	F	40	m	4	✓	p/t
05	Joy	F	57	d	12	✓	f/t
06	Jane	F	42	s	10	✗	p/t
07	Paul	M	38	m	2	✓	f/t
08	Ruby	F	36	m	4	✓	f/t
09	Will	M	32	m	4	✓	f/t
10	Griff	M	62	m	10	✓	u
11	Susan	F	40	m	14	✓	p/t
12	Davina	F	54	m	32	✓	f/t
13	Evie	F	39	s	20	✗	f/t

Note: F = female, M = male, age is in years, m = married, d = divorced, s = single, p/t = employed part-time, f/t = employed full time, r = retired, u = unemployed, ✓ = yes, ✗ = no

Methods: Data Collection

Semi-structured life history interviews

The qualitative interview is a construction site for knowledge (Kvale & Brinkmann, 2007) and forms the basis of the constructivist epistemological foundation for this study in relation to the chosen method of data collection. Semi-structured interviews were the chosen data collection method, performed in person and individually, with just the researcher and study participant present. A semi-structured interview has the purpose of obtaining descriptions of the life world of the participant with respect to interpreting the meaning of the described phenomena (Kvale & Brinkmann, 2007), making it especially suited to life history research. Semi-structured interviews have some pre-defined questions built-in to the interview, but the researcher is also permitted to probe further and ask additional questions as the participant responds, often leading to the collection of powerful data in the form of insights, experiences and perceptions (Peters & Halcomb, 2015). Semi-structured interviews are also unique among interview methods for the relevancy they provide a topic, whilst remaining responsive to the participant (Bartholomew, Henderson, & Marcia, 2000).

At the commencement of the interview, participants were provided with a verbal overview of the study, outlining my background and the study aims. I then asked each participant to tell their life history, in any order they wished, and covering anything they wished to, with particular thought to the question “What is the experience of living with RRMS?”. This approach ensured the information I gathered was consistent, rich and participant centred.

Although predominately unstructured in nature, I categorized the interviews as semi-structured for two reasons. Firstly, I provided reflection questions to study participants which gave some direction to the information I was seeking. Secondly, because the RRMS component of the research question gave direction about the topic I wished to explore in relation to their life history. The reflection questions were based on suggestions from Gubrium (1993) and Atkinson (1998) on key topics to guide life history and life stories (see Appendix 3) and were provided to participants by email approximately a week prior to the interviews. This process, as

suggested by Patching and Lawler (2009), allowed the participants to see the style and depth of the information required, as well as providing adequate time for consideration. The reflection questions served as a general framework for eliciting data about the participants lives, cultural background and the events around their diagnosis of, and living with, RRMS. Participants were instructed that they could use the reflection questions to think about their life, that they could use some of the questions, or they could elect not to use these reflection questions at all. The majority of participants used the reflection questions only as a starting point for thoughts and did not refer to them during the interview or bring them to the interview. One participant chose not to look at the reflection questions at all, preferring to tell his life story with no prompts.

Considering other data collection methods

One on one interviews were deemed to be a better fit to answer the research question than surveys, which do not allow for extensive exploration. They were also preferable to focus groups where participants may have felt inhibited to talk truthfully about their experiences in front of others. Focus groups in a permissive and comfortable environment can prove to be greatly beneficial for encouraging data generation with support from others in similar situations (Krueger & Casey, 2015). As I was clear that I wanted to understand each life history in considerable depth, I felt that a one on one interview would support this aim. Telephone or video interviews were also considered, but I felt that these might lack personal connection and rapport, which may have proven important to uncover sensitive parts of the life history. As will be discussed in the study findings, at times it was my observation of the study participant which added considerable depth to the story when witnessing physical reactions recalling emotions such as distress or joy. I was able to explore these emotions further, an opportunity that may have been missed entirely with telephone interviews.

Preparing for the interviews

As a registered nurse with over 30 years experience, I had developed a repertoire of interviewing skills, particularly as a clinical consultant in the last 20 years

performing solo consultations with patients in clinics. However, as part of my reflexive position (to be discussed in detail later in this chapter), I was aware that life history interviewing was going to be a very different form of interviewing than I was used to. In anticipation of this, I practiced conducting life history interviews with several work colleagues and friends in the months prior to commencing data collection. I refined and improved my technique considerably. This was to be an ongoing procedure throughout the study interviews, and I reflected after each interview in my field notes, on strategies I could use to improve for the next interview. Safety for myself was also a consideration as I entered people's homes to conduct most of the interviews. I had a short checklist to ask each study participant a series of questions by telephone prior to the interview date (see Appendix 4). In conjunction with my Supervisors, I developed a policy whereby I would notify a nominated Supervisor of my planned entry to an interview (in "real" time), and then again at the end of the interview when I had left the premises (Appendix 5).

I also consulted texts and methods for interviewing tips, especially in regards to the life history technique. Plummer (2001) recommended being aware of potential practical difficulties, performing dress rehearsals, considering seating arrangements (always on the same level facing each other), arriving early and being well organized, practicing relaxation techniques and keeping a list of interesting topics for discussion and probes should the interview come to a standstill.

Benefits of the interview techniques

One strength of the study was the lack of a formal structure in the interviews, thereby adopting a semi-structured approach. This allowed participants to express themselves openly and naturally and talk about their experiences as they wished, rather than using pre-determined questions. The personal interaction within the unfolding of stories and new insights were rewarding for both myself as the researcher, and the participant as the story teller, consistent with the thoughts of others (Atkinson, 1998; Plummer, 2001; Kvale & Brinkmann, 2007).

Methods: Data management

Good organisation and a systematic management of the data was key for later analytical thoroughness in the study (Tuckett, 2005). There was an overwhelming amount of data from the verbatim transcripts and also from the coding process, but every step of this lengthy process was viewed as an opportunity to further interpret the story on a deeper level. Core files of all data in unedited form were arranged in chronological order electronically and several hard copy transcripts were kept for different purposes; “noticings”, coding, story excerpts and quotes, as recommended by Plummer (2001).

Transcriptions

Interviews were recorded using two audio recorders, a primary recorder was used to transcribe the interviews while the second recorder was used as a secondary back up in case of battery failure during the interviews (which occurred in one interview, the first one performed). Interviews were then transcribed by myself verbatim as part of total immersion in and familiarisation with the data, as recommended by Braun & Clarke (2006, 2013). All interviews were transcribed completely within a week of the interview to retain as much detail as possible. I was able to engage deeply with the data and begin initial data analysis at an early stage.

Interviews were transcribed into a Word document in a half page vertical format with the writing on the left side so that “noticings” and “coding” could be applied on the right side of the page during the data analysis phase (these terms will be discussed in the next section). Line numbers were also added on the left side of each page for easy identification of quotes and location of important ideas during the findings and discussion section of the thesis. All observational data relevant to the interview, such as non-verbal behaviour I had noted (crying, tearful, expressions of joy) were inserted into the transcript as suggested by Miles and Huberman (1994), and pauses/times of silence were also noted. I often found these meaningful in interpretation, e.g. long pauses could alert me to intense consideration of the question and a particularly intense and meaningful answer.

An electronic copy of each interview was stored on a password-protected computer under a study number and pseudonym for each study participant, and also stored on a secure digital card (SD card) as a separate file. Following the transcriptions, each interview was listened to several times whilst reading the transcript to ensure accuracy of the transcript and to decipher words that may have been difficult to hear or misheard on the earlier transcription.

Field Notes

Field notes are writing up observations and comments on impressions and descriptions of participants and the study process after the interviews (Tuckett, 2005). I looked on these observations as an early method of data analysis. I took field notes as soon as possible after the interview (usually immediately) making it part of my personal debriefing ritual after I had left the interview. Field notes also helped me to remember details later in the analytical process and effectively took me back to the scene of the interview, which I often found extremely helpful to remember details specific to that particular participant. For example, what they were wearing and the setting of the interview that then helped me recall the meaning and emotions related to their facial expressions and other non-verbal behaviour. I closely observed the participants during the study interviews not just for non-verbal behaviour in general (laughing, crying, anger for example), but also specifically for signs of fatigue, and we took breaks when necessary. Field notes on each study participant detailed objective and subjective features of the interview as discussed, but also my thoughts, interpretations and advice to myself for future data collections. An example of the information collated in the field notes is shown in Appendix 6.

Data security

Using electronic technology both with data collection methods and in transcription, I needed to be mindful to prevent compromising participant confidentiality with lapses in data security. As suggested by Barnhill & Barnhill (2014), I maintained computer security on all hard drives, I used strong passwords on computers and devices, I used firewalls in hard and software, I avoided open networks and I disposed of deleted soft copy and hard copy information appropriately. This was in addition to using

participant numbers and pseudonyms instead of real names and also carefully removing potential identifiers from the transcripts.

Methods: Data Analysis

The life history aims to document a person's life (or significant part thereof) as a narrative, telling a representation of a story (Plummer, 2001). The participant constructs the history, but as Denzin (1989) suggests, it is up to the researcher to interpret and reconstruct the account into a story, which then provides understanding and perspective of the experience (de Chesnay & Fisher, 2014). The analytic process in the qualitative paradigm is all about moving from "pieces to patterns" (Thorne, 2008). It involves assembling or reconstructing the data into a meaningful fashion, in a way that is transparent, rigorous and thorough, whilst remaining true to the accounts of the participants (Smith & Noble, 2014). Several methodologies (such as interpretative phenomenological analysis and grounded theory) dictate specific and detailed methods of data analysis as part of their process, however this is not the case for focused ethnography and the life history. I found the freedom to choose from a variety of methods of data analysis a welcome component of the study design.

Data analysis is an interactive process where data is systematically searched and analysed in order to provide a description of phenomena (Smith & Noble, 2014). An important factor for any researcher to consider when determining the qualitative methodology or method to apply to their research design is what will be *the best fit* to answer the research questions. Having (what I saw as) the great benefit of no overarching methodology attached to focused ethnography/life history dictating the methods for data analysis in the current study, I was able to consider many possible methods of data analysis and apply them directly to the research question and goals. I was certain that I wished to use a robust and systematic method for data analysis, the idea that themes and patterns would simply "emerge" from the data after reading and re-reading transcripts (Morse, 2012) did not sit well with me, I needed guidance and a solid framework to ensure the data analysis was the most robust it could be. When examining the fundamental aims for answering the research question, "What is the experience of living with RRMS?" the analytic framework of thematic analysis, as

described by Braun & Clarke (2006, 2013), stood out as an excellent candidate. Thematic analysis involves looking for patterns in participant experiences across an entire dataset and has the capability I required in terms of being both robust and organised.

Considering the best method of data analysis for this study

There are many types of data analysis, and some are directly linked with an overarching methodology and are an essential part of that framework, such as those used in grounded theory and interpretative phenomenological analysis (Braun & Clarke, 2013). Other analytic methods such as content analysis and thematic analysis consider themes and patterns in data, and although often used interchangeably, there are important differences. Content analysis and thematic analysis can be more suitable for studies employing a lower level of interpretation compared to grounded theory and interpretative phenomenological analysis, which require a higher level of interpretation (Vaismoradi, Turunen, & Bondas, 2013), however thematic analysis in the current study was employed for a high level of interpretation. Alternative forms of data analysis such as narrative analysis and discourse analysis concentrate more on *how* things are said in data collection, rather than *what* is said and therefore were not suitable for the purpose of this study. The relative merits and drawbacks of employing these methods of analysis in the current research study will be discussed in further detail.

Comparing thematic analysis against other methods of data analysis

As briefly discussed, other forms of data analysis were explored before concluding that thematic analysis was the “best fit” for this research study. As discourse analysis and narrative analysis concentrate more on *how* things are said and the style and linguistics of words rather than what *was* said, they were eliminated early in the exploration of data analysis methods. However, there are shared elements of data analysis between the methods of interpretative phenomenological analysis, grounded theory, content analysis and thematic analysis that could have made those approaches a consideration for the current study. These will be briefly compared and discussed, and the use of thematic analysis justified.

Interpretive Phenomenological Analysis

There are some important differences between interpretative phenomenological analysis and thematic analysis, but the end result can look very similar (Braun & Clarke, 2013). Both interpretative phenomenological analysis and thematic analysis as qualitative methods of data analysis are particularly useful to answer research questions about the lived experience of people and their viewpoints and outlooks on life (Smith, Flowers, & Larkin, 2008). Thematic analysis has been referred to as a phenomenological method (Guest, MacQueen, & Namey, 2012) however Braun and Clarke (2013) identify thematic analysis as just an analytic *method* rather an overall *methodology*. Identifying interpretative phenomenological analysis as a *methodology* means that the overall study design is already specified as part of the ontological and epistemological foundations for interpretative phenomenological analysis, being critical realist and contextual in nature and based on the theory of phenomenology (Larkin, Watts, & Clifton, 2006).

Interpretative phenomenological analysis also targets a small homogenous sample, which would not be appropriate for this particular study exploring a heterogeneous disease such as MS, where there can be a wide variance of experience, with no two people experiencing the same course of the disease. A key difference is that in using interpretative phenomenological analysis the researcher codes the first data item then progresses to developing themes for that data item, rather than coding across the entire dataset, and then progressing to theme development as occurs in thematic analysis (Braun & Clarke, 2013). Overall, interpretative phenomenological analysis procedures focus on the unique characteristics of each individual participant, specifying coding and theme development along the way for each data item. This differs from the procedures of thematic analysis where the researcher identifies patterns across the entire dataset. I wanted to understand the meaning of living with RRMS across all of the participants, both individually and as a group, and in order to do so, thematic analysis provided a better “fit” than interpretative phenomenological analysis.

Grounded Theory

Grounded theory is a research methodology which discovers patterns and generates theory from data using a process of constant comparison (Braun & Clarke, 2013). Grounded theory was developed in the 1960s (Glaser, 1965; Glaser & Strauss, 1967) and was one of the first endeavours to develop a systematic method for analysing qualitative data. Currently there are now many versions of grounded theory, each with distinctive theoretical underpinnings and procedures. A key difference between grounded theory and thematic analysis is that grounded theory is a whole *methodology*, not just a method. As with interpretative phenomenological analysis, grounded theory comes with its own theoretical framework and ontological and epistemological position, and advocates the use of particular types of research questions with a focus on social processes or the factors that influence a particular phenomenon (Braun & Clarke, 2013).

Grounded theory differs from other manifestations of qualitative research in that the emphasis is on the theory as a product of analysis (Charmaz, 2006), unlike thematic analysis, which does not attempt to develop a theory (Braun & Clarke, 2013). As theory generation was not the aim of the current research study, grounded theory was not pursued as a viable option for data analysis.

Another point of difference between grounded theory and thematic analysis involves engagement with the literature. A common practice in grounded theory methodology is to not engage with the relevant literature prior to beginning data analysis, to avoid the analysis being shaped by preconceptions from existing research. As part of the preparation for identifying exactly where the significant gaps were in understanding the experiences of people living with RRMS, the topic was thoroughly researched over many years in advance prior to the final study design. Additionally, as reading the relevant clinical and research literature as it is published in MS is part of the expected clinical, educational and research role I was working in at the time of the study commencing, “not engaging” with the relevant literature was impossible. Due to these overwhelming factors, grounded theory was not going to be harmonious with this particular data analysis.

Content Analysis

The terms content analysis and thematic analysis have often been used interchangeably to refer to very similar approaches to qualitative data analysis, further confused by the fact that the boundaries between the two methods have not been clearly specified (Braun & Clarke, 2013; Vaismoradi et al., 2013). Content analysis is a general term used to describe a number of different strategies to analyse the subject matter of data (Powers & Knapp, 2006) and uses a systematic coding and categorizing approach to determine trends and patterns of words used by the participants during their interview, often in a large volume of text (Vaismoradi et al., 2013). This may involve looking at frequency of words, and the relationships between words (Grbich, 2007). The purpose of content analysis is to summarise quantitative messages (Neuendorf, 2002), whereas thematic analysis aims to identify, analyse and report patterns within the data (Braun & Clarke, 2006). The purpose of this research is the latter, rendering thematic analysis a stronger and more appropriate choice than content analysis for this particular study.

Choosing thematic analysis

After careful consideration of the methodologies/methods for data analysis described above, I chose thematic analysis to be the most congruent with my research ontology, epistemology, with the overarching methodology of focused ethnography/life history and with the other research methods chosen for sampling, data collection and data management. The various components of the research design fit together well to provide a robust framework for operationalising the study and meeting the study goals. Another form of data analysis, poetical analysis, was also used in this study, although in a very minor capacity. Poetical analysis was used to enhance the study findings from the thematic analysis and will also be discussed at the end of this section.

Method of Data Analysis 1: Thematic Analysis

The following section will briefly describe the historical development of the thematic analysis method, explore thematic analysis in more detail and outline how it differs from other methods of qualitative data analysis. An in-depth exploration of thematic analysis, as suggested by Braun and Clarke (2006, 2013) will demonstrate why this method of data analysis is congruent with the aims and goals of this research study and will also provide an overview of the framework used to guide data analysis.

Thematic analysis involves the search for common principles that extend through an entire dataset (DeSantis & Ugarriza, 2000). It is a method for identifying, analysing and reporting patterns or themes within a dataset, ultimately organising and describing the data in rich detail (Boyatzis, 1998; Braun & Clarke, 2006). Searching for patterns and themes is a common method in data analysis in general, and several methodologies in qualitative research (such as interpretative phenomenological analysis and grounded theory) actually use forms of thematic analysis as an important and basic *part* of their framework. However, fundamentally thematic analysis differs from other analytic methods seeking to describe patterns in qualitative data as it is not bound to any one type of theory or methodology, it is simply a *method* of data analysis (Braun & Clarke, 2013). This leaves the researcher free to choose their own ontological and epistemological framework and data collection method, improving flexibility in answering research questions in the *best* possible way.

As an adaptable method, thematic analysis can be approached in a number of different ways, and several of these are specifically aligned with the aims of this research study. Thematic analysis can be *inductive*, the data are examined from the “bottom up” and coding and theme development are directed by the content of the data. This approach is integral to answering the research question in the current study, exploring and finding meaning in the experiences of people living with RRMS from the those considered the experts when performing qualitative research - the participants themselves (Windle, 2011). This study is not based on any pre-determined theories, but will be shaped by the experiences of the individual participants and the group as a whole, from the emic perspective, which is also

congruent with thematic analysis. Moreover, thematic analysis can be *semantic*, deriving codes and themes from the precise, explicit content of the data, or more *latent*, reporting concepts and assumptions underpinning the data and interpreting the data at a deeper level. This is consistent with one of the aims of this research study, to provide both semantic and latent analysis of the themes and provide interpretations on how these themes may be important.

Congruence between methodology and analytic method

Thematic analysis can be a method to reflect reality and to “unpick” the surface of reality (Braun & Clarke, 2006), making it ideal for this research study seeking insights into the experience of people *living* with RRMS in *the real world*. Thematic analysis allows examination of the data within a relativist approach, focusing on reporting an assumed reality, but is also able to look at the data in a constructionist fashion (Braun & Clarke, 2006). This is congruent with the ontology (constructivist, relativist) and epistemology (constructivist) for the current study where the researcher and participant will co-create the data and the researcher will provide latent and abstract explanations from the data. Additionally, the researcher is able to determine the level of analysis and choose how to present the data in a way that is accessible to others interested in the field of study (Braun & Clarke, 2013). As an important goal of the research is to disseminate the information gained from the study across as many health professional domains of MS as possible, thematic analysis supports this approach.

The thematic analysis method as presented by Braun and Clarke (2006, 2013) suits the research question, fits the exploratory topic, allows choice of ontological and epistemological viewpoints, aligns with the data collection method, allows the researcher to grow and develop as experience is gained with the method, allows focus on the context of the research question, is robust and systematic, and allows both latent and semantic interpretation of study data. This is an ideal match for this research study and promotes congruence between ontology, epistemology, methodology and method, essential components of successful qualitative research (Carter & Little, 2007).

The history of thematic analysis

Thematic analysis was first named as a method by Gerald Holton in the 1970's (Merton, 1975). Initially thematic analysis was described in very simple terms only (Leininger, 1985) with little guidance provided in terms of process to actually perform the thematic analysis and no clear agreement about what the method entailed (Attride-Stirling, 2001). In particular, researchers often described themes “emerging” or being “discovered” from the data (Braun & Clarke, 2013; Ely, Vinz, Downing, & Anzul, 1997) providing very little in terms of process, transparency and confidence to the reader. This has been described as a *passive* account of the process when the process of analysis is very *active* and engaging and needs a clear description to enable others to evaluate the integrity of the data analysis and to understand the process (Braun & Clarke, 2006).

Frustrated by a lack of processes underpinning thematic analysis and poor demarcation of the method, Braun and Clarke (2006) outlined the theory, application and evaluation of their version of thematic analysis to the psychology community. Over the last decade, thematic analysis has grown to encompass many disciplines of health research with the “in psychology” reference to the method now largely disregarded (Braun & Clarke, 2013). However, some factors in the data analysis technique have remained in common with original descriptions (Merton, 1975; Aronson, 1995; Boyatzis, 1998) but with differing methodological paradigms and subtle analytic departures.

Several other authors have also described and explored thematic analysis as an analytical method (Boyatzis, 1998; Joffe & Yardley, 2004; Guest et al., 2012). The main difference between these method versions and the Braun and Clarke (2006) method of thematic analysis is that the former all promote the development of coding frames within the method, to enable multiple researchers with different expertise and perspectives, to code the same data in order to improve inter-rater reliability. This was identified early as being challenging when applied to this research study, as I brought to the study my own assumptions and beliefs about RRMS (based on many years of working in the specialty) consistent with the stated epistemology and my reflexive stance. Invariably applying this experience to the codes and later themes

would differ from those that others might determine from the same data. As coding is an active and reflexive process that inevitably and inescapably bears the mark of the researcher, with no one 'accurate' way to code data, the logic behind inter-rater reliability disappears (Braun & Clarke, 2006). Braun and Clarke (2013) further argue that inter-rater reliability scores can be viewed as two researchers being trained to code data in the same way, rather than that their coding being accurate (Braun & Clarke, 2013). As this study was only to be coded and themes developed by myself as the principal researcher, the Braun and Clarke method (2006, 2013) of thematic analysis was the preferred choice.

In summary, thematic analysis has gained more popularity as a method of data analysis in recent years, particularly since Braun and Clarke (2006) have detailed and described this qualitative data analysis method and made it more accessible for researchers. It is one of a group of methods that focus on identifying patterns across a dataset and is now anchored firmly as a flexible, robust, systematic framework suitable for many types of qualitative research (Braun, Clarke, & Terry, 2014). The specific method of thematic analysis based on Braun and Clarke (2006, 2013) teachings will now be discussed and explored in further detail.

An overview of the Braun and Clarke (2006, 2013) method of thematic analysis

The Braun and Clarke (2006, 2013) method of thematic analysis involves key stages, following directly on from each other: transcription, reading and familiarisation of the data, coding, searching for themes, reviewing themes, producing a 'thematic map', defining/naming themes and writing up the research. The major elements of the Braun and Clarke (2006, 2013) process of thematic analysis are outlined below.

1: Familiarisation with the data

This phase involves reading and re-reading the transcribed interviews, to become immersed and intimately familiar with the content. Transcribing the interviews personally can be an excellent way to start familiarising the researcher with the data (Riessman, 1990) but is not essential to the method. I elected to transcribe the interviews myself to promote deep engagement and connection with the data from

the earliest stage.

Familiarising with the data is an active process, pondering repeatedly about what the data could mean. In this research study, I would also go back and re-listen to the original audiotapes regularly. Hearing participant voices helped formulate a recreation of the interview to visualise facial expressions and other non-verbal cues, enhancing recall of the emotional aspects of the interview. As the method is recursive, the opportunity remains for the researcher to come back to this phase repeatedly as needed and perhaps identify new insights further in the process. I found this extremely helpful throughout the data analysis.

Immersing in the data and getting to know the words and feelings of the participants opens up areas of interest for the researcher, helping to notice things that might be important to answering the research question. Braun and Clarke (2006), term these thoughts as “*noticings*” and an important first step in engaging and analysing the data. At this early stage it is not a systematic and precise procedure, just more similar to first impressions of the data.

2. Generating initial codes:

The second phase involves generating succinct labels called “codes” which identify important features of the data that might be relevant to answering the research question. Codes identify a feature of the data at it’s most “basic segment” (Boyatzis, 1998). Coding may be *semantic* (explicit) or more *latent* (hidden and awaiting development) in nature. The researcher codes the entire dataset, working systematically and giving full and equal attention to each data item identifying interesting aspects that may form the basis of later themes. Coding should be performed widely and thoroughly and be constantly mindful of context.

3. Searching for themes:

The focus of the analysis now shifts to examining the codes and collated data to identify significant patterns of meaning, the broader level of developing themes.

Potential themes, known as “candidate” themes are developed and data related to each theme is collated to examine and support the viability of the candidate themes.

4. Reviewing themes:

This phase involves checking the candidate themes against the dataset, to determine if they tell a convincing story of the data, and a story that answers the research question. At this stage, themes develop and are refined, which sometimes involves themes being split into sub-themes to further clarify meaning, being combined with other themes, or being discarded altogether. A key component of the phase is developing a detailed analysis of each theme, working out the scope and focus of each theme; determining the ‘story’ of each theme individually.

5. Defining and naming themes:

The key feature of this phase is determining that each theme has a *central organizing concept* to securely and confidently anchor the theme in the dataset. A central organizing concept is the essence of a theme and is critical to sound theme development. Capturing something important about the data, the central organising concept unifies the data extracts and is essential for demonstrating coherence of a theme (Braun & Clarke, 2013). Each theme presented in the study findings will be introduced with a short discussion of the central organizing concept and how it unites the theme and subthemes, and how it is meaningful to answering the research question. A name for each theme is developed, ideally being both informative and succinct.

A thematic map of the data, capturing the “essence” of what each theme is about and demonstrating links between the themes often assists this phase of the analysis. Constant reference to data extracts by the researcher helps to organise the data into a coherent and internally consistent account. Sub-themes are assigned if they are needed to give structure to the dataset and also reveal the hierarchy of meaning within the data. A sub theme can be a less prominent theme that exists under an umbrella theme, or it may be an important feature of the stand-alone theme. By the

end of this stage, themes should be clearly defined and concise, demonstrating that the researcher has a clear sense of what the theme is about and have a clear, defined central organizing concept.

6. Producing the report

The final phase of the Braun and Clarke (2006) method of thematic analysis involves weaving together the analytic narrative from the participant, and contextualising the analysis in relation to existing literature. Data extracts are embedded in the analytic narrative to illustrate the story of the data and to go beyond a simple description of the setting and instead comprehensively answer the research question.

Although these phases are sequential, and each builds on the previous, Braun and Clarke (2006, 2013) emphasise that thematic analysis is typically a recursive process, with movement back and forth between different phases. In fact, some of the phases can often blur together, rather than having clear lines of separation, as the researcher moves around the data and explores different labels and themes. The process of thematic analysis can be time consuming, laborious and requires intensive effort (Guest et al., 2012). Additionally, the researcher needs to rely on their own opinions and develop their own understanding of the values and assumptions of different research paradigms and their own subjective positioning within those methods to ensure rigour in their findings (Braun & Clarke, 2013).

Intensive review of each component of the Braun & Clarke (2006, 2013) method of thematic analysis

The coding process

A code is a textual description of the semantic boundaries of a theme and is a short, descriptive mnemonic from the data (Guest et al., 2012). Coding is the process of identifying *aspects of the data*, which directly relate to the research question (Braun & Clarke, 2013) and is an important process to start early sense-making of the data (Averill, 2014). The coding process involves the researcher seeing important characteristics in the data and encoding it *before* interpretation begins, so that the

data is organised and reduced before developing themes (Boyatzis, 1998). Coding provides logical data organisation to form the basis for later data analysis (Miles & Huberman, 1994).

A fundamental step of all coding is to verify the applicability of the code to the raw information (Boyatzis, 1998). A researcher should be able to take away the unedited data from the codes and still be able to evoke the feeling of the data (Clarke & Braun, 2013). This provides an internal validity check prior to progressing to theme development and I performed this often to ensure I could “feel” the data in the code and that it was still appropriate when separated from the original participant transcript. In the current study, working through the stages of code development allowed ideas about candidate themes to slowly develop, sometimes days and weeks after the first coding exercise.

Coding is an important and integral step for most forms of qualitative analysis and different approaches have different labels inherent in their methodology for these codes, often with very similar goals and meanings. Braun and Clarke (2006) consider that there are two methods of coding practice - selective coding and complete coding.

Selective coding involves looking for instances of the topic of research interest and purposefully selecting only those instances in order to obtain data reduction. This is not applicable to this particular research study where there is a high degree of inclusion to explore the research question thoroughly.

Complete coding has a much broader focus and aims to identify anything at all within the entire dataset which may show potential to answering the research question. For this reason complete coding is more closely aligned with this particular research study than selective coding. All data potentially relevant to the experience of living with RRMS was coded from the transcriptions in this study, only becoming more selective later in the analytic process. This helped to ensure no data that may be important was missed, especially as themes are developed later in the process. Each code is essentially a “pithy” label (a brief, concise but meaningful label), which captures the core or essence of the data collected (Braun & Clarke, 2013). In

complex and data rich datasets, sometimes a second or third round of coding is needed to further reduce the data (Saldana, 2015). In the current study, over 2,000 initial codes were identified from the transcripts in the first round of coding. A second round of coding was required to reduce the data even further for theme development and resulted in approximately 300 codes, after codes displaying similar characteristics were grouped together.

The Braun and Clarke (2006) method of thematic analysis provides guidance on complete coding which was the chosen coding method in this study. The principles of the method require eliminating irrelevant data to answering the research question, but still coding everything which may *potentially* be important, coding widely and extensively and using data in as many ways as relevant to the research question. Examining the collated data for similarities and grouping together like codes occurred later in the process.

Semantic and latent codes in thematic analysis

Braun and Clarke (2013) identify semantic codes as reflecting the words and concepts of the participants directly, they are entirely overt within the data. When the researcher goes beyond this overt content and starts to invoke conceptual and theoretical frameworks to identify meanings implicit in the data, latent codes are developed (Braun & Clarke, 2013). Latent codes are developed by the researcher based on what they “see” within the data, not based on what is “said” by the participant directly. In general, a much deeper engagement with the data is needed for latent coding (Braun & Clarke, 2013). An example of the development of semantic and latent codes in the current study is shown in Appendix 7. This research study aimed to use both semantic and latent coding in data analysis.

Developing codes into themes

Processing techniques for collating the codes to develop themes can be performed electronically or manually. Cutting and sorting written codes and themes manually is a common method employed by researchers and involves identifying text that appear to fit together, placing the text into piles and moving them around until they

represent a theme where they appear to belong (Ryan and Bernard, 2003). As with all facets of thematic analysis this process is recursive, and may involve many steps forward and back before an ideal match is reached. I used a manual method to group codes together in a pile, using a different colour card for each participant code to group like codes together to later develop candidate themes. The more colours in a pile, the more heavily patterned the theme was. However, this colouring did not dictate the importance of the code, it merely raised the possibility of a beginning theme.

Manual and computer coding in thematic analysis

The term “computer-assisted qualitative data analysis software” (CAQDAS) refers to a range of computer programs used in data analysis. The value of CAQDAS depends on the purpose it is used for and the methodological underpinnings of the research study. Although CAQDAS can be very effective and assist in interpretation of data and developing theories (Silverman, 2016), it is still only a tool to *assist* with coding and analysis (Braun & Clarke, 2013). No computer programs are capable of the intellectual and conceptual processes needed to transform data into meaningful findings (Thorne, 2000), rendering the researcher the most important instrument in the process of developing latent or hidden, more abstract themes. CAQDAS may prevent the researcher “immersing” in the data and may cause some detachment from the transcriptions of the participants in this study (Braun & Clarke, 2013). If used inappropriately, there is also the risk in coding becoming related to *quantity* of times a concept is mentioned in the data and taking away from the significance of the data.

I briefly considered using a software program to assist with thematic data analysis, but I felt that deep engagement with the study data might be compromised if I did not manually code the data myself. I wanted to “embed” myself in the data and stay as close to the data as possible (Munhall, 2012). I was also concerned that using software to analyse the data thematically might remove context from the stories and reduce the stories to categories and frequencies.

Themes and sub-themes in thematic analysis

One of the earliest concepts of a theme was described by an anthropologist, Morris Opler (1945):

“In every culture are found a limited number of dynamic affirmations, called “themes” which control behaviour or stimulate activity...the term theme... is used to denote a postulate or position, declared or implied...which is tacitly approved or openly promoted in a society” (Opler 1945, p.198)

This work was further built upon by Spradley (1979), who described themes as:

“larger units of thought...they consist of a number of symbols linked into meaningful relationships...Themes are assertions that have a high degree of generality...they apply to numerous situations...some themes occur within a restricted context” (Spradley, 1979, p.186-187)

Desantis and Ugarriza (2000) have examined many nursing research texts in an effort to provide a uniform definition of a “theme” in the context of nursing. The concept of “theme” was examined and explored across 27 qualitative nursing research texts to ultimately define the concept of a theme as “an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations” (DeSantis & Ugarriza, 2000). A theme captures something important about the data in relation to the research data set (Braun & Clarke, 2006) and brings together components of ideas or experiences, which are often meaningless when viewed alone (Leininger, 1985).

How many themes compose thematic analysis?

There is no precise formula for determining the number of themes in thematic analysis, as it depends on many other factors, including the data itself, the research question, the length of the analytic report, and the focus of the analysis (Braun & Clarke, 2013). Thematic analysis can range from detailed and intensive reporting of

one theme as a focus for a research study, to a complete and wide-ranging overview of entire and multiple datasets, with less focus on individual themes. Therefore, dictating an ideal number of themes and subthemes to demonstrate rigour within an analysis is impossible and is not the aim of thematic analysis.

How does a theme achieve importance in thematic analysis?

Referencing exact numbers of participants in describing theme occurrence is also a challenge in thematic analysis, and one which Braun and Clarke (2013) address for researchers in their recommendations. Rather than using numerical expressions to report occurrence, they instead advocate using phrases such as “a common theme” or “many participants commented”, and this is for several reasons. Firstly, counting responses misses the point of qualitative research, as frequency does not necessarily equate to the value and importance of a theme (Pyett, 2003). Ideally, a theme will present itself a number of times across the data, however, the number of times the theme presents itself is not indicative of the importance of the theme (Buetow, 2010). When using unstructured or semi-structured interview method, the absence of a theme in an interview should not be regarded as an assumption that the participant does not experience or behold the theme as important or relevant. It may simply be that topic did not present itself in that particular interview. As the interviews were all flexible and interactive, different issues came up in each conversation, which were not necessarily discussed with other participants.

In regards to the importance of a particular theme, more instances of a theme across a dataset does not necessarily mean that one theme was more important than another, rather researcher judgment is crucial to determine what constitutes theme significance (Braun & Clarke, 2006). Additionally, the importance of a theme is not dictated by the prevalence of that theme across an entire or partial dataset. Themes will be discussed individually in the study finding chapters 6 and 7, and they will also be discussed in terms of how they link together to explore the journey of living with RRMS in chapter 8. This approach supports the gestalt of qualitative research analysis, ensuring that all data is analysed and presented as completely and thoroughly as possible.

Developing themes and sub-themes across the dataset

Identifying themes from coded data is entirely an *active* process with the researcher examining the codes to create potential patterns (Taylor & Ussher, 2001) and finding hidden treasure within the data (Braun & Clarke, 2013). Clarifying and making transparent the techniques used to develop themes is important for several reasons; as discovering themes is the basis of much social science research, it allows readers to assess methodological choices and also promotes research communication across disciplines and epistemological positions (Ryan & Bernard, 2003). Providing a step by step process of theme development demonstrates transparency in the analysis and promotes rigour in the method, as does using excerpts from the data to ensure that data analysis remains directly and firmly linked to the words of the participants (Fereday & Muir-Cochrane, 2006).

A sub-theme exists as a sub-category of a theme and shares the same *central organising concept* as the theme, but focuses on one specific element (Braun & Clarke, 2013). Sub-themes should generally be used in moderation, and only when there is one particular element of a theme that has a specific focal point, or is particularly important for the research question (Braun & Clarke, 2013).

Organising themes in thematic analysis

Collating and organising the themes and sub-themes is an integral part of the analytical method, and requires a process in order to demonstrate rigour (Fereday & Muir-Cochrane, 2006). There are several methods available for researchers to organise themes and provide structure to thematic analysis, including diagrams such as *thematic networks* and *thematic maps*.

Thematic networks are web-like illustrations that summarise the main themes of text in thematic analysis and provide a tool to systematically present analyses (Attride-Stirling, 2001). Thematic networks consist of different levels of themes, a global theme overarches an organising theme, which overarches a basic theme to build the overall network (Attride-Stirling, 2001). Similar to these networks are *thematic maps*, which are simple drawings to reflect relationships between themes and sub-

themes (Braun & Clarke, 2013). As a key part of the Braun and Clarke (2006) method, *thematic maps* have been developed as part of the data analysis for the current study (Braun & Clarke, 2006) and were used at every step of the analytic process. A *thematic map* is essentially a visual aid, which uses a drawing to summarise, define and name themes and sub-themes. It is simply a visual representation of how themes and subthemes *may* fit together to tell the story. As the study progressed, thematic maps changed to reflect new ways I was seeing the data and how themes and subthemes were linking in with each other and developing a story. I referred to the thematic maps regularly to act as a framework for the final analysis and to demonstrate theme maturation. An example of a thematic map used during the study data analysis is shown in Appendix 8.

Method of data analysis 2: Poetical Analysis

Poetical thinking is *felt* experience, being in the flow of what is being experienced and capturing and understanding the feelings of that experience (Freeman, 2017). It is a form of thinking that has roots in phenomenology, dealing with concepts of experience, perception and language (Freeman, 2017). It has been suggested that through poetry, names are given to ideas which were formerly nameless and formless, but already felt (Lorde, 2009). By using poetry as a form of art, we can experience moving the mind from routinely taken-for-granted assumptions towards a sharper focus on a situation (de la Fuente, 2014).

During the data management phase of the study, I began to write the feelings I was experiencing as poetry whilst listening to the recordings and reading the transcripts. I began writing without explaining, just feeling the words as they flowed for each participant. This continued in the theme maturation process of the data analysis, and as each theme developed, I then purposely tried to capture the essence of what I was feeling from the experiences of the study participants.

The aim of the current research study was not to pursue a poetic form of inquiry (de la Fuente, 2014; Freeman, 2017), it was a traditional and method specific systematic thematic analysis, but the opportunity presented itself to consider poetical analysis as

I dealt with my own feelings and emotions of constantly re-living the interviews and experiences of the study participants, especially through the theme development phase. The great majority of the study findings related to the thematic analysis, but I have strategically placed poetry (my own and others) in the thematic findings as an important adjunct to the data analysis and as a way of connecting and adding meaning to the data. Poetical thinking also honours my epistemological viewpoint of the researcher and study participant co-creating the study data and findings, by listening to the participant stories and finding methods to experience and feel the emotions of the study participants. It was a way to intertwine their experiences, my reactions and co-construct a new knowledge.

What differentiates poetical thinking from analytic thinking is the reach beyond searching for meaning or knowledge, into the difficult to grasp, experiential world (Freeman, 2017). I found the poetical thinking and the words that emerged from this provided me with a vehicle to release profound feelings I was experiencing, listening repeatedly to stories of suffering, of sadness and of constant battle. It was a catharsis of sorts and I positioned the poetry at the appropriate places so that readers might also gain an enhanced perspective of the data. In some instances, I found a better representation of my thoughts and feelings from other poets in the literature and they are included where appropriate. As Freeman (2017) notes, making sense of the complex interaction between theory and practice (being there, listening, seeking understanding) is difficult and poetry may enhance understanding as lived, experienced and yet undefined.

In qualitative analysis there is the opportunity to enhance and enrich ideas with deep contemplation, which cannot be expressed in other ways such as scholarly text (Averill, 2014). I wished to convey additional meaning to the insights I was gathering and beginning to understand during the data collection and data analysis, and sought to find ways to complement the study themes as findings. Where I have used the poetry written by others, it is appropriately named, otherwise the poetry is my own work (marked as TB).

Methods: Frameworks for the study

Theoretical framework

A framework is essentially a research map for the study, a guide to how the study should proceed. A single ***theoretical framework*** did not underpin this study, and the study was not linked with any particular theory. Due to the broad and multifaceted nature of the research question, a singular theoretical perspective would not have been possible. However, Green (2014) argues that the epistemology on which a study is based *is* a theoretical framework of sorts, as it provides an overarching philosophy for the study, a belief system and theory to guide process. In this regard I would agree with Green (2014) and present the constructivist epistemology described earlier in this chapter as an appropriate theoretical framework guiding the study.

Conceptual framework

A ***conceptual framework*** draws on concepts from various theories and findings to guide the research design, identifying worldview and the ontology and epistemology of a study. I developed a conceptual model to illustrate this framework, and how the various components of qualitative research work together to create knowledge. This conceptual model was mostly based on previous work by Carter and Little (2007) linking the importance of epistemology, methodology and methods in research, but also influenced by Guba and Lincoln (1994) and Cresswell (2008), and is shown in Figure 2.

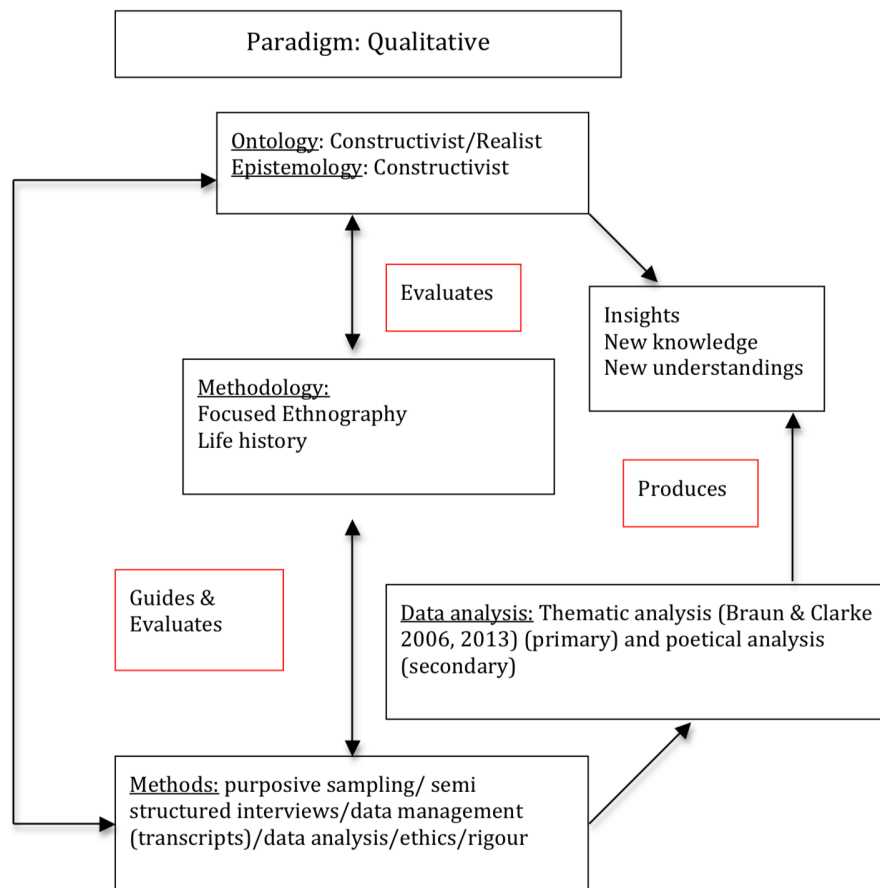


Figure 2. Conceptual model highlighting the relationships between ontology, epistemology, methodology and methods and the production of new knowledge.

Operational framework

A strength of this study design lies in the ***operational framework***. This framework provides an overview of the entire study, maintaining coherence and focus on the goals of the research study, it also demonstrates the important links between the qualitative paradigm, ontology, epistemology, methodology and methods involved in the research process as recommended by Carter and Little (2007) and shown in Figure 3. The operational framework is broader than the conceptual framework and considers many other elements influencing the research design, including ethical considerations, reflexivity, rigour, transparency, context, sensitivity, coherence of the research the quality of the product, and fit to empirical literature. The operational framework illustrates the framework I developed to ensure consistency in the study process and consideration of all the necessary components of high quality qualitative research.

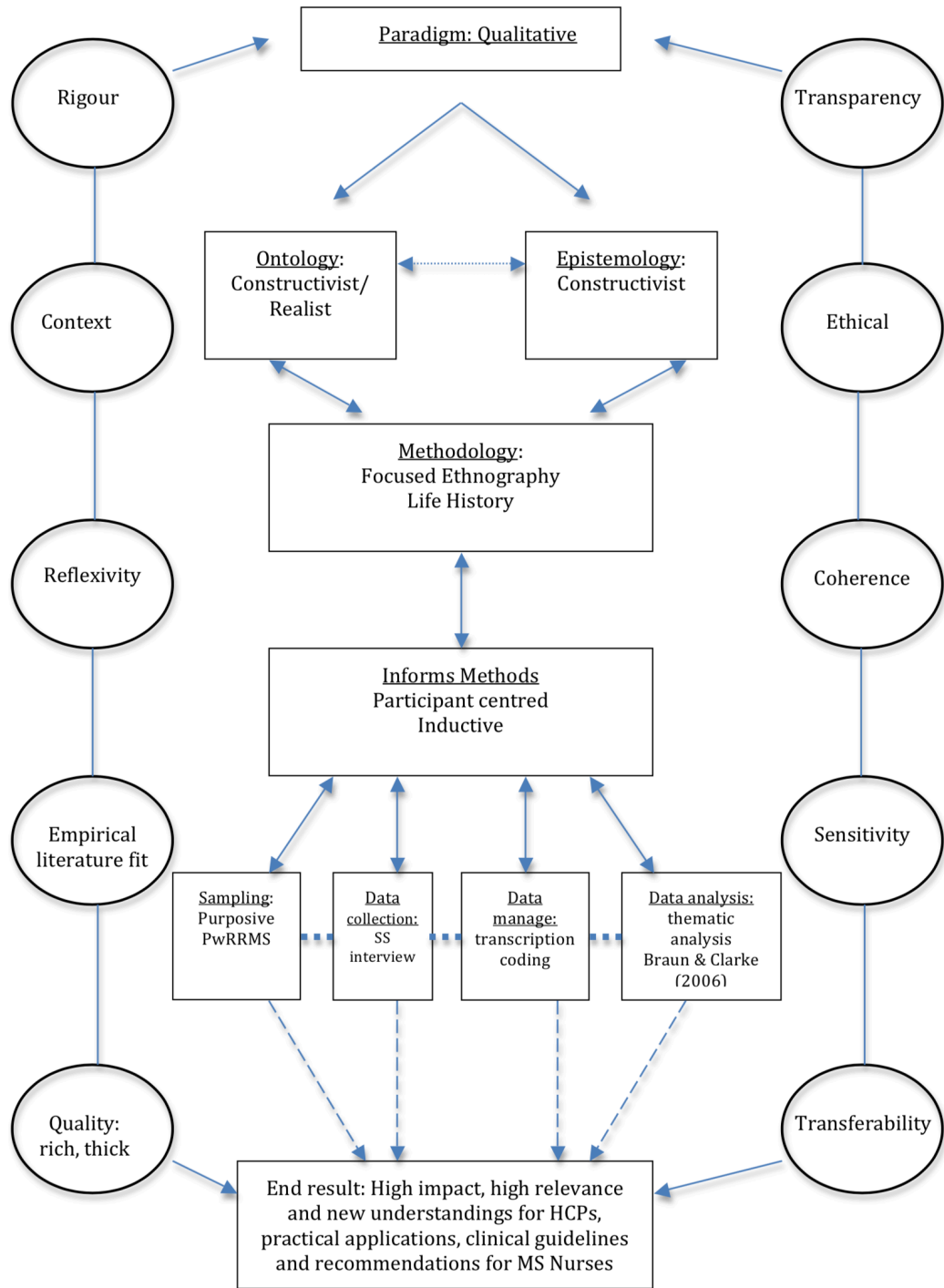


Figure 3. Operational framework highlighting the interplay between the processes of the current research study and the relationships between them to produce new understandings that are highly relevant, rigorous, context sensitive and impactful to clinical practice.

Methods: Ensuring rigour in the study

In social research, validation cannot occur through subsequent replication, since identical social situations cannot be recreated (Bloor, 1997). Instead, elements of a study are viewed as being possibly generalisable across settings, or not generalisable at all due to the research being in a truly particular setting (Bloor, 1997). It is up to the reader of the research to determine to what extent the findings of a qualitative study might apply to their own situation. The researcher can help the reader to make this assessment by being transparent in all aspects of describing the sample, data collection, data management and data analysis, as I have done in this chapter.

Qualitative research represents a distinctive paradigm, and as such, should not be judged by conventional quantitative measures of validity, generalisability and reliability (Mays & Pope, 2000). Instead, terms such as accuracy, confirmability, transferability and trustworthiness apply in qualitative research (Lincoln & Guba, 1985). The aim is to discover patterns that exist. In using the ethnography methodology and life history, no two researchers will elicit the same life story, and no one researcher will ascertain the same life history on two occasions, the aim in life history being to grasp unique experiences for what they tell us (Plummer, 2001).

Maintaining rigour in a study helps to safeguard the participant's point of view, so that researchers don't construct a fictional, non-existent world (Fereday & Muir-Cochrane, 2006). There are strategies that can be employed by researchers to establish and enhance rigour within a study. As Plummer (2001, p.155) suggests "the closer I am to the phenomenon I want to understand, the closer I am to validity". To accomplish this, I transcribed my own interviews verbatim and regularly re-listened to the original audiotapes to stay as connected to the original data as possible. By doing this I was able to build up layers of understanding, gradually building up ideas and concepts that eventually became themes and subthemes. Additionally, approaching data analysis in a responsive, inductive, transparent and systematic way has been reported to lead to openness and balancing quality, science and rigour (Averill, 2014). I felt that selecting such a robust and systematic method in thematic analysis, and using the method outlined by Braun and Clarke (2006, 2013) to analyse

the study data, was crucial to maintaining rigour in the study. Table 3 demonstrates elements of rigour and strategies employed during the study to support and maintain each element.

Table 3. *Elements of rigour identified and strategies employed during the study to maintain rigour.*

Element supporting rigour	Strategies employed to uphold rigour
Transparency	In depth discussion of chosen methodology and methods Systematic and robust data analysis method with visible and linked stages Reflexive diary kept throughout study
Triangulation	As the primary researcher, I was responsible for the initial coding and theme development and thematic framework → this was reviewed regularly by Supervisors for congruence and fit
Credibility	Findings discussed extensively with Supervisors and supported by both data and interpretative framework Peer debriefing of themes with MS nurse experts for “fit” of themes to clinical practice Prolonged and deep engagement in the field of MS The use of field notes to record impressions and describe situations in depth Participant quotes (raw data) provided as examples of particular themes and relationships between themes
Transferability, trustworthiness, authenticity	“Thick” and “rich” description Participant quotes (raw data) provided as examples of particular themes and relationships between themes Thematic framework of evidence of how the data builds the interpretation
Comparison with research literature	Interpretations and analyses compared with existing literature to confirm and expand study findings Negative case analysis consideration and discussion

Member checking

Member checking/ member validation is a common qualitative research method to improve rigour in a study by providing the data transcriptions or findings back to the study participant to review and comment on; aiming to validate findings by demonstrating coherence between the researcher's analysis and the feelings of the participant (Bloor, 1997; Seale, 1999). However, it was not a viable option in this life history study for several reasons. Firstly, in life history, participants can gain "new horizons" or new ways of seeing things after the interview and discussion, impacting on how they see things afterwards and often with a new perspective, which may then change the view of the original life story (Plummer, 2001).

Secondly, Morse (2015) suggests that the findings in qualitative health research are deeply analytical and abstract and are therefore not appropriate to give back to participants, who may not understand the differences and reasoning between what they disclosed in the interview and the researcher's final analysis. Thirdly, there is the question of what the researcher should do if there is a discrepancy with the findings and how this would be handled (Braun & Clarke, 2013; Morse, 2015). The concept of member checking is more appropriate for other approaches to research, such as phenomenology, where the specific aim is to record an individual's perception as closely as possible in data analysis (Braun & Clarke, 2013).

The concept of truth telling in life history

The life story told at the time of the interview is taken to be the truth (Denzin, 1989; de Chesnay & Fisher 2014). The guidelines of life history assume that no participants are lying as they tell their stories, accepting the word of the individual and also being aware that there is no such thing as absolute truth (Wiseman, 1974). Of course, some stories are not always factual, but the researcher usually accepts the story of the participant as true, even though they know that sometimes memory may be confused or the story may be overdramatic for effect (Holloway & Freshwater, 2007b). It has been suggested that storytellers in narratives rarely tell lies and even when not telling the truth, consciously or not, they demonstrate their intentions and motivations

(Holloway & Freshwater, 2007b). I accepted the life stories as presented by the study participants as being honest accounts of their experiences.

Data Saturation

Essentially, data saturation is reached when the ability to obtain additional information has been exhausted or when further coding is no longer feasible (Guest, Bunce, & Johnson, 2006). Data saturation assumes that a circumscribed and total amount of facts are available (and necessary) to be able to draw conclusions from research (Malterud, Sierma, & Gusassora, 2016). This concept is not in alignment with qualitative research and the epistemology of this study, which values the individual voice; assuming multiple realities, of which only some can be known.

An exception to this in qualitative research is in grounded theory, which has an inbuilt system of data saturation derived from data comparison, where every new observation is compared with previous analysis to identify similarities and differences (Glaser & Strauss, 2017; Malterud et al., 2016). In qualitative research in general, it is better to think of data as being both “rich” (focusing on quality, being layered, detailed and nuanced) and “thick” (focusing on quantity, a lot of data and codes) rather than “saturated” (Fusch & Ness, 2015). However, there are some general principles which indicate that enough data has been collected; these include no new data arising, identifying no new coding categories, no new themes emerging and collection of enough detail to replicate the study (Guest et al., 2006). Additionally, if the interview questions are not structured and consistent for every participant (as when using semi-structured or unstructured interviews), it is impossible to achieve data saturation against a constantly moving target (Guest et al., 2006).

Malterud et al. (2016) have proposed an alternative term to data saturation to guide sample size in qualitative research called “information power”. The more information the sample holds relevant to the study and answering the research question, the lower the amount of participants needed. Assessing “information power” involves a model considering the focus of the study (broad or narrow), sample specificity (dense or sparse), and the quality of the dialogue (strong or weak);

the model being particularly appropriate to individual interview studies such as life history (Malterud et al., 2016). I felt that the current study consisted of diverse informants who provided dense, specific and high quality insights; meeting the goals of the study, answering the research question and providing excellent “information power”. The quality of the interviews in the current study was excellent with the data collected giving rise to over 2,000 individual codes. Although I had no new codes or themes emerge after the eleventh interview, the final two interviews added a depth to the existing data that was exceptional and both were integral to richness in the final thematic analysis. As no new information was subsequently uncovered in the final analysis, no new interviews were therefore scheduled and data collection was deemed complete (Rubin & Rubin, 2011).

Methods: Ethical considerations

The concept of ethics is intrinsic to the constructivist epistemology because of the inclusion of participant values in the research (Guba & Lincoln, 1985). More than a checklist to simply tick off boxes, attending to ethical considerations is the moral responsibility of all researchers (Ryen, 2016). It has been openly discussed in the literature that ethical guidelines in general research are *inadequate* for qualitative research, as they focus more on the needs and nuances of quantitative research and clinical trials rather than the unique needs of qualitative study (Denzin & Lincoln 2000; Ryen, 2016). Denzin and Giardina (2016) explore these concepts further, suggesting that the biomedical model of research ethics presumes a static, monolithic view of the study participants. In life history research in particular, the subject and researcher develop collaborative relationships, which are not captured in ethics “rules” (Denzin & Giardina, 2016).

Despite these criticisms, the usual process for the ethical conduct of studies was followed in line with Notre Dame University guidelines. However, in agreeing with the concepts stated above, I decided to add additional considerations and precautions into the research design to provide added support to the study participants. The epistemological foundations of this study reflected my belief that the participants were key informants and that we constructed the reality together. Successfully completing the research study (for the sake of both of us) depended on the study

participants feeling comfortable, supported and valued. Their needs and welfare were critical to my study design.

Ethical approval

Ethical approval for the study was sought and granted by the Notre Dame University, Australia, HREC, approval number: 016002S (see Appendix 1). Following the recommendations of the Nuremberg code (1947), National Statement on Ethical Conduct in Human Research (National Health & Research Council (NHMRC), 2007 and updated 2015) and the Australian Code for the Responsible Conduct of Research (NHMRC, 2007), the study was subjected to a full ethical review, rather than abbreviated low-risk review. This was primarily because I viewed the data collection interviews as very likely to be sensitive in nature and potentially inducing vulnerability in the participants. In addition to the above ethical considerations, the four principles of medical ethics were honoured - autonomy, beneficence, non-maleficence and justice (Gillon, 2015).

The full ethical review and approval included the approval of the HREC submission form outlining the research design and study procedures, the Participant Information Sheet and Consent Form (PICF)(Appendix 9), and a flyer for participant recruitment (Appendix 2). As per the requirements for study approval, a PICF was provided to each participant and signed prior to any study procedures taking place. The participant and I signed two original copies and took one each for our files. As an added protection for the participants, I ensured that they were able to read the PICF at least a week prior to our meeting and interview date. This was to avoid the situation where participants may have felt obligated to take part on the day we met (if they were reading the PICF for the first time) because of the effort required by both of us to attend the scheduled interview. This system also provided participants the opportunity to ask questions, consult significant others and think about their participation ahead of time. I also reminded the participants that on the day of the interview they were free to withdraw from the study at any time, and for any reason.

The two specific areas that I identified at the beginning of the research process as being potentially challenging to the ethical conduct of the study involved protecting

participant confidentiality throughout all methods (transcriptions, coding, analysis) and the possibility of exposing the participants to distress and/or vulnerability discussing their experiences living with RRMS.

Confidentiality for the study participants was paramount, particularly as some stories were distressing or involved family members, friends or HCPs directly (who did not volunteer to be part of the study). Pseudonyms (false names) were assigned to each participant to protect their identity and were mostly chosen by the participant themselves, continuing the feeling of partnership in constructing the research together. Still, two participants were adamant that their real names be retained. However, after many discussions with the supervisory team for my study, I allocated a pseudonym to protect them and their significant others from identification. In both cases I felt their intention to keep their real name was for good reason and they wanted the world to know their story, however, I believed there were issues they didn't consider which could be detrimental to them or their family if their identity were revealed to the public. I also felt that I may inadvertently "hold back" on some of their story to avoid revealing their identity, and their stories and messages were too powerful to do this. I did discuss this with both of the participants after the interviews were completed and they understood and supported the use of a pseudonym with our further discussion.

The names of significant others, HCPs and friends were all deleted from the transcripts, as well as potentially identifiable data such as birthplaces and cities/towns of residence. Where important to the story, reference is made to living in a rural town or community rather than to a specific region. Instead of using a potentially identifiable occupation, I changed the position to a broader role to continue the protection of the participant story as much as possible, without losing the essence of the stories and the meaning that this occupation may have had for the PwRRMS. Protecting the privacy of participants is a core tenet of research ethics (Morse & Coulehan, 2015). I maintained privacy for the participants during the interviews by speaking to them away from distractions in their homes or offices (in a room, privately from other house members or colleagues) or in the case of two interviews that were performed in public places, we inhabited a corner away from noise or public traffic where we could not be overheard. All transcripts (audio and

written) were immediately coded with pseudonym/study number with no reference to real identity. Audio transcripts were deleted from the computer after written transcription and kept on a de-identified SD card locked in a safe.

The possibility of my research causing distress or enhancing vulnerability in the study participants was one of the areas I felt most strongly about, where I needed to have a clear and workable plan in place in case additional assistance was needed to cope by participants, particularly after the interviews were completed. I had no idea exactly what the participants would tell me about the experiences, but my years of clinical experience working in the field with people living with RRMS had shown me that often patients could become emotional and distressed talking about things that had happened to them previously in terms of their RRMS. I wanted to be well prepared in case of distress during or after the interviews. The study design included access to a psychologist experienced in MS care to be available to consult participants if needed, as well as a flyer (Appendix 10) for the participant outlining the procedure they could follow to contact me to institute this care (this information was available in the PICF, but also given as a separate flyer for ease of accessibility).

At the end of every interview, participants were given the opportunity to ask more questions. I contacted each participant after the interview to thank them for their participation in the study and to ensure they were feeling healthy emotionally. No study participant required additional care through the research process, and all participants expressed gratitude and thanks for the positive experience the interviews had provided them, to be heard, believed and listened to. I was also aware that participants may reveal thoughts or feelings they never intended to reveal in an interview, potentially making them feel even more vulnerable (Holloway & Freshwater, 2007a) after their “confessional mode of discourse” (Atkinson & Silverman, 1997). Making contact with participants after the interviews also gave them the chance to advise if they wished to withdraw information from the study. No study participant wished to take this option.

Annual reports were submitted to the HREC over the course of the study to continue ongoing HREC approval. Study participants raised no points of concern during the

course of the study and no incidents threatening the integrity of the ethical considerations were made to the study Supervisors, the HREC or to myself.

Methods: Reflexivity

Reflexivity fits into the wider perspective of ontology and epistemology (Berger, 2015) examining the role of the researcher in the generation and construction of knowledge and assisting the researcher to act without bias (Holloway & Galvin, 2016). Unlike quantitative research where an objective stance is necessary, in qualitative research the active role of the researcher is valued and appreciated as an important research tool (Braun & Clarke, 2013). However, it is important that the researcher makes visible personal reflexivity as a form of quality control within the research (Braun & Clarke, 2013), where the aim is for “empathic neutrality” (Ormston et al, 2014).

Personal reflexivity

In this particular study, it was important for me, as the researcher, to be specific about my background and possible subjective viewpoints, and to identify early in the research process both the potential strengths and limitations of these subjective viewpoints. The key to performing a successful life history is to develop a trusting relationship with the participant, developing the relationship through rapport (Hagemaster, 1992). I committed to using all of my personal and professional skills to develop and maintain trusting relationships with the study participants, and part of this was my already existing professional background. The majority of study participants had been cared for by an MS Nurse as part of their life journey with RRMS, and had all valued the MS Nurse, their skills, knowledge and support. Belonging to the “MS Nurse club” most likely held some definite benefits for me in terms of rapport and trust and I felt that for many participants, this gained me instant entry into their lifeworld. However, I was also aware that I could not automatically take this for granted, and have expectations because of this role. First and foremost I was a researcher, and my MS Nurse role was secondary to what we were there to construct together. I was open and honest about my professional background, but I didn't dwell on it.

My personal reflexive stance is that I am a middle aged, middle class, female, Caucasian MS Nurse with 34 years of clinical nursing experience and 23 years of (mostly quantitative) research experience, with the last 12 years of practice working solely in MS. I am married and the mother of two children who are in the prime age target of MS onset, in their mid-twenties. I am a spiritual person of a Roman Catholic background. I do not live with RRMS, nor am I disabled, but I do live with my own chronic illness of 26 years. I am a caring, empathic person and I acknowledge that I tend to want to “fix” everything for others and help as much as possible. I am not alone here, as a tendency to make suggestions and problem solve is a common HCP limitation in research (Windle, 2011). Assessing this situation and evaluating the possible effects of these characteristics on the research study was challenging, but necessary. The picture of embodiment I presented to the participants as an able bodied person inquiring about their world was also a consideration I had going into every interview. I wore plain clothing and tried to physically blend into the background as a conscious choice.

The positive impacts that my reflexive stance brought to the study were numerous. Due to my clinical knowledge of the disease and experience as a registered nurse, I was able to build rapport quickly with the study participants and to develop a trusting environment. I felt I was able to make them comfortable, to feel free to discuss any issue they wished and in any order they wished. As a consequence, I was able to obtain data relating to sensitive issues, such as parenting, sexuality, relationships, hopelessness, mental health, compromised care and fear. This enabled me to gain new insights into living with RRMS that have been reported infrequently or have not been reported at all in the specialty. I could also optimise my clinical experience in the data analysis phase to see nuances in the data that may not have been discovered by a researcher with no clinical MS experience. I understood the MS terminology that participants used in their life history and I was able to situate it appropriately due to my clinical knowledge; this was important as ethnography relies strongly on naturally occurring language of the participants in the field (Holloway & Todres, 2003). Additionally, I was able to be mindful of when symptoms (particularly participant fatigue) threatened to interrupt the integrity of the interview, and organise breaks and rest when necessary.

I specifically asked myself a set of questions before and after the life history interviews as a way of being mentally and emotionally prepared to set aside my personal opinions and put the study participants and their experience at the forefront of the study (Appendix 11). Even though at this stage I was collecting data to prepare for the later analysis, in qualitative research, analysis starts early and I needed to be aware of things that could potentially later affect the findings.

I kept a reflexive journal (Braun & Clarke, 2013; Hinton & Kirk, 2017) throughout the study process to capture times of indecision and times where I needed to work through possible areas of limitation in the study, prompted by my own personal views on data and findings. I also used the journal to chronicle how I was feeling at various times during the study, such as if I was particularly emotionally affected by the interviews, or aspects of the data analysis and literature review. An example of a diary excerpt from the study is presented in Appendix 12. I also wondered at times if many years of experience working as an MS Nurse in the field may have constituted a form of fieldwork in ethnography, where extended participation and observation in a culture occurs, but I decided that my experience did not meet the criteria of fieldwork as my previous exposure was always in a structured, non-natural clinical environment (a hospital clinic) with a different purpose (seeking healthcare and advice). My mindset was that this was all going to be new to me.

Functional reflexivity

Functional reflexivity involves giving critical attention to the way research tools and processes may have influenced the research findings (Braun & Clarke, 2013). I regularly engaged in asking myself if I was limiting what could be found by having such a broad research question (Willig & Stainton, 2008) and if the technique of interviews was the best way to answer the research question. Using individual semi-structured interviews provided a solid base to ask additional questions of interesting data, to probe further when it was indicated and to enable the privacy for study participants to talk about whatever they viewed as important, rather than being overwhelmed by other participants in a focus group. During the study, I constantly re-assessed if my methodological and method selection was serving the study well and I was confident that no alteration was needed to the data collection methods and

analytical methods as the study progressed. The more I practiced thematic analysis and the more immersed in the entire process, the more natural the analysis became.

Reflexive Analysis

Reflexive analysis involves consideration of how the patterns and themes arose from the data, it is up to the researcher to consider and explain exactly how this process occurred (Srivastava & Hopwood, 2009). Thinking about this with a reflexive lens, the patterns and themes I saw in the data certainly came about because they were linked in some way to my extensive clinical experience working in the field of MS and thousands of consultations with PwRRMS over the years, and the things I had seen and heard. I was concerned that at times, my clinical mindset might overtake my inductive qualitative research sensibility. To combat this, once every candidate theme was developed, I went back to the original data - the transcripts and the codes, to ensure that the themes were firmly embedded in the study data and not my own thoughts and opinions. If a candidate theme could not be supported entirely by participant quotes and stories, it was discarded, no matter how important I felt the theme was personally. This ensured an inductive, data driven analysis.

Emotional reflexivity

At times, the interviews contained highly emotive content and I had difficulty disengaging from the data, feeling emotional and vulnerable myself as I re-listened, re-read and re-analysed times of sadness and distress in the lives of the study participants. Some of the interviews were intense and the willingness of the participants to share their lives with me, a stranger, was overwhelming. Several participants had suffered neglected childhoods or had been subjected to horrendous events and re-living these discussions invoked sad and heart-rending emotions. I paid attention to nutrition and fitness and discussed my emotions with a few trusted confidantes; debriefing with peers and having regular breaks from the work. These measures improved the situation greatly. I read an article by Tanner (2009) exploring her experiences listening to sad situations and the difficulties encountered during her PhD work, which proved very helpful to me in facilitating this effective mental health plan for myself during the study.

There were several times during the interviews where the blurred roles between my role as researcher and my clinical role intertwined and left me with a strong emotional reaction, usually of anger. This was manageable, but there were several times when participants were telling me stories of compromised care from other HCPs that I became bothered and struggled to hide my feelings. Instead I opted to let the participant see that I was affected by their story and I was interested and listening, but not the full extent of my feelings. This situation usually involved other HCPs not performing to duty of care or treating the participant badly, in a way that was not harmonious with my values of nursing care. I wrote about these experiences in my reflexive diary so I could come back afterward and look at my responses with a reflexive stance to ensure that I was fulfilling my role as researcher and listener first and foremost.

In summary

As the ontology, epistemology, methodology and methods, and the links between them have been discussed and justified for the current study, the important relationship between the methodology and the data analysis and study findings will be presented in the following chapters. To introduce the study participants, the next chapter will present a narrative of each individual study participant's story. Essentially chapter 5 will consist of a brief overview of the life story for each study participant; their upbringing, families, friends, communities, events in their lives, work, play, important life turning points and their story of RRMS. Chapter 5 will provide context for each life story and important insights in order to gain deeper understanding of, and appreciation for, the study themes presented in the following chapters.

CHAPTER 5: STUDY FINDINGS - THE LIFE STORIES

As comprehensively discussed in the previous chapter, Methodology and Methods, the study participants share their life history, but the life stories are co-constructed by the researcher (Plummer, 2001). The life histories told by the study participants became the life stories co-constructed by me as the researcher, and formed the initial part of the study findings. The life stories provide context and understanding to the specific thematic findings in the following three chapters (chapters 6 to 8), as the reader is able to gain perspective about the lives of the study participants. This helps to appreciate each participant's challenges, joys and life happenings; with each narrative a unique story.

All participants were asked to choose their own pseudonym for the study, this process involved much thought and care. It is for this reason that I have kept two very similar names, Rudi (participant four) and Ruby (participant eight) in the study findings and report. For these two participants, their chosen names meant so much to them, having a great deal of personal significance. Two participants asked me to choose a pseudonym for them. It is impossible to include all of the information related to RRMS and other life happenings for the study participants within the word limit confines of this thesis, but these stories have taken the most relevant information from the history to represent a brief life story for each participant. I have included a short summary of the DMT story, because for all study participants, the DMT (or choice not to have a DMT) had some effect on their life journey, as told by the participants. The life stories of all 13 study participants are presented below, in chronological order of the interviews. I added an overarching phrase to each pseudonym, a short title of sorts, to describe their journey and to provide a deeper portrayal of their story with each pseudonym.

Participant number 1: Piper's story

Pushed around from pillar to post

Piper was 42 years of age at the time of our interview and has lived her entire life in the same rural town where she was born. Piper works casually as a volunteer,

enjoying her time with people and a chance to do something with meaning. Part of a very close migrant family, her extended family is a very important part of her life. Married to her childhood sweetheart, Piper is the very proud mother of two busy and spirited boys. Diagnosed with RRMS just over two years ago, Piper's story is interspersed with periods of mysterious illness of over 25 years duration, countless visits to doctors and a strong sense of determination to find an explanation for her unexplained symptoms.

Despite her bright and bubbly exterior, Piper's life has been tormented intermittently with unexplained physical and psychological symptoms, which at times have been completely demoralising for her, leaving her feeling "like a fraud" and "like a hypochondriac". Piper attributes part of the challenge of understanding her various symptoms to years of living in a rural community with a constant thoroughfare of family doctors called General Practitioners (GPs), "always someone new...starting again at the front end" and never getting to the bottom of her symptoms. Piper's earliest recollection of neurological symptoms occurred at the age of 13 when she experienced the first of many severe headaches, wrapping around her face and causing intense and unbearable pain. These types of pain episodes were to continue on and off for many years.

Piper recalls "always being at the doctors" and having "all the tests under the sun" to find the cause of her unexplained symptoms. From her mid twenties, she describes a regular pattern of "getting checked and never finding anything wrong". Piper suffered a severe episode of depression after her marriage and was also diagnosed with anxiety. She worked hard with a psychologist to turn her life around and change her thought patterns and was also treated with medication for depression and anxiety. Piper has since wondered if this episode might have been due to early RRMS, as depression is a common co-morbidity. Despite the emotional pain, Piper describes this time in her life as a major turning point for her and regards seeking help as "the best thing I ever did...I didn't realise til I was well that I was living half a life".

Over the ensuing years, Piper was diagnosed with other illnesses (such as underactive thyroid, Raynauds, low vitamin D) and also experienced significant back pain from disc issues and also suffered years of infertility. The time leading up to

Piper's diagnosis of RRMS was an especially frustrating time in her journey. Approximately 6 months prior to diagnosis, Piper was bedridden; suffering fatigue, pins and needles, a loss of bladder control and poor memory. She describes this time as feeling like she was "getting old really quickly...all of a sudden". Piper recalls saying to her husband "I think I really am going crazy, like the doctors think I am". After a few weeks these symptoms settled down and Piper decided to go on a holiday to another state and saw a GP there whilst she was away. This GP performed a neurological examination, surprisingly, her first one ever. MS was suspected and Piper was immediately sent for an MRI scan and then to see a neurologist in the closest large city.

In quick succession, Piper was diagnosed with RRMS and commenced on a DMT, the interferon beta1-b (Betaferon®) and she learnt to self-inject the medication every second day. Piper recalls her overwhelming feeling at diagnosis as being "relieved that I wasn't going mad". Unfortunately the DMT did not control the disease, and she suffered further relapses. Piper has since commenced an oral DMT, dimethyl fumarate (Tecfidera®) which has stabilised her relapses, but not her symptoms, which continue to be a daily reminder to Piper of RRMS. She suffers greatly from fatigue, nerve pain, insomnia and spasms but works through each day as best she can; eating nutritiously, working casually, caring for her family, exercising regularly and "walking through the pain" to be as healthy as possible. Piper's extended family have also been instrumental in providing support and encouragement, particularly when she hasn't felt well or has been experiencing a relapse. They have told Piper that they are amazed at her tenacity and determination.

When recalling her diagnosis, Piper says she was "probably lucky...a lot of people have to wait years and get pushed around from pillar to post". The interesting thing was, whilst listening to Piper's story all I could think about was how *Piper* was "pushed from pillar to post" around a medical system that wasn't really listening to her. In keeping with the new thought patterns she learnt from her therapy to overcome depression, Piper has spent the last two years since diagnosis enjoying life as much as possible. Piper is expanding her social circle (previously she kept to herself and family a lot), travelling overseas at every opportunity and trying to extract as much joy out of life as possible. Piper is making the most out of every day.

Participant number 2: Margot's story

Making the most of all I have and getting on with it

Margot, aged 57, at the time of our interview, moved to Australia with her parents and sister when she was just a baby. Margot recalls her childhood being dominated by multiculturalism, speaking, reading and writing English at school and then being required to immerse herself in her original culture once back inside her home. Margot went to university, worked in retail and customer service and eventually met her husband with whom Margot has two sons. Margot was fortunate to maintain good health until 16 years ago at the age of 41, when she suddenly tripped and fell heavily, causing injuries to both her knees. She didn't think much of it at the time, but Margot developed numbness up to her hips in the ensuing days, alternating constipation and diarrhea, and later numb hands. Totally perplexed, she arranged to see her local GP who sent her for some investigations. Margot then saw a neurologist and had a spinal MRI which revealed some "faded spots" on her spine. The neurologist felt it was probably due to a virus. In retrospect Margot recalls feeling like she was "patted on the head" on her way out as the neurologist said "there is nothing wrong with you, off you go" and that "that was the end of that".

As years went by, Margot noticed that she was tripping a bit more and reported to her GP that the nagging numbness from years before had never really totally gone away. She was referred to another neurologist who ordered both a spinal and brain MRI. This led immediately to a diagnosis of RRMS. Margot was convinced until this point that she had motor neuron disease (MND) and describes a feeling of "relief" on hearing she had RRMS. Margot disclosed her new diagnosis to several family and friends who were aware of recent events, however she made a conscious decision not to tell her parents her diagnosis. Margot felt that their limited English, poor understanding of MS, and her father's tendency to "worry", would cause too much anguish and apprehension for them. Margot also elected not to disclose her diagnosis to her workplace at this time.

Margot commenced interferon beta1-b (Betaferon®), a medication she self injected every second day until natalizumab (Tysabri®) was made available in Australia. Margot then attended a monthly hospital visit for an infusion of natalizumab for many years. She tolerated the medications well and was delighted to find when she started natalizumab that she was paired up with other people with MS having the same monthly infusions. This was the first time Margot came into contact with others living with RRMS and found it “fantastic”, sharing tips and stories with others and feeling a sense of camaraderie. Margot went on to fingolimod (Gilenya®) tablets after a couple of years relapse free, which she remains on to this day.

Margot considers herself lucky in that she has not had many troublesome relapses and has generally remained well, despite some accrual of disability in recent years. She was working part-time until a few years ago when she decided to retire. Travel has been important, Margot belonging to a tight knit group of friends who travel together regularly.

Margot also sometimes uses a walking stick to help with stability on stairs and uneven ground, mainly to alert others that “there is something wrong with her” and to “be more careful around her”. Otherwise Margot is gently ambulant, walking steadily, slowly and with a limp, but determinedly walking. She also enjoys looking “romantic” when out with her husband as they hold hands to aid her stability. She looks forward to more overseas travel with friends, conscious that she wants “to do more travelling, before I can’t”.

Participant number 3: Kate’s story

I get knocked down but I get up again, you can’t beat me

Kate, a clever and engaging scientist, was aged 42 years at the time of our interview, and has lived with RRMS for almost 20 years. She has recently retired from her career; initially because her job was made redundant and later because her MS symptoms have made returning to the workforce difficult. Kate’s husband of 25 years is supporting Kate through this momentous change in her life, which she admits she has still not yet accepted.

At the age of 23, and with a toddler son, Kate suddenly went blind in her left eye, paving the way for several years of uncertainty as specialists struggled to work out exactly what was happening to her. Kate was in the middle of studying part-time and working full time when her episode of sudden blindness occurred. It gradually resolved, only to be followed by several more episodes of unexplained blindness in the following two years. She feared the worst, especially when the first doctor she saw told her it could be a brain tumour. After a year or so, Kate was referred to a neurologist who told her abruptly at their first meeting that she “probably had MS”. Kate recalls that at the time she had no idea what this meant. He told her that she “may end up in a wheelchair and you will probably be blind in five years”. Kate recalls that she felt “a mess” and he prescribed her anti-depressants to, in the neurologist’s words “get over it”.

During yet another baffling episode of unexplained blindness, Kate was referred to a physician who immediately told her to throw out her antidepressants, which she gladly did and immediately began to feel “a lot better”. This doctor was to become one of Kate’s biggest supporters, treating her RRMS with some unusual but forward-thinking treatments at the time. He was always available for her to treat the numerous relapses and symptoms she would go on to suffer. These years were especially challenging as Kate juggled her family life, her full time job and her studies toward a higher degree, always under the constant threat of another MS relapse. Constant short courses of pulse steroids took their toll on Kate emotionally “boy, I was angry...I would get fired up so quickly”, causing arguments with her husband, as she struggled with the side effects from the various medications.

It wasn’t until a year after these episodes of blindness that the first brain lesions appeared on an MRI, to *confirm* a diagnosis of RRMS. In keeping with diagnostic guidelines at the time, it was still a “probable” diagnosis, but not a confirmed diagnosis of RRMS that Kate had had to contend with. Kate commenced treatment with the self injected interferon beta1-b (Betaferon®) every second day, struggling with the side effects, feeling “totally miserable and really, really sick”. She eventually relented and decided to stop DMTs for the next couple of years, continuing to suffer relapses. As new medications became available in Australia,

Kate eventually started on DMT again. She was commenced on glatiramer acetate (Copaxone®). Kate recalls the struggle to find a suitable injection site, being “black and blue around the tummy” from the daily injections. Kate later changed to the three times weekly interferon beta1-a (Rebif®). A couple of years later, once again, the interferon related side effects took their toll and Kate felt she needed to stop treatment.

Up until this time Kate had managed to keep her diagnosis of RRMS secret from her son, thinking “he’s a kid, there’s no need for him to know...I suppose it’s my idea of keeping him safe”. When he started high school and she could no longer disguise the side effects from the interferon, Kate felt ready to disclose her diagnosis of RRMS to him. She felt like he took the news well, although “you can tell that he was really upset”. About ten years after her RRMS diagnosis, Kate commenced the new monthly infusible monoclonal DMT natalizumab, but suffered a serious side effect which rendered her unable to have further treatment. Once again, there were no options left for Kate, but her tenacious nature saw her enroll in a clinical trial for a new medication. Today, Kate is being treated with oral DMT fingolimod (Gilenya®) and also takes other medications to help with spasticity, her most painful and unrelenting MS symptom.

Kate also weathered many storms through these years of living with RRMS, as her extended family struggled with grief and illness in other family members. As part of a migrant family, there was a sense of family commitment, with Kate vigilantly maintaining all of her family responsibilities, despite her own significant health issues. Kate also suffered significant injuries from a fall which has impacted her mobility in recent years. Since her employment contract was not renewed and Kate was forced to stop working in a job that she loved, she feels the great irony is that now she has the time to do things she enjoys, but sadly her body cannot keep up to do them.

Although Kate believes she is currently at a crossroads in her life, Kate remains a fighter. Kate isn’t after a miracle cure, instead she just wants to stay the same and not deteriorate further ...“if I can stay like this I’ll be happy”. Kate left a lasting

impression on me as an absolute powerhouse, as interested as she is in helping herself, it is for the many others also suffering that she goes the extra mile.

Participant number 4: Rudi's story

I've been through so much in my life, why more?

Rudi is married and the mother of four lively children and living in a country town, close to the community where she was born. Rudy was aged 42 years at the time of our interview and working part time in a local business, in a job that is “not very stimulating”, but affords her reasonable hours and is mindful of the fact that she has “bad days”.

Rudi recalls her childhood as difficult and sometimes it was very emotionally painful. Early in the interview, Rudi commented that she wasn't “going there”, however Rudi opened up as the interview progressed, and this openness helped me understand some of the childhood trauma she had been through. Rudi described living her childhood with an absent father and a mother suffering from mental illness. A self-declared rebellious teenager, Rudi left home at a young age, before returning years later. Tragically, in later years Rudi was also to suffer the stillbirth of her son, a time that she recalls as immensely painful...“not in my wildest dreams did I think that would ever happen”, continuing to experience much emotional pain.

Rudi was diagnosed with RRMS about 11 years prior to our interview at the age of 31. Working out with a personal trainer one day, she suddenly experienced a facial droop. Rudi immediately saw a doctor who wasn't concerned about the symptom. Nothing more happened until 4 years later when Rudi experienced an episode of facial numbness, which quickly developed into slurring of speech and limb weakness. She was rushed to hospital as it looked to others as if she had experienced a stroke. The symptoms gradually resolved over the next week. A subsequent MRI was performed and Rudi attended a visit to the neurologist for the very first time. She was diagnosed with focal migraines. Rudi recovered, although never completely, with some residual numbness down the left side of her body, she then sought a referral to a city neurologist. Rudi was diagnosed with RRMS at this first visit to the new neurologist. This diagnosis was based on Rudi's clinical history, neurological

examination and the MRI scans. Rudi commenced interferon beta1-b (Betaferon®) injections every second day almost immediately.

Rudi recalls feeling “very angry” after the diagnosis, specifically saying that “relief...I didn’t find that”. Rudi started treatment without wanting to learn more about the disease. Rudi’s mother went to visit the local MS Society and brought home brochures, which Rudi promptly threw in the bin. Within three months, Rudi was in the intensive care unit suffering another severe relapse, this time losing her speech completely. During this period in her life Rudi recalls “ I was sick for a very long time” with numbness, weakness and balance issues. Rudi was immediately escalated to the oral RRMS treatment fingolimod (Gilenya®). Rudi describes this time as very stressful for her young family. Several severe relapses over the next year and side effects from fingolimod saw another change in treatment to an oral DMT, dimethyl fumarate (Tecfidera®). Although her neurologist has suggested more efficacious DMTs such as natalizumab (Tysabri®) or alemtuzumab (Lemtrada®) Rudi says she’s not interested. From Rudi’s perspective, the potential side effects are just too dangerous with a young family.

Currently, Rudi looks forward to the future as her four children grow up and opening the door for more travel. Living with RRMS has encouraged Rudi to take more trips away, weekends with friends, and to start travelling more around the world... “I dream of that and I dream of me *walking* in that”.

Participant number 5: Joy’s story

Overcoming adversity beyond comprehension and returning to faith

Joy has suffered through many crises and health issues in her 57 years to the time of our interview, yet remains a strong, determined and courageous woman living with RRMS, while simultaneously defying and astounding her current health care team. Joy’s story invokes many feelings; sadness, shock, admiration and inspiration amongst them.

Joy was born in a small country town and her childhood story is one of unbearable pain and neglect, a time she sees as vital to making her the strong person she is today. Joy had limited time playing with other children due to “excruciating” pain, “I was so hypersensitive that she (mother) couldn’t even touch me, because with the pain it was like razor blades...I would wake up in the morning and I’d feel like someone had been beating me all night with a baseball bat”. She vividly recalls nights of screaming out from leg pain, which nobody believed, or if they did, could not put a name to. Joy recalls that her mother was labeled as having Munchausen’s syndrome by the local doctors, eventually nobody believed that Joy was suffering real pain, “they believed this is the child of the Munchausen’s mother, well of course she’s going to be a hypochondriac”.

Things came to a head when Joy was 16 and she developed a complex form of dyslexia overnight, not being about to read text type. Nobody believed Joy, and she left school at 16 years of age despite been dux of the school the year before. Unexpectedly becoming pregnant at the age of 17, Joy married, before developing several complications during the pregnancy including a terrifying loss of vision with no diagnosis. Joy suffered many other health care issues over the ensuing years and eventually her husband left her as a single mother. Joy then experienced further distressing and unexplained symptoms, including irregular periods of vision loss and deafness. Joy recalls that when she visited the local doctors, none of them doctors were interested in looking for a cause “they just didn’t believe me, I was a fruit-loop...they thought I was crazy and they weren’t remotely interested”. Joy later developed right-sided weakness, and reached a stage of utter despair when the doctors still did not send her for any tests or investigations, recalling the feeling that “it nearly broke me”.

Ten years after her first son was born, Joy gave birth to second little boy. Joy enjoyed a period of good health during this time with no further attacks of blindness, deafness or weakness. She continued to feel well until her second child was about five years of age, when “the fatigue and the pain...was just indescribable, sickening...my whole body screaming in pain, absolutely screaming”. The leg pain Joy had experienced as a child returned and was to become an everyday occurrence. Joy still had no explanation, diagnosis or a HCP who was interested in finding one.

Several years later, Joy remarried and with support from her husband, was referred to a neurologist. This neurologist subsequently diagnosed Joy with RRMS, Joy recalling, “they were amazed that no-one ever bothered to test me before”. Joy started on medication for the severe nerve pain and later glatiramer acetate (Copaxone®) daily injections as a DMT to treat RRMS. Joy then recalls feeling unwell and experiencing a “huge, huge reaction” where “I blew up to 3 times my normal body size, just huge”. Joy suspected her husband was poisoning her “my husband kept feeding me the medication (to treat nerve pain) and insisting...he would put the tablets in my mouth and I would pretend to swallow them and then I’d spit them out”. After about six weeks of pretending to take the medications, Joy eventually started to feel better and drove herself to the hospital for assessment by a doctor to find out for sure what was happening to her. Joy was diagnosed with medication toxicity. Joy believes that “I don’t think he necessarily wanted me to die...I will never know”. Joy stopped all medications at this point, including injectable glatiramer acetate to treat her RRMS.

An onslaught of migraines in the year that followed led to a referral to a new neurologist and more neurological testing. Joy was then diagnosed with complex partial epilepsy. The neurologist told Joy that there was no way of knowing if her previous symptoms throughout her life had been caused by RRMS, the epilepsy, or both. As Joy recalls “she said...how have you had any sort of normal life...how did you ever learn to walk and talk?”. Joy refused the offer of DMT to treat RRMS, preferring to take her chances on no treatment at all and avoid any side effects.

In the meantime, Joy’s home life was deteriorating, she was feeling constantly stressed, not allowed to take time off work when her MS symptoms were at their worst. Then, Joy’s husband died suddenly. Joy recalls that her husband collapsed “on top of me and squashed me so I couldn’t breathe”. This led to an intense few minutes where Joy experienced a surge of “I must live...that adrenaline surge...that kicked in because I was dying...I got myself out from underneath him, something...changed something in my chemistry...I started to improve...I made a heartfelt decision that I would get better...no matter what”.

Gradually, Joy began to gain independence and returned to the faith she had with God as a little girl. Joy believes she is currently enjoying life to the full, working full time in an advocacy role to help others. Joy is a grandmother and remains very close to both of her boys and their families. Looking to the future, Joy is not keen to take any medications to treat RRMS, “if they can’t come up with a cure...I’m not going to take anything that will make me sicker”. Joy’s message is that it is always possible to change, to make an effort to overcome difficulties and that it is definitely worth the effort.

Participant number 6 : Jane’s story

Losing what’s important to me, but looking on the brightside

Jane, aged 52 years at the time of our interview, has been living with RRMS for about 15 years. She has always worked in the field of education, is single, and has enjoyed travelling the world for both pleasure and work for most of her life. Jane currently lives with her father and is currently working part-time, still in the field of education, having recently attained a higher degree of which she is incredibly proud.

At the age of 37 years, Jane, who rarely saw a doctor, was troubled by a severe headache and consulted a local GP. The GP ordered some scans but did not provide Jane with a diagnosis. Not long afterwards, Jane suffered sudden vision loss when she was cycling and it was recommended that she see a neurologist. After several tests, the neurologist diagnosed Jane with RRMS. Jane recalls saying to her parents at the time “don’t worry about it...it’s MS” after initially being terrified of having a brain tumour. Jane elected not to take medication at this stage and decided to start her adventures overseas where she worked for many years. Jane came back to Australia regularly to see her family and to stay in touch with her neurologist.

Jane returned to Australia several years later following a severe relapse and began self injecting interferon beta1-a (Rebif®) for the next few years, feeling “disappointed” in starting therapy and beginning a time in her life which she recalls as “really, really, really depressing...I don’t think people realise how bad it makes you feel”. For about 4 years Jane didn’t do any exercise and stopped travelling as she

felt “like a drug addict” carrying her supply of interferon beta1-a needles around with her.

Finally, Jane was switched to the oral DMT fingolimod (Gilenya®) about two years ago and says she now feels “much, much better”. The swap to an oral treatment has opened up her travel options again and her horizons on life. Presently she is working part-time on the advice of, and with the support of, her manager who is aware of her RRMS diagnosis, a diagnosis which has not been disclosed to others in the workplace because she is worried about losing her employment due to RRMS. Support has been essential for managing her severe fatigue, by taking time off in the working week to rest. Currently Jane’s symptoms include visual disturbances, incontinence, hand weakness and balance issues.

Currently, Jane is planning for a future where she may need a wheelchair, but is not dwelling on it, continuing to travel independently. She still worries about “not being able to speak or read or write”; skills she needs to be able to do her job properly, but for now, working part-time in a profession she loves “is phenomenal”.

Participant number 7: Paul’s story

I am not going down with RRMS, I’m just not

A 37 year old married father of three young children at the time of our interview, Paul currently works in the travel industry. Paul greatly enjoys his working role it allows him to work from home, travel often and participate in outdoor and adventure sports whenever he can. Initially from a science background, Paul is interested in all things to do with RRMS, often reading science and medical articles and taking a very active role in his own care and treatment decision-making.

Paul recalls a trip to an ophthalmologist to investigate his initial symptom, blurred vision, about eight years prior to our interview and was told that he probably had a virus causing some inflammation and that his vision would go back to normal, which it did. A few of years later Paul woke up with trouble breathing and chest pain. Exhaustive tests were performed but no explanation was found. A further episode

occurred a year afterward when Paul describes feeling “psychologically not right”, a period of time where he recalls “literally a cloud...sitting in this cloud...I looked around and there was this cloud”. With no medical explanation for this sensation he was feeling, Paul was left wondering what was happening to him. Subsequently, his GP referred him to a neurologist who spent two hours with Paul, exploring his symptoms, conducting further tests and eventually diagnosing him with RRMS in 2014.

Paul recalls suffering significant anxiety in the immediate time following his diagnosis. Before starting on a DMT, Paul was admitted to hospital and seen by a second neurologist who unfortunately, negatively affected Paul’s life journey. Paul felt pressured into a research study by this new neurologist investigating an MS treatment. At that time Paul was feeling particularly vulnerable due to his recent diagnosis of RRMS, his anxiety, a recent relapse and a course of intravenous high dose steroids (which can affect mood and thinking). Despite his misgivings, Paul completed the research study assessments because he wanted his negative experiences at the beginning of his RRMS journey to count for something and to help others. Shortly after this experience, Paul began care at a new MS Clinic where he feels he has found great medical support, together with his local GP.

Paul has been discreet about disclosing his diagnosis, choosing to only tell his immediate family, no friends and only one work colleague. Paul feels that he wants to manage RRMS on his own terms and that disclosing to only a chosen and trusted few, gives him the control of RRMS he craves.

Paul’s main RRMS symptoms currently are leg pain, which he describes as “walking on ice in wet socks, crumpled wet socks”, and neuropathic pain that comes and goes. Paul manages his symptoms mainly by grinning and bearing it, and generally gets on with life each day. Although relatively stable on his current oral DMT fingolimod (Gilenya®), Paul has recently acquired a new brain lesion on his last MRI scan. With his science background, Paul voraciously reads science papers reporting on MS therapies and wonders if now is the time for a DMT change to a higher efficacy medication.

Paul has tremendous hope for the future with RRMS, reasoning that science has come along so far in medicine in recent years and that advances in other disease such as cancer will also help in MS. He continues to research new advances in MS and advocate for himself to receive the best care and DMT treatment that is possible. It is impossible to come away from meeting Paul without feeling the same sense of hope.

Participant number 8: Ruby's story

If I could turn back time, I'd do things differently for my children

At the time of our interview, Ruby was 38 years old, married, the mother of two young children and currently the main wage earner in her household. Ruby's husband has taken time off to care for the family whilst Ruby works full-time. Working in the field of education, Ruby is a passionate and finds great inspiration and delight in her work. Part of a small but involved extended migrant family, Ruby lives close-by to her relatives who provide much needed support as she works, manages RRMS and looks after her family.

Troubled by some leg cramps on an overseas trip about 14 years prior to our interview, Ruby didn't think much of her early RRMS symptoms, and certainly did not think they were significant at the time or the first presentation of RRMS. Further neurological symptoms of leg weakness and clumsiness several years later saw Ruby consult a neurologist and undergo tests, where she was informed that she had RRMS but not offered treatment at the time. Instead, newly married Ruby was advised to start her own family now and to come back after her family was complete to discuss further management. Two years after her diagnosis when her first child was still a baby, Ruby noticed pain and cramping in her arms, but put it down to physical work that she was doing at the time. Her symptoms worsened and could no longer be ignored. Ruby was subsequently seen by a new neurologist and started the DMT Tysabri® shortly afterwards, but her RRMS continued to progress.

Although it was still early in her life journey with RRMS, by this time Ruby had already gained significant disability, particularly in regards to mobilising and she was only able to walk short distances without help. Adding to Ruby's burden is that

she remains troubled by a decision she made four years ago, when deciding on a DMT after the birth of both her children. Due to concerns about safety and the potential for significant side effects, Ruby decided to take more conventional DMT rather than the more efficacious medication recommended by her Doctor. Unfortunately Ruby has gained considerable disability over the last few years and she feels as if the decision she made at that time, understandably based on fear, has negatively influenced the progression of her RRMS. The drug is now registered in Australia and Ruby has recently commenced the medication, alemtuzumab (Lemtrada®). Ruby has great hope that she will improve and return to living the life she wants, to be a more active mother to her little children.

Being diagnosed with RRMS has caused considerable heartache for Ruby. She misses simple things like walking to the local shops with her children for icecream without any planning or running around with them in the local park. Perhaps one of her greatest disappointments with RRMS is the pressure she feels it places on her husband, her children and on her extended family, “I just wish it wasn’t all about me”. Ruby would much rather be in the shadows and not the focus of family life. She still hopes that one day this may become a reality.

Participant number 9: Griff’s story

I’m a pretender to the throne

Griff was 62 years old at the time of our interview, and the married father of two teenage boys. Griff describes himself as a “house husband” caring for the family and home whilst his wife works full time in a demanding job. Initially trained in the public service, Griff worked for many years in a government job and believes he did very well in this position. Years later in his forties, he retrained and ran his own business, only to suffer a serious relapse of MS which led to his eventual diagnosis. This diagnosis and significant symptoms of fatigue, ultimately led to unemployment, and loss of the business. Griff has not worked outside the home since that time.

After a childhood fraught with unrelated lung illnesses, Griff experienced what he feels were the first symptoms of RRMS in his early twenties. He was hiking in the

snow and noticed that he had no sense of where his feet were in relation to his body and experienced weakness in his hands. He decided not to disclose this to his partner at the time and recovered over a few weeks. In retrospect, Griff feels he experienced many more short relapses of MS over subsequent years but was not seen by a neurologist or diagnosed with RRMS and until he was in his late forties. This was mainly because Griff did not report his symptoms or seek help for them from his family doctor.

A tumultuous few years followed Griff's RRMS diagnosis. He was commenced on the injectable therapy glatiramer acetate (Copaxone®) which he needed to administer to himself every day. Griff recalls that this became more and more difficult, he detested the injections and missed many doses. He later started on natalizumab (Tysabri®) necessitating a half day stay in the hospital clinic. These were the most stable years of Griff's journey with RRMS, he suffered no relapses, felt well on the medication and greatly enjoyed the clinic visits at the hospital. These hospital visits were his major social outings and finally gave him the social contact that he was craving. After several years Griff returned a positive JCV test which indicated that he was at a higher risk of the serious side effect of PML if he continued taking Tysabri®. Griff then transitioned to fingolimod (Gilenya®) and has remained on this DMT ever since. Although he has remained relapse free, he is still hopeful of a better and more effective treatment in the future.

Griff feels that RRMS has impacted greatly on his socialisation, largely due to not working but also from the severe fatigue he suffers. As his two children have become teenagers and require less help, Griff feels his days are "spent wastefully" and that he has been a less than optimal role model to his children who see him resting and tired most of the time. The second negative effect of RRMS on Griff's life has been in the area of sexual health. Griff discussed several times in the interview his disappointment that there doesn't appear to be the help available that he needs to deal with sexual health issues related to his RRMS, despite several attempts to do so.

A key event occurred shortly after Griff's diagnosis with RRMS, when he attended an event at the MSL to learn more about his new diagnosis. At that stage Griff showed no signs of physical disability and his major MS symptoms were all invisible

to others. Griff recalls that the mother of a severely disabled young girl in the same meeting “attacked” him, coming over to his group and yelling “What are you? You haven’t got MS!” This confrontation left Griff shaken and upset, although he did feel sorry for the mother in her situation. However, this experience has stayed with Griff over the years and has led to him sometimes feeling like an imposter to the MS world and a “pretender to the throne”.

Participant number 10: Will’s story

Fitting everything into life I possibly can...and then some

Will was born overseas and migrated to Australia in his late teens, before his diagnosis of RRMS in his mid twenties. He was aged 35 years at the time of our interview, and is the married father of two children, enjoying an active life with plenty of team sports and individual exercise.

Will experienced a traumatic childhood, after his single mother died when Will was in his teens, he was raised by his grandmother. After experiencing an episode of optic neuritis at 17 years of age, Will had some tests but never attended follow-up visits to find out results. Will travelled to Australia, where he started a new career. A few years later, Will was hospitalised for a number of weeks as doctors battled to diagnose his unusual neurological presentation. Will recalls feeling depressed during this time. Eventually, after several months, Will was diagnosed with RRMS by a neurologist who was consulted on his case. This neurologist continues to look after Will and provide significant support.

Following his diagnosis, Will began treatment with interferon 1-a (Rebif®) and things went along well for a short period of time, but not long afterwards, Will recalls becoming depressed again. He recalls how he lost his focus, quit his job and stopped attending his MS Clinic for follow-up. Very quickly things spiraled out of control and Will had worries for his own mental health and for his future. He called on his resilience from childhood and managed to stop the negative cycle he was in without any medical intervention. He reconnected with his MS care team, started on the monthly infusion natalizumab (Tysabri®) and began to enjoy good health, the

relapses stopped and “I just felt great”. Will started going out socially after months of staying at home, and started making a conscious effort to talk to others, he joined various sporting teams, made new friends and reconnected with old friends. Will then met his future wife and felt like he had true support, embracing positivity and a healthy future.

Will's continued on this journey to wellness, he was thriving on the new treatment, enjoying his new level of fitness and remaining relapse free for several years. The only thing Will did not enjoy about the hospital visits for his monthly infusions was meeting with other RRMS patients having treatment at the same time. Rather than bonding with them, Will kept a deliberate distance because he did not want to be around those with RRMS who wished to talk about their disease. Unfortunately after several years of disease stability, Will returned a positive JCV blood test which indicated that the natalizumab treatment was no longer safe for him due to a higher risk of PML, and so he stopped the treatment. Shortly afterwards Will commenced a new medication alemtuzumab (Lemtrada®), given in two annual cycles as an intravenous medication, also in a hospital setting. At the time of the interview Will was about three months post his first treatment cycle and still not feeling “back to normal”. However, Will is hopeful this new treatment will keep him healthy, active and able to play sport with his two children. Appearing fit, healthy and strong to others is very important to Will. In his words “I want to be able to tell my son (about RRMS), I don't want him to notice it first”.

Will's main symptoms currently include headaches, fatigue and numbness in his hands. He manages his symptoms and prefers not to discuss RRMS daily in his life. He has worked out a system with his wife, as he doesn't want to complain of his symptoms all the time, he will only tell her *sometimes*. For Will, this works and helps to keep RRMS in the background and happiness and positivity in the foreground. This is how Will wants to live with RRMS.

Participant number 11: Susan's story

Dreams really do come true, you just have to get through a lot first

Susan, 40 years old at the time of our interview, is married and a busy mother of one toddler. Susan works part-time in health care, a job she enjoys. Susan spends the rest of her time nurturing her family. After many years of being single and worrying about her future, Susan met her partner and married at the age of 37 years, she describes her dreams coming true when she later gave birth to her cherished little girl.

Susan began her journey with RRMS in her twenties when she suddenly experienced sensory lower limb symptoms whilst at work. She initially blamed sleep deprivation for her leg numbness, but soon realised that something more serious was happening. Susan sought help from her GP who refused to refer her for assessment and testing, even though Susan was a HCP herself and had specifically requested a referral to a neurologist. Susan realised her symptoms were serious and neurological in nature. Finding help elsewhere, after many tests, and several months of waiting, Susan was eventually diagnosed with RRMS. Susan was living at home at the time and her parents were devastated at her diagnosis, her father in particular blamed himself for her illness with Susan suffering substantial grief watching him try to make sense of what was happening. This led to several years of struggle where she sometimes felt that she would never find a partner to share her life with. She believed it would take a special type of person to accept her diagnosis of RRMS and the uncertainty that goes along with it.

Starting with an injectable interferon 1a treatment soon after her diagnosis and later glatirimer acetate (Copaxone®) daily injections, Susan managed her early DMT years well. She suffered three relapses over the next ten years but recovered well physically from each relapse. She gradually progressed to an oral DMT, dimethyl fumarate (Tecfidera®) in later years and has been relapse free now for some time. Susan had some issues with becoming pregnant and sought the help of a fertility specialist, which resulted in the birth of her only child. She had to remain off DMT for a period of time during the preparation for and during pregnancy, but remained free of relapses.

After struggling emotionally for many years living with RRMS, Susan embarked on a counseling course, which changed her life for the better. She learnt skills with a

group of other people, not with MS but other mental health issues and illnesses, which has transformed her approach to her own illness. Susan applied her new learning and thought processes to her life with RRMS. This changed her mindset from “struggling” to a “can-do” attitude and more confidence. Susan feels this attitude helped bring her future partner into her life and saw the start of her dream to be a wife and mother become a reality.

Currently Susan feels well, remains positive and is excited about her future. Susan continues to work as a HCP and has embraced the learning she has from living with RRMS to apply to her HCP practice, teaching people how to live better with chronic illness. Susan also encourages and helps those newly diagnosed with RRMS by speaking with PwRRMS experiencing difficulty. Susan advocates living healthily, maintaining a nutritional diet, continuing exercise and paying attention to mental health, Susan lives this by example.

Participant number 12: Davina’s story

A second chance at love, support and happiness

Davina was aged 55 years at the time of our interview and has worked as a HCP for most of her life, a role she greatly enjoys. Davina was due to be married a few weeks after our interview and she was very excited at the prospect of her future. Several years prior, Davina had divorced the father of her four adult children, after a tumultuous marriage that was marked by many years of little support, accentuated by her husband’s lack of insight and understanding into RRMS.

Davina was diagnosed with RRMS shortly after her first marriage, when she was in her very early twenties. Davina had just received news that she was accepted into a course and was to embark on a new career. A few days later she developed her first MS symptoms, sensory symptoms along her spine and leg weakness, and was taken to the emergency room and admitted to hospital. After several days she was given the news that she had RRMS and was devastated at the way she was told, by a specialist at the end of the bed who told her that she “likely had MS” and “if children were something you were thinking about, it’s better to be a disabled younger mother

than an older one". Davina was devastated, she withdrew from the course she had dearly wanted to complete and sadly received little support from her husband throughout the early years after diagnosis. Following the specialist's comments about starting a family, within a year, Davina had her first baby, then three more children. Although these years living with RRMS and with four children were very demanding, Davina recalled that being a mother gave her the wonderful feeling "that I was finally good at something".

Davina suffered occasional relapses during this time, but always recovered back to her usual function. There were no DMTs available when Davina was first diagnosed, but in later years she commenced an injectable interferon, interferon-1a (Avonex®) as soon as it was registered in Australia, which she remained on for over a decade. Only recently has Davina switched to her first oral DMT, fingolimod (Gilenya®). This was a difficult decision for Davina, although she had felt miserable from side effects self-injecting, she persisted for many years because she felt "safe" taking the medication. The thought of new, oral tablets was attractive, but she was fearful of the unknown side effects on her body and resisted changing therapies for a long time. Although happy with her decision, she still is mindful that things could change at any time. Davina has been relapse free now for several years but still suffers significant fatigue and Uhthoff's phenomenon (a temporary recurrence of earlier relapse symptoms due to heat, infection or stress) from time to time.

Davina's early years living with RRMS were also marred by her extended family arguing over whose fault it was that Davina had developed RRMS. They searched for a genetic link because Davina had a close relative with MS who had been wheelchair bound and eventually was placed in a nursing home, the family refusing to acknowledge that he had MS to others outside the family. This refusal to acknowledge the disease left Davina feeling unsure and vulnerable within her own family unit. Although Davina's mother was very supportive, Davina's husband and father regularly contributed to her sense of low self esteem and loss of confidence, often refusing to believe her invisible symptoms, such as severe fatigue. On one occasion her husband ridiculed her in front of the children when she was extremely tired, telling her "don't play that MS card again". Her husband never attended

medical appointments with Davina and did not want to know anything about the disease. Davina's mother was her primary, and often sole, support and cheerleader.

After many years of struggling, meeting her new partner has instilled a great sense of hope for Davina in her future. Davina was formally diagnosed with depression a decade ago, but had resisted counselling and medication for her mood disturbances. However, recently Davina has sought psychological counselling and feels she is more positive in terms of both mood and attitude to life. Davina looks forward to the future, has supportive, loving relationships with her adult children and believes that she has a life partner who understands and supports RRMS. Davina is keen to do as much as she can living with RRMS, whilst she can.

Participant number 13: Evie's story

RRMS, you can run but you can't hide, I'm coming to get you

Evie is a vibrant, strong and fit campaigner, acting as an advocate to others about her life living with RRMS. At the time of our interview, Evie was 38 years old and living with her partner, had never married nor had any children. Evie's career has always been very important to her. She works for a government agency and because of her covert occupation, I have to be very careful about personal life details in this narrative, and unfortunately have to leave out some relevant details because of this situation.

Evie experienced a turbulent childhood, suffering various respiratory and allergic conditions and she recalls being bullied at both school by classmates, and at home by her father. Evie's first MS symptoms started in her late teens just after she finished school. Troubled by sensory symptoms in her hands, she then experienced changes to her gait, which were noticeable to others and she was referred to a neurologist. Over the next two years Evie had extensive testing, without a conclusion, but after another relapse was subsequently diagnosed with RRMS. Despite her young age, Evie took the diagnosis in her stride, understanding fully that she could do well with RRMS, or "she could bomb". Evie has had an extremely challenging journey with the disease,

suffering well over a dozen relapses since her diagnosis, several of the relapses being very serious and requiring hospitalization.

Eventually when it became available, Evie commenced on her first DMT, an injectable interferon beta 1-b (Betaferon®). She describes it as a time which made her unhappy due to this “God awful drug”. Evie stopped taking the medication, preferring to be on no DMT for several years than to experience side effects, but after several serious relapses she felt compelled to restart treatment. Evie was happy when natalizumab (Tysabri®) was introduced, attending a hospital infusion clinic monthly for the treatment and being relapse free, and almost completely symptom free, for many years. During this time, she was in the best physical condition she had been in many years. However, after several years, natalizumab needed to be stopped after a positive, high titre blood test for JCV revealed that Evie was at considerably high risk for the side effect PML. Evie then progressed onto an oral therapy dimethyl fumarate (Tecfidera®), but she suffered a significant increase in disease burden in a very short period of time. Subsequently Evie commenced the new monoclonal antibody infusion alemtuzumab (Lemtrada®). Having recently completed the second of the two annual cycles of alemtuzumab Evie is still waiting to see if the treatment has been effective but is extremely positive about her condition and hopeful for the future. Evie strongly believes a cure *will* happen.

Currently, Evie’s main symptoms are fatigue, Uhthoff’s phenomena, gait instability and occasional episodes of motor weakness. Despite her many serious relapses, Evie is grateful that her vision has remained relatively unaffected and so she has been able to continue in her working role. To Evie, this is a saving grace of RRMS.

Despite her advocacy for MS, Evie still has times when she would prefer to be known for other things she does than being someone who lives with RRMS. Evie is passionate about showing the bright side of MS and regularly participates in sports and riskier pursuits such as skydiving and rock climbing in order to prove that you can do anything with RRMS. She wishes that these moments were the ones captured and advertised for people living with MS rather than showing people in wheelchairs or with significant disability. Evie is a strong believer in doing everything you can, whilst you can, and has refused to be labeled as only a person with MS. Despite her

significant disease burden, Evie participates in life to the full and is committed to showing MS in the best light possible. Meeting Evie made me, and I am sure others, feel the same.

Narratives and further findings

The life stories presented in this chapter highlight the diversity of the study participants, and contextualise their individual suffering, their joys, their strength and their resilience living with RRMS. Each story offers so much to MS Nurses to gain insights into living with RRMS. Each story has a unique perspective about things that have happened along the life journey, independent of RRMS, which may affect the life lived with RRMS. Ultimately, the narratives display a sense of hope, despite the many life challenges the participants have experienced.

The next two chapters will present and discuss the study findings as themes and related subthemes. Each theme will be introduced individually and then be supported with direct quotes and stories from the participants to support the analysis. This is where the participant life stories presented in this chapter will support the more formal study findings, allowing the reader to have some appreciation of the lives of the participants and their journey, in order to better understand the themes abstracted from the study data. Understanding the journey of the study participants also makes the experience more personal and allows a more intimate connection with each story, a concept very much in alignment with qualitative research methodology and with the ontology and epistemology of the current study.

CHAPTER 6 – STUDY FINDINGS: “WALKING THE LOW ROAD”

Following on from the narratives in the previous chapter introducing the study participants with their life stories, this chapter presents the first five of a total of eight themes developed from the study data analysis and findings. The five themes comprising this chapter titled “Walking the Low Road”, reflect the difficulty, struggle, hardship and a redefinition of self following a diagnosis of RRMS. Although this chapter is mostly a story of challenge, there are some key moments of positivity, of finding hope and of moving forward with optimism and with anticipation. Hints of what is yet to come. In the early years after diagnosis these times of positivity seem to be frequently interwoven with times of struggle, especially in the very early days after a diagnosis of RRMS. However, as the story progresses, PwRRMS develop their own set of expert skills in managing RRMS and work towards a better future living with RRMS. There are suggestions of this in Chapter 6, but these skills really came to the fore in the following chapter “Finding the High Road”, as study participants identified key ways in “Taming the Beast”, as they shared their experiences living with RRMS.

This chapter Walking the Low Road, consists of five themes, each possessing its own *central organising concept*, as suggested by Braun and Clarke (2006, 2013) to succinctly outline the inclusions and boundaries of each theme. Themes have been categorised into subthemes and sub-subthemes to further clarify and highlight specific areas and concepts related to the overarching theme. A discussion of each theme will follow, interwoven with what is known from the MS body of knowledge to further introduce, explain or justify the concepts. Quotes from the participant transcripts will demonstrate the grounding of the themes in the study data and provide support to the theme development. The participant quotes are *italicised* and will be documented by the line number the quote commenced in the transcript. If data unrelated to the theme was then discussed within the quote, it will be left out and be represented within the quote by three ellipses (...) in the transcript text. Often participants would discuss a concept, go on to something else and then come back to

the original thought. As the quotes are taken out of context, if any clarifications on exactly what the participant is referring to are needed, they will be placed within brackets in the quote. As per APA guidelines, each developed theme will only be in “quotation marks” until explained. Table 4 demonstrates a summary of the themes, subthemes and sub-subthemes comprising Walking the Low Road.

Table 4. *Summary of themes one to five of the study findings; demonstrating central organising concepts, subthemes and sub-subthemes developed from the study data.*

Theme	Central organising concept summary	Subthemes	Sub-subthemes
1. Piecing Together the Puzzle	Experiencing or dealing with the initial neurological symptoms, seeking help for them, undergoing tests and being told the diagnosis of RRMS	What’s happening? Pieces start to form Tests, tests, tests (the puzzle starts to come together) The puzzle is complete (the day my life changed forever)	<ul style="list-style-type: none"> • Seeking help • “Brushed off” • Exposure to vulnerability –as the pieces form • Vivid recall of the diagnosis • Relief at the diagnosis • Disclosing to others • With-holding disclosure
2. (Re) defining Me Now That I Have RRMS	Making sense of the world with a diagnosis of RRMS, working out how to manage life, family and community, balancing the losses and the gains	Getting acquainted with RRMS Dare to compare Negotiating normalcy, disability and independence Working out work Parenting with RRMS	<ul style="list-style-type: none"> • I think I’m normal, aren’t I? • How others see me • Maintaining independence • To be or not to be (a parent) • Breaking the news to children • Impact of RRMS on parenting • Parental losses • Joys of parenthood

		Balancing losses and gains (my life plan (re)defined)	<ul style="list-style-type: none"> • Battling losses • Accepting gains
3. Battling the Demons	The battle of negative or difficult emotions that can get in the way of life enjoyment, threaten vulnerability and steal away joy	<p>Facing fears</p> <p>Weary with worry and anxiety</p> <p>Depression and despair</p> <p>Struggling with the saboteurs</p>	<ul style="list-style-type: none"> • Fear of symptoms/relapses • Fear of DMTs & side effects • Fear of progression/disability • Fear of the wheelchair • Worry about being a burden to family • Existing with Anxiety • Dealing with depression • Face to face with despair and hopelessness • Coping with uncertainty • I'm never free from RRMS • Social isolation
4. Surplus Suffering	Suffering over and above that imposed by the diagnosis and disease state of RRMS and often inflicted by others	<p>Surplus Suffering inflicted by HCPs in clinical care</p> <p>Surplus Suffering inflicted by "brush-off"</p> <p>Surplus suffering inflicted by HCPs in research care</p> <p>Surplus Suffering inflicted by family, friends and community</p>	
5. High (In)Visibility	The presence of invisible symptoms which cannot be seen by others and cause chaos and misunderstandings, but may also provide a refuge from chronic illness	<p>Striving to make the invisible visible</p> <p>When my RRMS isn't enough- reverse stigma of RRMS</p> <p>Invisibility as a welcome cloak- the downside has an upside</p>	<ul style="list-style-type: none"> • Please see me • Exposing the "secret one" • I'm not enough MS for you, devaluing the impact • A "pretender to the throne"

Theme 1- “Piecing Together the Puzzle”

It's silent, it's dark

I try to sleep but the burning pain stops me

Where is this coming from?

This pain stopping me being able to see

Do I get some help or see what happens?

Risk sounding silly and complaining

Or hope it goes away

It goes away, there it goes, it settles again

I no longer have to worry

Hold on... back it comes

I'll need a day off work again

They will wonder what's wrong with me

The problem is...I don't know

What you say, what is this?

It is MS, of that they now are sure

What does that mean, how will things be?

Regarding that, no-one can tell me

I don't know what to expect

How to act, what to do

What's going to happen, what's true

But I'll keep going, keep getting up

And hopefully I'll get through

TB

The **central organising concept** for the theme “Piecing Together the Puzzle” is the participant’s recall of experiencing initial neurological symptoms, seeking professional help, undergoing multiple tests and finally being told that RRMS is the most likely diagnosis. The theme is anchored by the notion that diagnosing RRMS is essentially about putting together a puzzle piece by piece, as symptoms are initially often vague and remitting in nature. After confirmation of the diagnosis, the theme

then explores dealing with the immediate aftermath and impact of the disease. Often the journey to diagnosis involves exposure to intense vulnerability, and for some, involved long periods of waiting time before an answer was given. Most study participants vividly recalled the day they were diagnosed formally with RRMS, dealing with their own feelings and emotions and also negotiating disclosure of the diagnosis to others. The theme of Piecing Together the Puzzle involves three distinct subthemes as the puzzle starts to materialise and progress: “What’s happening?” (pieces of the puzzle start to form), “Tests, tests, tests” (the puzzle comes together) and “the puzzle is complete” (the day my life changed forever) the first and third subthemes having several sub-subthemes to provide further clarity.

The time prior to a diagnosis of RRMS is often burdened with challenges, with research suggesting that the period from the onset of symptoms, to when diagnosis is delivered is a time where communication challenges between PwMS and HCPs are particularly heightened (Thorne et al., 2004). This was certainly the case in the current study, where almost all participants faced challenges communicating with various HCPs, including family doctors [known in Australia as General Practitioners (GPs)], along their journey to the diagnosis of RRMS. Participants were desperately trying to make sense of strange and frightening symptoms, and often went on to seek the help of a GP, who may or may not have been actively thinking about or aware of the symptoms of, a diagnosis of MS. The diagnosis of MS is always challenging and generally there may be poor awareness of MS by GPs (Hinton & Kirk, 2015).

The vagueness and intermittent nature of symptoms also plays havoc with the diagnostic process, patients seeking help to legitimise their symptoms and the HCP trying to piece together the puzzle, sometimes on very limited evidence. For several of the participants in the current study, the process of being investigated for, and diagnosed with RRMS, was viewed as traumatic and left a lasting impression. During our interview, several participants cried or became distressed as they recalled the time of diagnosis, and some participants were visibly distraught. For some of these participants, the diagnosis was decades prior to the study interview, but they recalled the event in fine detail and with much emotion.

What's happening? Pieces of the puzzle start to form

Recent research from Hinton and Kirk (2017) in the field of paediatric MS found the process of diagnosing MS to be lengthy and frightening, with the involvement of multiple HCPs, each giving conflicting opinions, different labels and expressing professional uncertainty, further intensifying parental anxiety in the possibility of the diagnosis. Uncertainty was a recurring theme, and similar to many participants in the current study, making sense of being ill and experiencing symptoms without a definitive diagnosis was difficult. Interestingly, previous work has also reported that PwMS had trouble differentiating MS symptoms from routine ailments and found it difficult to know exactly when to go to the GP for advice, regardless of the severity of their disease (Moriya & Suzuki, 2011).

Pieces of the puzzle were the little clues that something was amiss, but usually in the beginning never progressing to the thought that this could be a sign of a chronic neurological disease. Usually, but not always, the initial symptoms (the first pieces of the puzzle) were sudden in onset, were vague in nature, stayed around a little while and then disappeared. They were not severe enough to prompt a visit to the doctor or to seek help at that point, but nonetheless they caused some worry for many participants as they described feeling “different”. At times, participants wondered if they were imagining symptoms, self-diagnosing that they were sleep deprived, too busy or too stressed at work. Sometimes symptoms were forgotten about, only to resurface as memories at a later date when HCPs questioned directly about vague and unexplained symptoms in the past. Participants such as Ruby suffered vague symptoms at first, Ruby’s symptoms coming on after a plane trip which led to her reasoning that the sensory leg symptoms she was experiencing were related to flying. Ruby did not to seek medical help for some time after this first event.

*One of my first symptoms...the calves got very tight and tingly and numb...that lasted a couple of years...I thought it was just the flight...because it happened on the flight...then when I got home I could walk fine, it was just uncomfortable...it must have been a year...two years...the first sign that things aren't going quite so well.
Ruby line 288*

Others experienced long periods of remission after the first symptoms disappeared, times of silence and seemingly, no connection between the various symptoms. Paul did not link any symptoms of the “funny” episodes he was experiencing, mainly because they occurred several years apart. The medical staff Paul had consulted along the way did not link the episodes together either.

*I had L’hermitte’s (an electric shock-like sensation along the spine when moving the neck forward)...it only lasted a couple of days...but it was a really funny feeling...a bit odd...it lasted a couple of days and disappeared...a couple of years later I had optic neuritis and it (my vision) just went completely white...I went to the ophthalmologist and he gave me some prednisone...he said it was probably a virus.
Paul line 15*

Susan described initially being a bit concerned with the sudden onset of her first neurological symptoms, but made a self-diagnosis of sleep deprivation as she had been working on night shifts.

I was at work one night and I thought my legs feel funny, it’s a bit numb at the calf...maybe I just need to sleep...it went on for a few days. Susan line 151

For some, the background pieces of the puzzle, the symptoms, became harder to disregard. For others, new symptoms, new puzzle pieces, appeared and could not be ignored due to their intensity and severity. For many participants in the study, this was the time that they decided they had to tell others about the symptoms they were experiencing and to seek help. For many, the GP was the first port of call, and then participants described the response as being “brushed off” by being ignored or the symptoms minimalised, left in a holding pattern with recognition but no plan to investigate further, or referred on to a neurologist.

Seeking help

Most participants were stalled at the start of their MS journey for varying periods of time, but eventually found a HCP who recognised that RRMS might be a possibility and referred them on appropriately. Very few study participants were fortunate to be

referred on early to the appropriate professional and begin the journey to a RRMS diagnosis promptly. After initially seeing her own GP who trivialised her symptoms, Susan sought alternative help for her vague sensory symptoms from an acupuncturist, who gave the help she needed. The acupuncturist (also a GP) realised there something serious was happening, refused to treat her with acupuncture, but referred her on to a neurologist. Piper had been unsuccessfully trying to have her vague symptoms diagnosed for many years with local GPs in her country town, but exasperated after yet another neurological event, sought advice from a HCP girlfriend who immediately recognised what this could be.

(for help with sensory symptoms) I went to this acupuncturist, an old Chinese man...he said I'm not going to touch you, I want you to go and see a specialist...a neurologist...and I said "I've been going to my GP and he's not listening to me, he thinks nothing's wrong with me" ...the acupuncturist was also a doctor and referred me on. Susan line 176

I called my girlfriend, she was a doctor...she straight away said..."it sounds like MS to me...I can't believe nobody has sent you for an MRI" ...(she referred me to a neurologist) and she (neurologist) diagnosed me straight away...I was probably lucky...a lot of people have to wait years and get pushed around from pillar to post. Piper line 556

"Brushed off"

"I was becoming more and more anxious, knowing there was something wrong but people were just brushing me away". Piper line 506

Almost half of the participants in the current study described being “brushed off” in their initial encounters with HCPs, meaning that they presented and described their symptoms, but weren’t taken seriously or investigated any further. The term “brush-off” is more formally defined as rejection or dismissal in which someone is treated as unimportant (Oxford dictionary, 2017). For several participants, this was their first encounter with the hospital/medical system and they simply did not have the health literacy or the awareness to request and insist on investigative tests or a second

opinion. Health literacy is a multidimensional concept referring to a person's ability to acquire, understand and use information about health and health services (Batterham et al., 2016). Health literacy is important as people possessing health literacy often have better health outcomes than people with low health literacy (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011), a skill which could effect the entire life journey living with a chronic illness such as RRMS. Participants in the current study already possessing greater health literacy moved on quickly to other HCPs after initially being brushed off, and were subsequently diagnosed with RRMS not long afterwards. Other participants tried to help themselves when told nothing was wrong by their HCP, by increasing or decreasing exercise, changing work hours, reducing stress, anything to help the strange and unexplained symptoms they were feeling.

Recent studies in adults exploring the diagnostic period and diagnosis delivery in RRMS are lacking, although some recent paediatric studies exploring these themes have shone much needed light on this topic. Hinton & Kirk (2015) explored the life experience of children with MS and found that many early symptoms of MS are misinterpreted, because they are vague and non-specific in nature. Parents began to feel unease as symptoms returned and the realisation struck that something might be wrong with their child. Communicating these concerns to HCPs was met with a variety of responses, some meeting expectations to investigate symptoms further and others not. Parents also expressed difficulty in communicating symptoms that were intangible and without physical evidence (headache, sensory symptoms) and many felt as if they were dismissed by the HCP. These findings present a very similar pattern to some of the adult participants of the current study.

Piper suffered for many years struggling with her unexplained and undiagnosed symptoms, her situation exacerbated by living in a small rural town where there was a constant stream of GPs coming in and out for short periods of time, offering little continuity of care. Piper describes being regularly brushed off by the GPs when she presented with her symptoms and how it made her feel. At times she felt like she was "going crazy" and spent many sleepless nights during a severe relapse just prior to her RRMS diagnosis, worrying about what might be happening to her.

You feel like a hypochondriac because you are always at the doctors and nothing ever found. Piper line 251

The doctor said “there’s nothing wrong...you know, go away”...I went to a few doctors actually...I feel like a fraud because I can feel these things...I’m not dreaming it...I was really struggling to grip and turn...no strength and I was told it’s cold, because this is winter go home and put some gloves on...it actually makes me cranky because I’m not making it up...I know what’s normal. I said” I think there’s something neurologically wrong with me” and she said “no there’s not, there’s nothing wrong with you”...new doctors would come and do a 12 month stint and move on...I feel like a fraud because I can feel these things...I’m not dreaming it. Piper line 407

Susan, a HCP herself, consulted her long time family GP and requested a referral to a neurologist on numerous occasions, but her GP ignored her symptoms and did not provide the referral.

(My GP) he’s not listening to me, he thinks nothing’s wrong with me and I’ve asked him “could you send me to a specialist because I think something’s wrong” but he kept pushing it aside saying “no, you’re fine, you’re fine”. Susan line 184

Margot also felt like she was not listened to when seeking help for continuing vague sensory symptoms in her legs. She had waited a long period of time, firstly for an appointment with the neurologist, and then for an MRI scan. Margot was keen for some answers to explain what was happening.

I saw him (neurologist) and he said “there are a couple of spots on the spine...so I think it’s a virus” ...in hindsight, as if he patted me on the head, well off you go, nothing wrong with you, it’s only a virus. Margot line 309

Joy had experienced a childhood where her mother had taken her to the doctors repeatedly for her many symptoms, but her mother was known in their small town as a “Munchausen’s mother”, so Joy felt the backlash of that label as she tried to piece together the puzzle of the mysterious symptoms plaguing her. She feared nobody

would ever take her seriously and investigate what was happening; in the end she gave up and lived in silent agony for many years.

I was sick...and they just treated Mum like she was a Munchausen's mother...they thought she was crazy, so when I went to the doctor's and said "I'm sick" they just believed that this is the child of the Munchausen's mother, well of course she's going to be a hypochondriac. Joy line 375

The form of brush-off discussed in Piecing Together the Puzzle relates only to the time in the lead up to the RRMS diagnosis. The concept of feeling brushed off will be explored again in a later theme "Surplus Suffering".

Exposure to vulnerability as the pieces form

Previous studies in the adult population of PwMS have supported the theme of vulnerability when dealing with MS, which was also experienced by many of the participants in the current study. Isakkson et al. (2006) used content analysis to investigate the illness experience of PwMS from onset of symptoms to diagnosis, interviewing 61 PwMS (type not specified). Findings from the study revealed that when initially diagnosed, most PwMS perceived disablement and death to be their future with MS. The lack of efficacious MS DMTs available over a decade ago may have strongly influenced this perception. Participants in that particular study also reported that MS was a disease that no-one talked about after the diagnosis. It is possible that the changed perception nowadays to openly discussing the disease is because of current levels of patient education, internet availability of accurate and up-to-date information and social media support. However, participants in Isakkson et al.'s (2006) study did report that the period from symptom onset to diagnosis was stressful, exposing them to immense vulnerability, as most of the participants in the current study also experienced. It appears the concepts of a decreased time between symptom recognition and the introduction of DMTs have not changed these feelings in this population.

For several participants in the current study, the onset of symptoms provided the PwRRMS their first experience in hospital or with specialists, and many were

overwhelmed by this experience and felt intensely vulnerable. Participants felt anger and mistrust when they felt they had not been taken seriously or brushed off with a dismissal or a psychosocial explanation. However, other participants felt confidence in the HCP when they were treated kindly and offered support through the process. An earlier study found that many PwMS were treated for depression and emotional issues prior to their diagnosis, and it was common for PwMS to feel like they were “going crazy”, were hypochondriacs or that they were imagining the symptoms (Russell, White, White, & Parker, 2006). For some participants, just the validation that they weren’t “going crazy” and that something was physiologically wrong, was all the support they needed.

The early days of unexplained and strange symptoms led to intense vulnerability as several study participants struggled with whether to let anyone else into their world and share the load of worry, or whether to just keep pressing on and hope things would settle down. Periods of symptom remission often confused them and made it hard to work out what to do, if anything. Alternatively, for participants such as Piper, earlier visits to the doctor without any resolution had led them to feel that they weren’t coping with life and the fault lay firmly within them.

I got to a point that I remember laying in bed one night...I was becoming more and more anxious with it, knowing there was something wrong...and I said “I really think I’m going crazy...I must be going crazy like the doctor’s think I am”...in the end I gave up almost...they can’t find anything wrong. Piper line 506

Even with intense and dramatic symptoms, some participants reported that they kept things to themselves, worried they would expose their vulnerability, not be believed or not be able to explain their symptoms well enough to be understood. Participants described how the symptoms could be frightening and scary, occur without warning and leave most of them clueless as to what could be causing the symptoms. Trying to pretend nothing was wrong and keep the symptoms secret from her work colleagues failed for Davina, exposing her to intense vulnerability when the symptoms suddenly took hold.

So, a year to the day (after the first relapse) I was at work again and every time I bent my head...I got this strange sensation down my back and in my feet...and I ignored it...and I felt like I had a really tight belt on...it just got...worse...and they had to put me in a wheelchair and take me to emergency. Davina line 410

After initially seeking help, the investigative phase also led to feelings of vulnerability for participants, wondering what it could be, what was happening or what they possibly did to cause the symptoms. Many participants recalled this period in their lives, expressing emotional pain and distress, at being given no immediate answers to quieten their minds. Susan, working as an HCP, intrinsically knew something was wrong whilst she was undergoing nerve tests and feared the symptoms were a result of something she had done, she wasn't told the diagnosis for several weeks after testing.

I got in and they said...well, something's not right here...and they got a doctor to come in...but they would not say anything to me, everything was hush hush and I could tell something wasn't right...and I thought...did I do something when I bunjee jumped?...I was so scared. Susan line 219

Other participants put the symptoms aside as they remitted and forgot about them and moved on with life, not sharing their experience with anyone else. At the age of 18, Will had some initial tests after some neurological symptoms but never went back for follow-up after his first episode resolved and never told anyone else about them. As a teenager with no parents and little close family around him, he felt vulnerable and uncertain without close support of others.

I never went back for results...I forgot all about it...had I followed up back then probably I would have been diagnosed much earlier...but just...young...naïve...there was always something in the back of my mind that something was wrong...in my early teens I could always run but if I stopped, I couldn't run again...I am telling my foot to do one thing but it's not doing what I'm telling it to do...I never told anyone about it. Will line 506

For those lucky few participants (such as Jane) who were sent to an MS Specialist neurologist early on in the journey through the medical system, there was mostly a rapid diagnosis of RRMS made and a treatment plan commenced. For several participants, specifically Rudi and Davina, being transferred to a specialist caused further frustration as they were brushed off yet again, or sent on their way with no real answers or guidance.

(the neurologist told me) “your symptoms sound like it might be MS...but it isn’t conclusive...before we go any further, you’ve just married, have your family and once you have children, come back and we will do the next phase”. Ruby, line 49

He (the neurologist) told me I was a textbook case of optic neuritis and a severe one...he said he knew I would go home and look it up, and that it was a symptom of MS...but I wasn’t to panic because I had no other indications of it. Davina, line 389

Tests, Test, Tests...the puzzle comes together

Although diagnosing MS earlier is advantageous (with efficacious DMT choices to alter the course of the disease), it is more important to be correct in the diagnosis (Giovannoni et al., 2016). Meticulous care should be taken to exclude the many conditions that mimic MS, and this can take time and patience (Aliaga & Barkhof, 2014), which is hard to explain to a patient experiencing symptoms. What is now emerging is that MS has a variable and sometimes long pre-symptomatic phase of years, potentially decades, and this may include a significant amount of cognitive deficit (such as issues with information processing and memory) (Giovannoni, 2016). Possessing cognitive deficits could also hinder PwRRMS in coping emotionally with the long and arduous diagnostic process because of these issues with information processing. However, a frank discussion from the HCP and MS Nurse about the reasons for the careful and thorough testing at the beginning of the journey could potentially change the goals of the journey for PwRRMS and significantly lighten their emotional load.

For some participants, the constant stream of tests and more tests was a trial in itself, trying to find the elusive answer to what was happening. Many participants recalled

this time as challenging and difficult as they played a game of test, wait, doctor, another test, more waiting, another test, doctor again and hopefully, but not always, an answer. Evie, Paul and Will describe the ongoing barrage of tests over extended periods of time, which still did not always conclude in a definitive diagnosis.

My GP said...straight to a neurologist...go...then that led to two years worth of tests, which are just the worst...lumbar punctures and electrode tests. Evie line 525

(I took myself off to the hospital to have it checked out) I ended up having an angiogram, I had a colonoscopy, an endoscopy they did everything to find out what's going on...(with no answer), but I went back to the doctor and said "something's not right" ...Paul line 63

I was in hospital for 4 weeks, I wasn't recovering...I was having MRIs, tests...I was diagnosed with sarcoidosis...nothing was happening...then I had test after test...biopsies behind the eye...it was just so hard...I had a breakdown...I hid it from everybody...I was released from hospital without a diagnosis. Will line 683

Piper describes having numerous tests done but they were not appropriate tests to determine a diagnosis of MS. She had test upon test, but never once a simple neurological examination, even though the majority of her symptoms were sensory in nature.

I had all the tests under the sun. Piper 131

I've had everything and they can't find anything wrong. Piper line 259

Because she (diagnosing GP) did a lot of the neurological things that the neurologist would do...nobody had done any of that to me, nobody had checked for sensitivity. Piper line 573

Other study participants suffered the opposite experience, with no investigations what-so-ever. Joy pleaded for most of her life to be investigated, when she developed new symptoms and when she experienced blindness and deafness, but to no avail.

Finally, there was one participant, Rudi who had testing completed but the results were either ignored or misunderstood by her HCP. Rudi recalls reading her MRI report herself and noting the comment that it was likely demyelination given her age and sex, and yet was diagnosed with migraines and sent away, only to be diagnosed with RRMS years later after a relapse so severe she was admitted to intensive care.

They couldn't work out what caused it (blindness) they didn't really do a barrage of tests, they couldn't understand, again, they didn't believe me. (and later on) they weren't really interested, they didn't believe me...I was a fruit loop, they thought I was crazy. Joy line 130

Even though the MRI report indicated that I had lesions, demyelination, consistent with my age and female...the report was saying...he (neurologist) treated me for focal migraines and I slowly got new symptoms. Rudi line 92

The puzzle is complete- the day my life changed forever

It was only about 30 years ago that it was discussed in the medical literature the merits of even telling a patient that they had MS. In some cases it was advised that this was not always a good idea, potentially causing unnecessary upset and stress in a disease with no cure (Sencer, 1988). Two decades later, research into receiving a diagnosis of MS reported that PwMS often felt intense feelings of abandonment and isolation from their neurologist following their diagnosis of MS. Most often this was likely because they were sent away with no plans for follow-up or treatment (Johnson, 2003). This was not replicated in the current study, possibly because there were no, or limited, treatments for RRMS in the years prior to the earlier study reports and no need to be reviewed again by the neurologist, with family doctors and community care taking over care in many cases. However, this has changed greatly in recent years and now close follow-up care after diagnosis and commencement of a DMT is expected by the Neurologist and MS Nurse, and crucial to ongoing management (Giovannoni et al., 2016). Imparting a diagnosis of MS is the start of a transition between HCP/MS team and the PwMS, which needs to provide information, offer advice and continue support in an ongoing manner (Johnson, 2003).

Vivid recall of the diagnosis

For several participants in the current study, recalling the day they formally received their diagnosis of RRMS was fraught with emotional distress; for some it was the method in which the diagnosis was delivered and for others it was recalling the lack of support or information received afterwards. It has been reported that the day of MS diagnosis can be recalled by PwMS vividly and with a great deal of emotion and detail (Isaksson et al., 2006; Solari et al., 2007; Malcomson et al., 2008; Solari et al., 2014). This highlights the importance of the conversation and the amount of effort the HCP needs to invest in the consultation. As highlighted in previous sections of this theme, sometimes PwMS have been waiting years (and occasionally decades) for a diagnosis and most often the diagnosis will come from a Neurologist. The power of this interaction and the potential impact on the future life of the PwMS cannot be underestimated. PwMS have reported frustration with the vagueness of the diagnosis, lack of commitment, and lasting negative impressions of the HCP (Malcomson et al., 2008), themes strongly supported by several participants in the current study. An honest, frank discussion from the Neurologist/HCP explaining the reasons for the delays of making the diagnosis, the need to be certain of the diagnosis, the difficulties in prognostication, together with the potential for hope and the power of current research, could counteract much of this negativity and set the PwRRMS on a more hopeful and positive path for the future.

All study participants recalled in detail the day (and the way) they were diagnosed and given the news that the symptom cluster and diagnosis of RRMS was confirmed. Participants recalled how they felt as the words “MS” were verbalised, sometimes for the very first time. Some participants were alone when they received the news, others had the support of others, but no matter the circumstance, the day is firmly etched in their memory. Even though it was over 20 years ago, Evie recalled what she believed were the exact words from her neurologist.

I remember the day I was diagnosed (20 years prior)...I remember the exact wording...he said to me “ I think you have a mild case of MS”...and I went “Oh OK”...I knew it wasn't good, it could have been bad...”there is potential for it to be

very bad” ...I wasn’t scared, I wasn’t upset, I wasn’t angry...so OK...what do we do about this? Evie line 567

Rudi recalls how she felt as the diagnosis was being delivered, as sensory symptoms started to ascend in reaction to the stress she was feeling as the words she had feared became reality.

And she (the neurologist) was starting...I knew where she was going and I could feel the numbness coming in my face, I remember that vividly...and then...I had the wheelchair in mind. Rudi line 1616

After months of waiting for a diagnosis, Will begged his neurologist to tell him the diagnosis over the phone, and so he was in his car in a garage on the side of a major freeway when he heard the news that he had RRMS.

(the neurologist rang and he wanted me to come in) I said “can you tell me now because...it’s killing me...I’m waiting for your call” ...so I pulled over to a garage and he said “this is most likely what we’re going to have to...the route that we’ll take” ...I wanted him to tell me...he said “I can’t tell you over the phone...I cannot have that conversation with you”...but I said” if you don’t...I’m not coming in...what are you going to do?”. Will line 755

For many, having solved the puzzle and leading to a diagnosis of RRMS left them deeply wounded by the revelation. They felt the covert message from the HCP was this is your new life, accept it, move on, I’ve done my job now. This was heartbreaking for some, and was the start of a difficult relationship with RRMS and with their HCPs. The manner in which the diagnosis itself was delivered caused utter devastation for both Kate and Davina, who can both clearly recall the encounters over 20 years later.

The first thing he said to me was “you know what, I think you have MS”... I said...”oh what does that mean”? Because I had no idea what MS was ... and he turns around “and you may end up in a wheelchair and you will probably be blind in

five years time” ... I said “I’m only going to be 27 and I’m going to be blind?” ...and I was a mess. Kate line 234

The consultant I wanted to see was away so the one I had (in hospital) stood at the end of my bed and said “it’s 99% definitively MS because you fit the sex, the age, your symptoms are very textbook...so I suggest to you that you think about your future and perhaps if children were something you were looking forward to, it might be something to think about now, because better to be a disabled young mother than a disabled older mother” (starts to cry)...I was distraught. Davina line 467

Other participants felt resentment at the diagnosis and a sense of unfairness, particularly Rudi who felt a sense of anger upon hearing the news.

Even though I read the report...after I was diagnosed I became very angry... (another friend with MS) say’s it’s relief...but I didn’t find that, I wasn’t researching anything...it didn’t come as a complete surprise...later Mum went down and got some pamphlets...”Mum” I said “you can stick these up your arse, I don’t want to know anything about it”, I was at that angry stage...I don’t want to know. Rudi line 777

Griff was grateful to have a diagnosis after many years of trying to find the cause of his symptoms, but didn’t feel as happy as he thought he might in finding an answer. Solving the puzzle was “cold comfort” for what lay ahead.

I feel like death warmed up...then I have a name to it...but it’s a cold comfort... because the name comes along and all of a sudden, now I have “it”. Griff line 1312

Relief at the diagnosis

Although some participants felt devastated at their diagnosis of RRMS, and others felt anger, some participants felt a sense of relief. Making downward comparisons is very common, both in the lead up to diagnosis, and in the immediate period afterwards (Taylor, 1983). Downward comparisons happen when patients compare themselves favourably with the lives of others whom they believe to be worse off

them themselves (Taylor, 1983). This was echoed on multiple occasions in the current study as participants pieced together the puzzle themselves; fear of having a brain tumour, cancer, motor neuron disease (MND) or permanent blindness were common, and felt to be a far worse outcome than MS. Perhaps this was a coping mechanism which assisted participants survive the period from symptom onset to diagnosis, and beyond. For several participants, the day they were diagnosed with RRMS was a day of relief and the puzzle was solved, and in their minds, solved in their favour. The fact it was RRMS brought a lightening of their burden and possibilities for the future. Piper, Margot and especially Joy had all imagined illnesses they considered worse than RRMS and were grateful to have an answer they considered to be less of a burden.

I said (to the neurologist) thank you...I was relieved...I was relieved that I wasn't going mad. Piper line 614

You go through every scenario...what could it be...could it be cancer...and I don't think MS came to mind really...I was thinking motor neuron disease...so I was really quite worried...two to five years of expectancy...it was a relief...thank goodness it wasn't MND. Margot line 385

I said what have I got again?...and he said "MS"...and I said "is it going to kill me?"...and he said "no"...and then I said "you've just given me my life back again...I'm laughing yes, I'm not going to die from this"...I don't have to line up foster care for my son, I can finish raising him myself...I don't have to live in fear anymore. Joy line 1879

Disclosing to others

Piecing together the puzzle and confirming the diagnosis of RRMS was one thing, however telling this story to loved ones was another, and often induced feelings of dread and uncertainty. The journey wasn't over with confirmation of the diagnosis, in many ways it had really only just begun. Many participants struggled with sharing their news, even though they may have been relieved themselves, they were still mindful that they were about to change the lives of their loved ones forever. Telling

someone they loved that they had an incurable neurological disease, of which no-one could tell them where or when the next relapse would strike, how severe it would be, if they would recover and that they would need to take a medication which could make them feel worse, or do serious harm, was a mammoth task. They would often have to put their own feelings aside so they could comfort others, and sometimes this came at a high price for their own mental health.

Most participants were diagnosed between the age of 20 and 40 years and were reluctant to tell their parents of their diagnosis for fear of worrying and upsetting them, particularly if parents were elderly and would base their understanding of MS on that of years ago, when wheelchair scenarios were common. This was especially difficult for Susan, who had to halt her own intense feelings, to deal with the hurt and responsibility her parents felt upon learning her diagnosis.

I think they (Mum and Dad) didn't understand it...they were very emotional and blaming themselves...how could this happen? It was very emotional (and Dad) sobbed like a little boy...I didn't show any emotion, I held it all in because I had to be strong for them...that didn't help me because it delayed my grieving and delayed me dealing with it because I was trying to be strong for Mum and Dad. Susan line 374

This time was also difficult for Davina, whose diagnosis of RRMS caused a family rift. Davina's uncle, who was diagnosed with MS decades prior, had been hidden away at home and denied the diagnosis of MS by his family, associating the disease with shame.

I also had my two families...my father's family and my mother's bickering about whose fault it was genetically...so that was a bit hard to deal with and I was in the middle...and my mother was frightened...because on top of all of this I had an uncle who had MS and was wheelchair bound...so that was a lot for my family...because my grandmother used to tell everybody he had a head injury when he fell off a ladder and he didn't have MS. Davina line 568

With-holding disclosure

Other participants held the diagnosis close and from diagnosis to retelling their story to me, told only the bare minimum number of people they needed to. Paul had still only told his wife, his parents, his brother and his work boss of his diagnosis, not one other friend. Paul says he doesn't need other people worrying about him, he does enough of that himself.

Not many people know...I told my CEO...nobody else knows...I much prefer it that way...no friends know...I just get enough canoodling from Mum, I don't need any more, that's enough you know...I'm reminded enough of it as it is. Paul line 994

What next?

Now that the pieces of the puzzle have completed a picture of RRMS, it was time for the study participants to work out the next step on the journey of living with RRMS. However, just because the puzzle was solved for now didn't mean that it was solved forever. The unpredictable nature of living with RRMS ensured that new pieces of the puzzle were very likely to form, at any given time in the future, and often suddenly. The next theme, (Re)defining me now that I have RRMS, begins the story of how PwRRMS make sense of their new diagnosis and how they move forward in their lives.

Theme 2 :” (Re)defining Me now that I have RRMS”

Who is this new me I find in my old body?

How do I belong? Where do I belong?

Do I belong? Will I belong?

I didn't choose to change, it choose me

Finding my way without warning is difficult

I struggle to be

The road isn't sign posted and I cannot see the lights

Does the old me even exist anymore?

What fate awaits me?

I need to be, I need to see
Let me try and find how to be me
TB

The first weeks, months and years after being diagnosed are critical for the PwRRMS to define, or (re)define their identity now that they are living with RRMS. For some, the confusion and devastation of the diagnosis of RRMS played heavily on their minds and bodies and they struggled greatly, as discussed in the previous theme. Others seemed to take the diagnosis in their stride and march on, eager to find out more about the disease they had acquired and boldly declare that they are ruling it, it's not ruling them. How do PwRRMS make sense of the time after diagnosis and move along on their life path, still the same person, but now different?

After the diagnosis of a chronic illness such as RRMS, people are confronted with new situations that challenge their habitual coping strategies, strategies they may have used in past illnesses or times of hardship, and now they must find new ways of coping (Taylor & Aspinwall, 1996). It has been said that a diagnosis of RRMS opens the door to uncertainty and variability and has specific challenges (Koopman & Schweitzer, 1999) as well as extremely complex ones (Dennison et al., 2010). Additionally, as RRMS occurs in the prime of life, it is likely to leave a strong psychological imprint, with very real changes in values and beliefs in how the PwRRMS views him or herself (Irvine, Davidson, Hoy, & Lowe-Strong, 2009). Defining oneself, or (re)defining oneself, in the face of a newly diagnosed chronic illness is always difficult, but the challenge is amplified in RRMS where the long term prognosis of the illness is not known and the future is highly unpredictable.

The ***central organising concept*** of the theme “(Re)defining Me Now That I Have RRMS” is about how the PwRRMS makes sense of the world with their new diagnosis. This involves discovering more about the disease, working out how to manage feelings relating to work and finances, relationships, parenting and finally balancing the losses and gains of now living with RRMS. It is a mammoth task. Six subthemes presented during the current study, each distinct but sharing the central organising concept of defining a part of self or finding a part of self in their context as a PwRRMS. The subthemes that are grouped under the theme (Re)defining Me

Now That I Have RRMS are: getting acquainted with RRMS, dare share compare, navigating normalcy, disability and independence, working out work, parenting with MS and balancing losses and gains, each with further sub-subthemes to provide more detail and clarity.

Getting acquainted with RRMS

“Diagnoses, especially those that relate to serious illness, mean much more to patients than simply the identification of a particular disease state. Diagnoses are permeated with cultural and personal meaning”

(Toombs 1995, p7)

In the time immediately following a RRMS diagnosis, the majority of study participants were determined to find out as much as possible about their new companion in life, RRMS. Of course, the uncertainty and unpredictability of RRMS in general ensured that many questions remained unanswered. For several participants, this was extremely difficult, as they were provided with minimal information at diagnosis and received little follow-up care.

Prior to the 1990's, the MS neurology consult was sometimes referred to as “diagnose and adios” or “MRI and goodbye”, first coined by Neurologist Labe Scheinberg at an MS meeting in 1986 (Pearce, 2004). Thankfully MS practice has moved on since this time, mostly due to the introduction of DMTs. Now the primary role of the neurologist and MS team is not just to diagnose an untreatable condition and then say farewell, but to continually assess and monitor after the diagnosis for the entire life journey with RRMS; to ensure DMT safety, to detect relapses and to observe for signs of disease progression.

In order to (re)define self, many study participants set out to acquire knowledge of what RRMS was and what was most likely to happen to them in the future. Most PwMS find information on MS empowering (Malcomson et al., 2008), but unfortunately for many, there is a lack of information given at the beginning of the journey (Rintell & Melito, 2013). This reality applied to several participants in this study. Kate, Ruby and Davina recall that they were provided with little information

after diagnosis, no chance to ask questions and no health management plan. A systematic review addressing the information provided to PwMS following diagnosis reported that there is growing evidence that information provision can increase disease related knowledge and may have a positive effect on decision making and quality of life, with no negative effects noted (Kopke et al., 2014). Information for PwMS needs to be given in a way that allows appropriate time, repetition, flexibility and must be individualised according to needs (Krahn, 2014). HCPs also need to be mindful that the information and resources are appropriate for the individual and take into account factors such as education, occupation, financial status and social level. If these factors are not considered, PwMS can be left feeling vulnerable and the information rejected as useless (Sharifi et al., 2016). This was the case for Jane, who literally threw the initial information booklet and resources straight into the rubbish bin. Jane felt that the information provided and the method of delivery did not meet her individual needs at the time.

Lode et al. (2007) revealed that almost half of their study participants (n=86) were dissatisfied or very dissatisfied with the information provided to them at the time of MS diagnosis. As optimising information delivery early in the disease course induces coping styles that provide a better adaptation to living with MS (Lode et al., 2009), MS HCPs and MS Nurses need to manage this important process in a method which is supportive of individual needs. A later study interviewed 61 PwMS at their first MS clinic appointment regarding their on line MS research activity, and discovered that 82% of people in the study gathered medical information on line before their first appointment, yet only 36% discussed what they found with the physician (Hay, Strathmann, Lieber, Wick, & Giesser, 2008). This area needs further investigation so HCPs can stay engaged and aware of information seeking habits of PwMS, to provide guidance on appropriate, relevant and reputable websites and to truly partake in shared decision making, based on the same shared information. Careful and individualised education planning (incorporating written, verbal and electronic methods) is needed in newly diagnosed PwRRMS, and with reassessment as necessary along the disease trajectory.

Nowadays typing the words “Multiple Sclerosis” into a Google search results in almost 29 million “hits” at your fingertips in less than a second. However, there are

unfortunately no systems in place to advise what is factual and trustworthy information, and what is not. For someone newly diagnosed with RRMS, possibly medicated with high dose steroids and dealing with the suddenness and havoc of the new diagnosis, trying to negotiate 29 million websites and work out what is helpful must be almost impossible. Many study participants in the current study commented that there was “a lot of junk” out there and that the sheer volume of information was overwhelming. Other participants tended to wade through the minefield of information and narrow down the websites that seemed to make sense to them. A recent Australian study explored online information seeking in PwMS (n=51, type not specified) using focus groups (Synnot et al., 2014). The study revealed that all participants had used the internet for information at some stage of living with MS and mostly indiscriminately soon after diagnosis. Many participants in this study also described the dichotomy that exists for MS information; in that they felt there was too much information in general, but too little information on what they really needed (Synnot et al., 2014). Worry about parents or children obtaining information on the internet about a family member with RRMS, particularly if there was a focus on wheelchairs in MS, also concerned several study participants. This phenomenon has not been supported by recent literature, however is worthy of further exploration.

There was a great deal of difference between participants in the current study regarding how they acquired knowledge, depending on the decade they were diagnosed. Participants such as Davina and Evie, who were diagnosed over 20 years ago, had to rely on books, pamphlets and phone calls to receive information, others diagnosed more recently such as Piper and Paul, were able to embrace the internet immediately. Most participants were somewhere in between, relying on help from the MSA for initial information, finding others with MS in their local community to ask questions of, or receiving information from their MS Neurologist, MS Nurse and local MS clinic, where these were functioning. However, information gathering is not static, initial information at the start of the journey was sought, but in MS, information needs are continual and all participants relied on the internet and websites for their current updates and new information. Some participants such as Kate, Paul and Will preferred highly scientific websites for their knowledge, but others such as Ruby and Piper favoured more low-key blogs and real-life stories.

I just have this...overwhelming...overwhelming thirst for trying to understand reality I think...I mean there's a lot of trash out there, but there's a lot of good stuff as well...I register with on line scientific journals...at night I don't have very good sleep...I get on my phone or my ipad and just read about all this stuff...for hours at night, every night. Paul line 647

Absolutely yes (I go to the internet)...some of the stuff, I take with a grain of salt...I'm registered with a couple of scientific journals, I get a bit from there as well. I hate the MS Australia stuff because it's all wheelchair shit you know...it's all worst case stuff. Paul line 693

Margot also realised that not everything on the internet was factual and helpful; and was grateful because her elderly parents didn't have a computer and wouldn't be exposed to that information to cause them further worry.

The good thing with elderly parents was that they didn't have a computer and they couldn't look things up on the internet...but everything on the internet, just because it's on the internet doesn't mean that its true...so I've kept that in my head... so you don't trail for all sorts of quick fixes and horrible stories. Margot line 532

Seminars and webinars seemed to be an effective way for PwRRMS to gain the information they needed and also garner support to educate their family and friends. Positives for some participants included the fact that the information was freely available at a time when it was convenient for them, and in the case of webinars, that they could do this in the privacy of their own home or office. Susan found MSA helpful in her quest to learn more about many aspects of her new illness.

I always thought knowledge is power. I joined MS Society because I asked them what to do, what do I need to do, where do I get my information...I used to go to a few talks...whatever drug I was on at the time...how to live with MS...anything to help me. Susan line 448

However, not all participants valued the sources of information in the same way. Rather than turning towards the information available to them, some participants

turned away. Not all study participants were ready to take on the wealth of information in RRMS at the beginning of the journey. Rudi had definite views that they would acquire information in their own time, when they were ready to do so. This highlights the importance of gathering and providing information appropriate to the individual at suitable times in their RRMS journey.

My Mum went down to the MS Society here and got pamphlets...I was sitting there rolling my eyes and I said "Mum, you can shove these...I don't want to know anything about it...I've got MS, don't talk to me about it, I don't want to know. Rudi line 797

Jane wished to keep a positive mindset from the beginning and didn't want information focusing on negative aspects of RRMS around her.

(after diagnosis) Mum gave me the book about MS...and you end up in a wheelchair and incontinent...all the horrible things with this...it was a really old book...and I just binned it. Jane line 105

Following diagnosis, many participants had some sort of contact with the MSA, whether in person, by phone or internet. However, no participants mentioned any contact *during* the diagnostic process. Ruby, Piper and Susan all gained value from the help of MSA as a professional organisation in the early days of acquiring knowledge, and Susan also took family and friends along to educate them directly.

The MS Society is brilliant...I used to love the blogs but I can't handle negative...(there is also) a facebook page that was a really good site to be on (for a particular DMT)...I think on line there's a fair bit but I use it quite discerningly and I try not to look at too many blogs...there's a few on there that whinge too much and I can't stand that, I know there's a lot to whinge about, but when you're feeling low anyway, it doesn't really help. Ruby line 995

I went and saw (our local MS Society representative) when I was first diagnosed to find out whatever information she had. Piper 1793

I've done a few webinars, I love those...just to be updated with anything that's new...there's that much junk out there. Piper 1921

I took a couple of girlfriends and my Mum with me (to the MSA) just so they could understand what was going on because...they see me as...as I'm OK, they don't know what's going on inside...I wanted them to understand what MS is about. Susan line 498

Dare to Compare

Another source of information to acquire knowledge to help (re)define self involved daring to compare oneself to others also living with MS. For some study participants, there was struggle in deciding whether to engage with the world of MS, or whether to avoid the world of MS. This was reported by participants in Dennison et al.'s (2010) study as whether to engage or avoid "the cripple club". Engaging with other PwMS and witnessing disability can potentially have three effects: helpful interactions (support and advice, sharing tips), to be shown the spectre of what may happen (dare to see) or to not relate at all (compare and not fit in) (Dennison et al., 2010). Moreover, being with other PwMS can lead to empowerment in the peer community and to shared resources, a mutual recognition of ability, social relations and an environment that displays no "stereotyping shame" (Skar, Folkestad, Smedal, & Grytten, 2014).

Following diagnosis, many study participants described how they needed to see what RRMS looked like in others, but the participants differed greatly in their reasons for doing so. Most initially knew very little about what RRMS meant, the little they did know was through MS read-a-thons conducted in primary schools in Australia many years previously. If they dared to compare they sought out MSA meetings where they could meet others dealing with the same disease, or what they thought was the same disease. Other participants tread more carefully and sought out individuals they knew through others to gain access to the MS world. This subtheme is concerned with several aspects: daring to see what was out there in the MS world and seeing what they may become as a PwMS, comparing themselves on the MS severity scale and also hopefully learning more about RRMS in the process.

Whatever their motivation, attending MSA meetings was a common event for participants to dare to compare in their journey. Some participants went to MSA meetings solely to make downward comparisons, to prove to themselves that their MS was less severe and that they compared more favourably than others. For Paul, this marked an important line in the sand to make sure that he could cope with the diagnosis. Paul harboured guilt, daring to compare himself against others with MS, but mostly in the progressive state and not the RRMS type he was diagnosed with. Paul did this early in his RRMS journey when he was relatively unaffected by disability. He attended a meeting, knowing the meeting would attract people living with progressive MS, and in a worse situation than himself. He felt as if he needed to see the worst the disease could do, and found comfort in doing so. It was part of daring to see what could happen and comparing himself more favourably against that outcome. He utilised the information to actively do every thing he could possibly do to stave off the same future, he (re)defined himself as someone with MS but not *that* type of MS.

I don't know if this is a little bit morbid...(MSA were running seminars)...and this is the morbid bit...I wanted to see what other people with the condition were like...I think people that have been more severely affected were probably more interested in being there...I hope that was the case because it was pretty depressing actually...and I don't know if I was going there to be depressed...I was thinking...with everything I'm reading, maybe this isn't a very big deal...so I wanted to go and see... this sounds really terrible, but it was a comfort thing...well, I'm alright. Paul line 1310

Jane also went to a meeting with people with progressive MS, but her experience was very different, suffering reverse stigma about her own RRMS. Jane's "dare to compare" didn't go as planned.

I did go to a few MS meetings...the first meeting I went to was really depressing and these young kids who have the other type of MS...we were all just sitting there crying and I thought...I don't want to go back to this because this is just too depressing...and it was like I was the lucky one in the room...it's almost as though...well, you're lucky, it makes them feel even worse. Jane line 202

Susan also went along to a group meeting, but what started out as an uneducated glance at her possible future, ended with Susan acquiring new knowledge about RRMS, which she used to empower herself and move forward. Margot sat back and watched the reactions of others in her physiotherapy group, as a severely disabled PwMS began therapy, and felt that everyone in the room was glad it wasn't them. The comparisons for them were favourable.

There were a few people in wheelchairs...really bad ones...that scared me...confronting...I thought...that's going to be me...that's how I felt...but then, doing more reading and research...that's the worst of the worst...it doesn't always have to be like that...everyone's different. Susan line 506

(on seeing patients in a wheelchair today) I feel OK because I know that I'm not going to be like that...I'm better...I'm different because there's all different MS's. Susan line 1239

(in my physio group) there's people there a lot more disabled...they get driven by community transport and they're in wheelchairs...there's a woman...and she has to be wheeled in...I don't think she can do much herself at all...there were a few people with MS around...I just glanced at them...everybody was looking...I could imagine in their mind, thinking "oh gosh, she's worse than me, it could be worse"...they're probably all thinking "at least that's not me, I'm better than her at this stage". Margot line 2204

Signing up for the nearest MSA meeting straight away was not for everyone and some participants chose a more measured approach to joining the MS world. Will avoided others with MS as much as possible, not wanting to compare with them. When Will attended the day admission centre at the hospital for his monthly DMT treatment, he carefully avoided PwRRMS, preferring the company of "cancer patients" also attending the same centre for treatment, who he felt had a better and happier disposition.

I stay away from other people with MS ...because I don't want to hear bad stories and I don't want to know how other people cope with it, because I believe the way I cope with it...works for me...I would purposively sit with the cancer patients because you could have fun with them. Will line 289

Other participants such as Margot and Griff enjoyed their time receiving their medication in the infusion centre at the hospital surrounded by others with RRMS. They both expressed their sadness at the loss of their readymade social RRMS network when their DMT infusions were stopped and they were switched to different DMTs, demonstrating the experience as a helpful interaction.

Although the majority of study participants sought to dare and compare against others with RRMS, several participants sought comparing with others who had difficult life circumstances but were non-RRMS, in an effort to (re)define themselves. Susan enrolled in a course to help with making positive life plans, attended by people with mental health issues, loss of family members and other sad events. Davina was directed to a church group by her Church Minister to help her come to terms with her own diagnosis by appreciating and sharing the hardships of others who had been in war zones and lost children. Both Susan and Davina were able to spend time with people they considered to be worse off than themselves, helping them to build positivity and to have hope in their own futures.

In that group course, I met lots of beautiful people who had lots of sad stories who came there to learn, also how to be strong and cope with difficulties in life...people had lost children or partners or also dealt with illnesses...it gave me a lot of strength...also people didn't understand what they were going through, weren't listening to them...it's similar, it's similar. Susan line 731

(as I struggled after my diagnosis, a Minister) got me in contact with women in the church where they had been in some really bad situations overseas, where they had lost children to diseases...older women... it made me stronger. Davina line 1178

Daring to compare for the PwRRMS is an important part of (re)defining self after their diagnosis. PwMS organising their own network can function as a coping

system, assisting with stigma and introducing role models who have accepted MS into their lives and adjusted (Grytten & Maeside, 2006). However, as demonstrated by participants in the current study, this needs to be the right group for the right person, there is definitely no “one size fits all” approach. Mixing PwMS of different types and stages can be disastrous to self-identity and image, as Jane discovered at her first MSA meeting with progressive PwMS and no people living with RRMS. Jane recalled how many in the group cried as they heard sad and demoralising stories and how it left her feeling depressed afterwards. However, when Jane connected with a group of people living only with RRMS, the situation was vastly different and she gained much more out of the meeting and left feeling positive. It is important that MS Nurses are able to assist, advise and educate PwRRMS on how to engage in meaningful and appropriate social relationships with others living with MS, and how to negotiate social contexts and comparisons of MS in a fair and realistic way. Referrals to appropriate sources of support in this regard have the potential to be life changing.

Negotiating Normalcy, Disability and Independence: what's what and who's who

Trying to (re)define self as a PwRRMS led to numerous participants struggling with the idea of what being “normal” actually meant, against their existing perceptions of disability. I feel normal, am I normal? What is normal? Am I disabled if I just have numbness in my little finger? Do I need to be immobile to be disabled? Do you have to see disability for it to be real?

One way to manage chronic illness is to construct and live a story of “life as normal”, for people to think of themselves as living a normal life, just with a few problems (Robinson, 1993). At the beginning of the RRMS journey this can be particularly difficult, but is possible once the disease is under control, less active and the PwRRMS has had time to process the changes and acquire knowledge about living with the disease. Normalisation is a chiefly positive response to illness acquisition and involves actively adapting to changes wrought by the illness, allowing resumption of previous roles and responsibilities (Joachim & Acorn, 2000). Returning to work, or usual daily activities, and minimising disruptions as soon as possible after a relapse also provided opportunity to assume to live “a normal life”

(Dennison et al., 2010). Kate demonstrated this repeatedly, suffering a relapse, going to hospital for treatment, straight to work and home again without telling her family, much preferring to keep things as normal as possible.

I think I'm normal, aren't I?

The body of work by Charmaz (1983, 1987, 1990, 1999, 2006) in chronic illness explains how living with a chronic illness implies feelings of living a restricted life with loss of the former self image (Charmaz, 1983), sufferers striving to include the illness in their daily lives and their identity (Charmaz, 2006). Several of the study participants either still viewed themselves as normal, or tried to give the illusion of being normal, either to themselves, or to others (or in most cases, both). Some participants queried what normal was, particularly in terms of vague symptoms such as fatigue and tiredness. To most study participants, looking and behaving normally meant not looking disabled to others. Susan took a pragmatic view to negotiate her symptoms and for Ruby and Kate, the appearance of normal was very important.

*I get tired... but I work four days...they're tough days...and I look after a house, my husband, a little one who is full of beans...that's normal...I'm just like a normal everyday mother doing all the normal things a mother does...and she gets tired.
Susan line 1144*

Just normal, I want a normal lifestyle, I want to be able to teach my kids to give...I want them to be happy...I just don't want to be in bed...or on the sofa...I want to be moving. Ruby line 1575

I do make an effort every morning to have my shower, get dressed, put some make up on...to get my nails done...so I can be a normal person. Kate line 1930

For Davina, the quest for normalcy was so central to her sense of self that it led her to overachieve, to work harder to be accepted as normal. In contrast, just maintaining the function of mobility constituted normal for Piper, and is her goal living with RRMS.

I would say that since I was diagnosed I have tried harder in everything to be normal...I have not worked on a normal level, I've worked above target...now I am exhausted because I've tried so hard to do that to make myself look normal. Davina line 978

Being diagnosed has...now I can hopefully control it...I feel more confident...I do envisage myself...hopefully...never being with a walking aid...so that's what I'm hoping for...I think you can live a normal life. Piper line 2017

How others see me - not being defined by my diagnosis

Even if the PwRRMS view themselves as normal and not disabled, ill or sick; if others look at them differently or treat them as different, frustration and anger can develop as PwRRMS are judged against their disease instead of themselves. In essence, others judge them as a person with MS based on what they know about the disease. Both Rudi and Ruby felt that RRMS had hindered them from appearing normal to others.

I notice still to this day, that people treat me differently since my diagnosis...I'm fine, just treat me like I'm normal! So I found that a bit condescending...they look at me as a person with a disease now, which is a bit frustrating. Rudi line 1435

The hard thing is...when people look at you like a basket case and you lose your identity...Oh...that's MS. Ruby line 707

Not wanting to be seen as disabled, Will did not disclose his diagnosis to his extended family for some time and only wanted to see them in person when he was at his best and not as someone who appeared disabled.

I only went to see them (extended family) for the first time, two years ago...and I think I know what it is...being seen, I don't want to be seen as having a disability...I think that's the first time I've used that word today...I think that's the first time I have used it, ever. I want to be seen as Will, everyone knows Will as the big, strong guy. Will line 1235

Dealing with episodic disability presents further challenges for PwRRMS in negotiating normalcy, possibly being disabled one week with a relapse and not the next, and can prove a difficult concept to deal with. Most people with episodic disability inhabit the space between illness and wellness, a space that is fluid, dynamic and open to change at any time between sick and well, normal and disabled (Vick, 2013). Thus, they can be living under the appearance of, and genuinely feeling, normalcy for long periods of time. Additionally, invisibility of symptoms encourages the belief that the PwRRMS is normal, especially if they look normal to others and function well most for the time, challenging the notion of what it is to be disabled (Vick, 2013). For those with episodic disability holding onto the appearance of normalcy and being reluctant to disclose their diagnosis, stress and worry about others uncovering their secret was ever-present. Several participants were determined to present the persona of normalcy and not disclose their diagnosis (to be discussed further in the next section), hiding their episodic disability and thereby proving to themselves and to others, that they were functioning as normal. Success in this was essentially proven if others around them did not notice any issues.

Maintaining independence

Maintaining some degree of independence was extremely important to many study participants. If they could possibly manage to do a task, they certainly wanted to try. Asking for help was simply not something that came easily to them. This may be a reflection of wanting to appear normal to others or reinforcing normalcy to themselves.

I have plenty of family, everybody's here...so I'm lucky in that regard I don't like to ask people to do anything...I do it myself thanks if I can...I'll do it myself...it's only when I'm really down and out with fatigue and I can't do much...then I'll ask for help...but I will push on if I can. Piper line 1300

It's hard to ask for assistance...it was hard to ask for help...I didn't want to seem needy, I guess. Margot line 1188

(when I needed steroids) I would do things myself, I don't really depend on anybody...you can't be seen as you're moaning and groaning all the time...and half the time (my husband) didn't even know I'd just had steroids...I did things myself.
Kate line 946

It's really tough when you go through a relapse and you've got to give up your independence...the simplest thing...that was a big struggle...having to ask for help for simple things like giving kids lifts and things...I know it's no hassle because I do it all the time for people...to do that and ask yourself was a big hill to climb. Rudy line 1743

Working out Work

Part of (re)defining self for many participants involved negotiating employment and what their work future might look like with their new diagnosis of RRMS. For some study participants this was a positive experience, and for others a more negative experience. This proved to be an issue at many times during the life trajectory (not just in the post diagnostic period) and could be an issue for a different reason at a different time. For example, a relapse could suddenly bring a new symptom (such as loss of sensation in the hands) which impacted on work performance. Making the decision to disclose a diagnosis of RRMS at work was a significant decision for many participants. For a few participants, secrecy and non-disclosure ensured that they could maintain control over who knew the diagnosis and allow them to try and maintain normalcy at work. For others, disclosure meant they were able to secure the help they needed at work to allow them to keep working and performing in their position, albeit with some adjustments.

Most participants in the study were still working, part time or full time, only Kate and Griff (not by choice) and Margot (by choice) were not currently employed. The situation in regards to MS and employment in Australia appears to be improving, with a recent longitudinal study of 1260 participants suggesting that employment rates for PwMS (type of MS not specified) increased over the study time period 2010 - 2013 compared to the general population and was thought to be related to positive organisational responses to work adjustments and work roles for PwMS (van Dijk,

Kirk-Brown, Taylor, & van der Mei, 2016). However, the news was not as good for men living with MS, as the data showed that male unemployment rates in MS remain significantly lower than the general population (van Dijk et al., 2016).

Rudi needed over 2 years off work to recover from a severe MS relapse and recalls her feelings from this time and how she turned it around into a positive (re)definition of self.

When I lost my job I thought...I can be down and think that I'm unemployable, I can't work...or the path I chose to take was well, work's always going to be forever, the kids are going to grow up and I need to look at this as I'm lucky because I get to spend this time with my children...whilst it was tough financially, we adapted. Rudi line 944

It has been reported that fatigue, cognitive difficulties and mood disorders may have an enormous impact on work ability for PwMS (Sterz et al., 2016). A recent study exploring the meaning of work in the lives of PwRRMS found that becoming familiar with the disease, adjusting expectations, having a supportive, realistic manager and seeing work as meaningful, were all helpful in facilitating employment (van Gorp et al., 2017). For several participants, they took the opportunity to (re)define themselves in terms of work. Ruby enjoys her job, it gives her purpose, and although ambulation is difficult, she can perform her role in education with adaptations and has excellent support from work colleagues. Davina worked harder to prove herself at work, and Susan was given an opportunity to change her work environment to suit her new needs living with MS. For Rudi, whilst the work itself is not interesting, she values that she can choose her days and hours to suit her lifestyle and this is currently more important to her.

I'm really supported, I've got lots of friends there who check on me and I feel very supported. I'm working full time but have asked next year to have part-time so hopefully I will get a day off a week...to do a little gym...and I want a day with (my daughter) at home. Ruby line 790

Workplace was good...I was very close to my boss and on a level of that first line management...the rest of management didn't know, where I worked was such a big organisation that I was protected...I think I showed them that it didn't worry my ability to work. Davina line 946

(after my diagnosis, a manager I knew offered me a role)...so you don't get as tired and without shiftwork so you can stay healthy...I liked where I (already) worked, so I decided to do half in both, two days and two days...they looked after me and they understood, so I was very grateful and very blessed. Susan line 579

I'm now back working 12 hours a week I chose the hours and the days...this just landed in my lap so I was lucky...whilst it's not the most stimulating job, it's a job, this is good for now. Rudi line 955

The decision to disclose or to not disclose an MS diagnosis at work was one of the most important and personal decisions for study participants. Protective disclosing is a tactic used by many PwMS to successfully inform others the diagnosis of MS, in their own words and in a way that is acceptable to them, as a form of information control (Grytten & Maeside, 2006). This enables PwMS to protect themselves and exert some control over who knows the diagnosis and exactly what they know, a concept important in the workplace. Individuals with MS develop strategies and utilise resources, identifying priorities, and planning, part of (re)defining themselves not just as a PwRRMS, but also as an employee/ worker after diagnosis. Some participants in the current study chose to fully disclose their diagnosis at work with good outcomes (Piper, Evie, Ruby, Susan), others partially disclosed (Davina, Paul) practicing information control, and others have never disclosed (Jane, Joy, Will) because they don't feel it is necessary. No study participants in the current study expressed regret at their decision.

Several participants had chosen not to disclose their RRMS diagnosis in their workplace and were committed to keeping the secret, for reasons of privacy, fear of losing employment and/or fear of being stigmatised. Employment discrimination has been reported in MS, primarily through not providing needed accommodations at work, unfair working conditions, denial or delay of promotion and different

standards of performance (Roessler et al., 2011). However, it has also been suggested that early disclosure at work may help maintain employment, if disclosure is followed by appropriate work adjustments (Frndak et al., 2015).

I still haven't told my current workplace that I have MS...I don't want to tell them...I'm only on a year's contract and they might not employ me full-time...better if I don't. Jane line 504

Not many people know...I told my CEO, he's provided support in knowing...I got a major promotion a few months ago...and he knew at that point...very supportive, but nobody else knows, I much prefer to keep it that way. Paul line 994

(when I was being diagnosed) my workplace were being very difficult at the time about the amount of time I took off and they actually put me on performance management...it was really hard to hit my (work) target...and my manager was not supportive, or the company...they didn't give me any help at all. Will line 740

For Joy, who did not disclose her diagnosis at work, in hindsight losing her job gave her the chance to recover fully from a previous relapse and allowed her the time to rest and later to (re)define who she wanted to be and what she wanted to do. Joy changing her area of employment to one which she enjoyed more and gained fulfilment in.

I pushed and pushed and I just deteriorated, it was really hard and I was just trying to hold down a job...I'm so sick and I can't work (and my husband wouldn't let me leave my job)...I was just heartbroken...I lost my job...I wasn't doing my job...but not working gave me the reprieve...I could just sleep and heal. Joy line 853

(and now) I really do love my job, my job is to give other families' hope...I teach what I've learnt. Joy line 1851

Evie experienced an interesting situation at work, where a work colleague newly diagnosed with RRMS became aware that Evie also had RRMS and started asking her questions during work time. Eager to help in the beginning, Evie was soon

overrun with questions and conversations from this person, which started to impact her own work role in both time spent talking about RRMS (and therefore not working) and in how others viewed her (always talking about RRMS). She had previously disclosed discreetly at work to a selected few but Evie had not openly told all of her colleagues, who were now aware of her diagnosis. Evie had preferred to have a division in her life between RRMS and work, but that was now dissolved.

(the colleague with MS would constantly ask questions and advice at work) so, my MS had now infiltrated my personal life and my work space...so I was forced to think about that whilst I was at work too...I couldn't get away from it. Evie line 1089

Re-establishing a new identity after the loss of the role as a worker has been identified as often leaving a void in the life of the PwMS (Hunt, Nikopoulou-Smyrni, & Reynolds, 2014). Griff has felt this most keenly as he has struggled with financial dependence on his wife and maintaining any sort of social circle since leaving employment due to his MS. For years he was reliant on attending his monthly treatment infusions to provide social stimulation, and with a change in therapy and no longer a need to attend the centre, he has struggled to maintain any social interaction. Leaving the workforce has been reported as shrinking the social and geographical worlds of PwMS, as lives are now hidden from view, particularly as disease progression occurs (Dyck, 1995). For Griff, losing social contact was a major casualty of not working.

No income, that's a bit hard...all of a sudden I'm a dependent, financially dependent and that's never sat comfortable with me. Griff line 837

After working for 22 years...reality slaps me in the face...social contact is what you're trying to establish so people have a community to operate in...all those links have gone...I don't have those links anymore. Griff line 504

It has been reported that mourning the loss of a meaningful occupation is a real threat for PwMS (Matuska & Erikson, 2008). In the current study, this was experienced profoundly by Kate, who suffered greatly with the loss of her identity along with her

employment, a world where she felt accepted and valued, moving to her new reality of unemployment and struggling to make a meaningful contribution.

(losing my job last year) it was a bit of a nightmare at work...they wanted to shut down my department...it didn't make sense...I fought really hard, to the point where I got sick...and I thought...I can't do this...I've done everything for them, and this is the way they treat me...there was a lot of anger as well...I can't cope with it, I'm a real mess...there are times when...I'm lost...I'd rather work...I loved my job. Kate line 1899

If new roles, identities and interests could be established, participants spoke of how losses could be turned into gains with new hobbies and new opportunities. For both Griff and Kate, they have still not recovered from the loss of the work role in their lives, whilst others such as Piper, Margot and Rudi, have made the most of their enforced time off work and have found new ways to enjoy their time, travelling, exercising, maintaining wellness and expanding social circles.

The MS Nurse has an important role to play with support, education and guidance on aspects of work and employment in living with RRMS. Early referrals for advice from MS organisations to assist with work disclosure decisions and allied health professionals such as occupational therapists for practical work management solutions (Yu & Mathiowetz, 2014) can significantly impact the journey. (Re)defining self in regards to employment is an important part of the life journey with RRMS.

Parenting with RRMS

One of the most surprising revelations when analysing the current study findings was realising what an enormous impact the role of parenting had on PwRRMS. As a parent myself, I was always cognisant of the fact that the parental role was important in chronic illness, yet I was completely unprepared for just how important this role is to PwRRMS. It may be due to the unpredictability, which threatens to change the parental role, or being at the mercy of a disease which could render disability at any given time. It may be the heightened sense of value placed on parenthood living with

a chronic illness. All but two of the participants in the current study were parents and they all became visibly physically changed during the interviews when talking about their children, their faces and voices softening, becoming animated and happily discussing the positive aspects, and becoming sad and upset when discussing the challenges of parenting as a PwRRMS.

To be or not to be (a parent)

Historically, women with MS were advised not to have children, and if pregnant, to terminate the pregnancy (Smeltzer, 2002). This is currently not the case with pregnancy reported to have some protective effects on the course of RRMS and on disability progression (Pozzilli & Pugliatti, 2015). The impact of MS on family planning was an issue for several participants in the study. Plans for more children in families were curtailed as a direct result of the impact of RRMS, and also as a result of unknown effects of some of the RRMS treatments. Ruby wanted a third child, but understood that the bulk of the childcare would probably fall to her husband as she was gaining disability and so elected not to contemplate further pregnancies. For Kate, there were simply too many unknowns to consider a second pregnancy, and coming from a science and medical background, she felt very strongly that this was the right parenting decision for her and how she wanted to (re)define herself with RRMS.

(with two kids) we were blessed...and now that my body is so worn...there is no way that I can put that pressure (another baby) on him (my husband)...I would if I was physically able to take care of the child...I think we're very blessed to have the two that we have, I can't be too greedy. Ruby line 1320

And the decision not to have any more children...it was related to MS...I was scared, thinking, what if I have another child, I get sicker, how am I going to bring up two children? And I've got no idea what these drugs are doing to me and what they're going to do to a baby...I did make the right choice, I know that. Kate line 1377

Breaking the news to children

Breaking the news of an MS diagnosis to children could be a daunting process. The impact of MS on children has been shown to be a concern for parents with MS, supported by research reporting that MS can have a negative effect on children (Bogosian, Moss-Morris, & Hadwin, 2010) with most children having a poor understanding of MS (Bostrom & Nilsagard, 2016). A recent study identified that children may also worry that their parent with MS would die, highlighting the importance of support and communication to strengthen the child's ability to cope (Bostrom & Nilsagard, 2016). Rudi needed professional help for her daughter, who experienced emotional trauma after witnessing Rudi suffering a severe relapse.

I had to get my 12 year old into therapy because she didn't cope, she became quite anxious and she thought I was going to die every time I got carted away by the ambulance. Rudi line 600

At the time of diagnosis, more than half of the participants were already parents. Rudi (four children under 12) and Paul (three children under the age of eight) described how they set out to explain RRMS to their children.

You know what it's like as a mother...you just get on with it, as hard as it is...I got them (four kids) all together and explained as best I could to a child...they knew I was sick, no hiding that...the youngest took off halfway through the conversation to go play on the swing...it was hard...it was hard work. It's been distressing, especially my two young girls...I find that tougher than the physical side of things sometimes. Rudi line 568

I really haven't gone into too much...I have explained with...Dr Seuss's book "Inside Outside" and he (son aged seven) always goes "they're yucky white blood cells...you've got yucky ones"...and sometimes he asks me "how's your brain today, Dad?". Paul line 980

The impact of MS on parenting

Recent studies have shed light on the impact of MS on parenting, although most of this literature has concentrated on mothers and MS; with a paucity of literature exploring the experience of fathers and MS. An Italian study interviewed 16 female PwMS, of varying types and stages, aiming to uncover the value of motherhood in PwMS (Willson, Tetley, Lloyd, Messmer-Uccelli, & MacKian, 2017). The researchers described how the participants strove to maintain control of their MS, how they compared themselves to other mothers and how they frequently felt different to other mothers (Willson et al., 2017). Several participants in the current study echoed these concepts. Rudi, a mother of four, reported that she felt different to other mothers because of what she could not do related to her RRMS.

My girls look at that (what I can't do) and see that I'm not like other Mums and that's hard for them when I say "I just can't go because I'm too sick"...and that, that's hard on them. Rudi 685

A study exploring the lived experience of mothers with MS (type not specified) has reported that PwMS who are mothers of young children describe the experience as physically challenging, yet highly rewarding (Plumb-Parlevliet, 2015). Mothers with MS recognised that energy is limited, and this is often challenged by children, causing the mother to regulate and limit activity (Payne & McPherson, 2010). Many mothers have support networks in place to help them cope with MS and this includes partners, family and friends (Payne & McPherson, 2010; Pakenham, Tilling, & Cretchley, 2012). In the current study, Piper, Margot, Kate, Rudi, Davina and Ruby all reported the importance and value of a close network to assist them in their motherhood challenges with partners and family being particularly supportive.

My mother-in-law...if I tell her I'm crook she'll be around in a heartbeat, so that's good. Piper line 1329

When we moved here, Mum and Dad bought around the corner, they knew that that there was a potential diagnosis...I'm pretty close to my family, and my sister lives close by...this has brought us closer together for sure. Ruby line 1122

Parental losses

It has been reported that mothers also experience loss related to their ability to fully engage/participate in their children's lives due to MS (Willson et al., 2017). In the current study this was expressed by a father, Griff, who struggles greatly with the impact MS has made on him as a parent, his sons observing their father exhausted with fatigue instead of playing with them and taking them to the park.

My kids have grown up with someone who struggles...when I should have been going to the park, when I could have been kicking a ball... their primary role model was probably somebody who fell asleep at 3 o'clock in the afternoon. Griff line 1323

As Ruby experienced a severe relapse shortly after delivery, she missed out on crucial time with her first baby, those memories still haunting Ruby seven years later.

(my new baby) it was hard not being able to take care of my baby...I couldn't pick him up, I just had no strength, I couldn't get up to him, I couldn't change him...(cries)...it was so...hard...the kids have seen a lot...it's hard on them as well because it limits us from what we can do. Ruby line 430

The joys of parenthood

In the current study, all mothers and fathers valued their parenting role and several participants felt that parenting with RRMS left them feeling empowered and bringing out their best qualities. Being a mother may bring some beneficial psychosocial effects to the life journey with MS, enriching lives and providing purpose (Plumb-Parlevliet, 2015) which may be important given the high rates of depression reported in MS (Feinstein, 2011). Possible rewards from parenthood cannot be underestimated, it has been reported that PwMS who are mothers have higher quality of life and more social activities compared to childless women with MS (Twork et al., 2007). Davina gained a sense of empowerment from motherhood and Will uses his love of fatherhood to give himself hope for a future where he is active with his children.

I was desperate to have a third child...I was good...at least I was really good at something...I really enjoyed being a mother and I felt I was quite successful at it...it gave me a sense of empowerment. Davina line 675

I want to be able to play sport with my son and daughter...we are the best of friends...we play netball and we play golf...I want to play football with my son and I want to take him on the golf course! Will line 1488

The immense value of the role of a mother remains evident, regardless of the degree of disability or whether the MS diagnosis or motherhood came first in the equation (Willson et al., 2017). The fathers in the current study also expressed happiness and delight in fatherhood, although it wasn't always easy to keep up with the children. Balancing both the challenges and the joys of parenthood takes skill, patience and time. The MS Nurse has a vital role to provide guidance, education and support on parenting issues at all stages of the life journey with RRMS.

Balancing losses and gains – my life plan (re)defined

Chronic illness has been described as a disorder that persists for an extended period, affecting a person's ability to function normally (de Ridder, Geenan, Kuijer, & van Middendorp, 2008) and profoundly impacting day to day lives (Moss-Morris, 2013). The presence of chronic illness has the potential to induce intense changes in a person's life and can result in negative effects on both their wellbeing and quality of life (Sprangers, Hanneke, & Haes, 2000). However, chronic illness can also provide the potential for individuals to find advantage in the situation and a positive effect on lives, known as benefit finding (Pakenham 2005a, 2005b). Findings from the current study to be discussed in this section demonstrated examples of both scenarios, and sometimes both scenarios in the same person, at different times. Balancing these losses and gains was an important part of (re)defining self and setting a new life plan with RRMS.

It should also be noted that the onset of MS doesn't necessarily bring into question a person's sense of self, rather it is the degrees to which symptoms impact on a

person's ability to fulfil roles important to their pre-MS self, that appear to have the greatest re-defining impact (Mozo-Dutton, Simpson, & Boot, 2012). MS symptoms, which have the power to threaten the PwMS's perception of self, may also contribute to emotional issues such as depression and anxiety (Mozo-Dutton et al., 2012). For several participants in the current study, this was certainly the case. Kate's burgeoning career in academic study was grossly threatened by sudden blindness, rendering her unable to read intermittently and leading to failure to complete a course for the first time in her life. On treatment, Kate's relapses lessened and she gradually regained some control and resolution of her symptoms. Accepting this particular symptom into her life story was not easy for Kate and involved years of anguish. MS HCPs can apply this knowledge to their dealings with PwRRMS by assessing patients and clients for symptoms which impact the most upon their life; and not just the symptoms that HCP working within the medical model, believe to be the most important.

Battling losses

Feelings of loss dominated the immediate post diagnostic period for several participants and for some, this was repeated again at various times later on in the life journey. The fact that RRMS could occur randomly and cause relapses at almost any time could potentially lead to the loss of important life milestones. Piper believes she lost the opportunity for a memorable wedding and honeymoon due to RRMS symptoms, suffering continuously from severe headaches and facial nerve pain in the weeks prior to and involving her wedding.

*I'd be in tears with those headaches...I had this new bout just before I was married...they don't go away and they just wrap around my face...it's just horrible.
Piper line 384*

(my honeymoon) was a disaster actually...(and the) wedding day was a disaster...I again had really severe, severe headaches...my wedding day was a blur...(and the honeymoon) we actually came home early...and called the doctor. Piper line 361

The onset of a new relapse and/or significant physical disability could induce feelings of loss for the normal body, and loss of independence without warning. Rudi keenly felt the loss of her normal life during a severe relapse and the degradation of not being able to perform activities of daily living. Jane was an avid athlete who was not able to go back to her usual level of competition after her diagnosis and continues to feel this loss of physicality.

(with a severe relapse) it was degrading...have to be wheeled to the toilet...the basics...and that was hard to cope with...things are just taken from you...that's what I find hard with MS, giving up simple things like not being able to go for a walk...because that's my time out and I enjoy doing it...and you don't think it's much to ask. Rudi line 276

My balance and the way I hold a pen isn't good...my balance isn't good...I don't ride a bicycle any more...(MS) has curbed my lifestyle...not that I was ever a risk taker, but I used to do a lot more...things like that are disappointing. Jane line 552

Margot had a difficult time dealing with her gradual loss of mobility. Her husband began looking at wheelchairs as they enjoyed travelling and he felt it would be a safer option, but he was met with stiff opposition from Margot who didn't give in easily.

It's a real mental block...(crying)...it's really hard to do that...it's the elephant in the room...it was a real mental block to sit in that (a wheelchair)...in public. Margot line 1533

Accepting gains

Appreciating the gains that may occur in RRMS will be discussed more deeply in the theme of positivity and hope, but for many participants, finding some benefit in their new life with RRMS was crucial to them finding peace and courage to move on and integrate RRMS into their life. Benefit finding is a specific type of coping strategy whereby, despite adversity, individuals positively evaluate their circumstances and report gains such as personal growth, improved relationships and changes in

priorities and goals (Pakenham 2005a, 2005b). Research has shown that benefit finding has been strongly and directly correlated with positive outcomes in MS (Pakenham 2005a) and practicing benefit finding by valuing life and acknowledging simple pleasures could be beneficial in MS (Irvine et al., 2009).

Benefit finding was a positive and active process for Rudi, who appreciated the personal, family gains she found directly as a result of living with RRMS.

I got really angry (after my MS diagnosis), but by the end of it I actually think of it as a gift because it's made me live my life differently...it's made me start to travel whereas I would have put that off...I was heavily involved with my kids anyway...but I just have a different outlook on life now, I tend to care less about things I don't have time for gossip, I've let all that go...so I view MS as a gift. Rudi line 835

Margot overcame her fear of the wheelchair to gain new awareness and opportunities and find benefit in the things she had learnt.

I think I accept things a lot more...I think you become more patient, you tolerate a lot more and you become...more accepting of people and maybe you develop a thicker hide...overseas people are so good to people in wheelchairs...they were just fantastic...and straight to the front of the queue...it was great...I thought, I can't believe I haven't done this sooner, it was the best thing. Margot line 964

Enrolling in a course to help her cope with her new diagnosis, Susan gained so much more and greatly valued the insights she learnt which improved other areas of her life as well.

I had lots of fun and went on more holidays...I hadn't had any relapses and I felt better about myself and I was doing a course...in that group I met lots of beautiful people...what I've learnt through this has made me a better person. Susan line 731

Balancing the losses and gains after a diagnosis of RRMS often led to constructing a new life plan. Gathering new information, working out what is important to the self, what doesn't matter and what might matter in the future takes time and effort. How

participants managed this, and how long this took, was highly individual, but always involved a personal decision to move on and to embrace a new life, with changed attitude and values. The majority of study participants had moments where they made a decision to embrace the new self and move forward with purpose. It was as if they reached a cross-road and actively chose to embrace their life living with RRMS.

I said, from that point, nothing's going to stop me I'm sick of being...that guy that just goes home...I never used to go out (following diagnosis)...I used to go home from work, go to sleep...I just said I'm not going to go home and sulk on my own...go to work and live in circles...so I joined a basketball team, I joined a football team...I'd go and play poker with my friends...I just lived this active life. Will line 1151

I thought well, I've got to try harder...to try and meet someone or do other things...so I started up doing other hobbies and taking up different interests to try and meet people...and also to learn other things to make myself feel better. Susan line 697

So I got really angry and obviously went through the stages of grief, but by the end of it I actually think of it as a gift because it's made me live my life differently...it's made me start to travel whereas I would have put that off. Rudi line 835

I take each day as it happens, one day at a time. I don't plan for the future, if things happen, they happen...you've got to put things in little pigeon holes...with my studies and my work I did not put too much emphasis (on relapses)...it was an inconvenience...but it was not my biggest problem...you're (RRMS) not going to beat me. Kate line 2419

(I had an experience) where I said "fuck you body, you will do what I tell you to do" ...so I got my two walking sticks out and went for a six kilometre walk...and I pushed hard and the more it hurt...you are not doing this anymore and I took back...took back control of my own life...yes, the disease doesn't control me, I control my own body. Joy line 1090

It is true that although MS does present complex challenges and signals a difficult period of adjustment, the majority of PwMS do adjust successfully (Eeltink & Duffy, 2004), and we as HCPs can openly discuss this with PwRRMS early in the journey. Pakenham (1999) has also shown that adjustment to MS improves as the time since the onset of symptoms lengthens, meaning that for many PwRRMS, that time will often be their friend. Time will heal emotional pain and time will help (re)define who they are and where they fit in, not just within the MS world, but within their own world and what is important to them as an individual. Adjusting to RRMS, like many chronic illnesses, is a process that continues throughout the course of the life lived with MS, and responds to changes in the illness status over that time (Sharpe & Curran, 2006). In RRMS, these changes are likely to present many times and particularly around times of relapse, new symptom onset, pregnancy, medication change, and disease progression. A PwRRMS is likely to require many redefinitions of self throughout their lifetime.

Participants described their losses, different for everyone depending on their individual beliefs and values. As previously discussed, loss of employment was a major concern for several participants, and for Griff and Kate, this continues to be a major issue in their lives. Other losses, affecting the participants in the current study, such as loss of independence, physicality and mental health have also been discussed in this chapter (Clair, 2003; Courts et al., 2004). The sense of loss and regret for PwMS who are parents knowing that children are observing the journey and possibly missing out on life (Willson et al., 2017) was replicated in this study (by study participants Rudi, Ruby, Griff and Davina). There is a paucity of recent literature on the experience of being a PwMS and feelings of loss.

There have been several research studies identifying benefit finding in MS acceptance and adjustment (Pakenham, 2005a, 2005b, 2009) and thereby impacting positively on (re)defining self. A study exploring story making and living with MS uncovered that for some, being diagnosed with MS was akin to MS being a saviour, delivered to save them from the person they were becoming (Clair 2003). No study participants in the current study expressed their feelings in this regard, although Rudi discussed how she changed her “attitude to gratitude” after living with MS for a while and recovering from her initial relapse. Most participants in the current study

viewed MS as a partner, finding new ways of working with the disease rather than against it.

Many PwMS change negative reactions (denial, concealment, loss of confidence) into positive changes and outlooks, including an increased appreciation for life and spirituality (Irvine et al., 2009). Most PwMS modified their lifestyle to do the things they wanted to do and needed to do (Matuska & Erikson, 2011). This was also demonstrated by several study participants, most notably Rudi, who described how if she wants to “play hard” and enjoy activities and sports, then she also needs to “rest hard” and nap regularly, even if it means missing out on other things.

Coming to terms with a new life plan may mean consequences to current lifestyle for PwMS. These concepts will be discussed further in the following chapter but it is important to recognise what these changes might be in terms of (re)defining the self with MS. The amended life plan for many study participants meant changes to family life, to relationships, to social lives, a new strategy of planning, changes to workplace and employment, to new methods of stress management and to seeking joy and happiness in their lives. Some looked at the balance scales of life and chose to openly accept the gains (Joy, Evie), some chose to focus on the losses (Paul, Griff, Kate), some participants accepted both (Piper, Rudi, Susan, Will). But, for all study participants, the process was fluid and dynamic, it could change regularly and swiftly, and signalled a new life trajectory. It became the nature of living with the disease for many, part of who they were now, an identity that was constantly open to change and (re)defining. It prepared participants for one of the next important steps in their lives living with RRMS, to Taming the Beast and set up their life in a way that they felt they were in control of RRMS. This will be discussed further in the next chapter. Before this time however, many participants needed to embark on “Battling the Demons” before they could regain some of this much needed control.

Theme 3: “ Battling the Demons”

My Demons

Though quiet

Are never quite silenced

Calm as they may be

They wait patiently

For a reason to wake

Take an overdue breath

And crawl back to my ear

Sarah Boswell

For the purposes of this study, “demons” were conceptualised as negative emotions, sometimes very strong emotions, which can threaten the livelihood of PwRRMS. Demons can be subtle, creeping in every so often on a bad day and upsetting routine and peace of mind, or they can be like a runaway freight train completely annihilating all in its path. The end result is that PwRRMS are mostly never free, even when clinically or physically things are in quiescence, there’s potentially always something beneath the surface, where demons lay. For all participants in the current study, a variety of demons threatened them at different times, and for different reasons.

The *central organising concept* for Battling the Demons in this study encompasses the experiences of confronting and living with the negative emotions that PwRRMS may feel throughout the life course, the things that steal away joy from life. There are many potential trigger points in an RRMS life journey to disrupt emotional equilibrium and quality of life (Dennison et al., 2009), including the time of diagnosis, the presence of new or chronic symptoms, with a relapse, change of DMT, when meeting other PwMS, or with disease progression. MS has been described not just as a journey of feelings, but a journey of feelings that change over time (Lysandropoulos et al., 2015). Adding to the burden is that people with neurological disability may be more likely to resort to ineffective ways of coping with emotions, which adds additional strain (Gedik et al., 2017).

Psychological problems in MS have been recognised for many years. A seminal paper on common psychological problems in MS from Burnfield and Burnfield (1978), described emotional reactions to MS as being inevitable, having serious effects on both the patient and their family, and also recognising at this early stage that they may be responsible for more disability in terms of suffering, than physical effects of MS.

Too often in our busy clinics today, a patient's emotional well being generally takes a back seat to discussions about DMTs, medication side effects and physical symptoms (Minden, Turner, Kalb, & Burke, 2014). Unfortunately, necessitated by the highly efficacious, but also potentially dangerous medication armamentarium of the modern day. The presence of these new, and longed for DMTs and earlier and more rapid diagnosis clearly does not remove the emotional burden in PwRRMS. At times it can be just the opposite, they can be the cause.

The theme of Battling the Demons comprises four intricate sub themes, which all fall under the umbrella of demons, stealing away happiness and causing angst to the PwRRMS. These subthemes are facing fears, weary with worry and anxiety, depression and despair, and struggling with the saboteurs. Each of these subthemes also contains additional sub-subthemes to provide deeper exploration.

Facing Fears

Fear can be best described as an unpleasant emotion caused by the threat of danger, pain or harm (Oxford dictionary, 2017). This threat can be real or perceived, which is an important point in RRMS as so much is unknown, and nothing can be guaranteed. This means that some threats are connected to reality, but some may not be. For the purposes of coding and analysis in this study, and to separate fear from some similar emotions such as worry, stress and anxiety; fear was conceptualised as being frightened to the point of terror, invoking physiological body changes such as body heat, shaking, sweating and crying (Scheff, 2015). Some of these body changes I witnessed when the participants talked about fear and what they were fearful of. This reference to fear being a *distressing* emotion was essential in the initial coding for this category. For example, during Paul's interview, he started to turn red in the face

and loosen his collar when talking about his fear of wheelchairs, he started to perspire and needed to have a short break, his fear was intense and physiological.

It has been reported that for PwMS, the first two to three years after diagnosis can be marred by distress and worry about the future, from being seen as healthy, normal and able-bodied to sick, abnormal and disabled (Mortensen & Rasmussen, 2017). A mixed methods study using both questionnaires and semi-structured interviews of 85 PwMS explored the theme of uncertainty in MS (Boeije & Janssens, 2004). The type of MS was not specified, but many were on DMTs and had a low-moderate disability score, suggesting a high proportion of RRMS participants. Uncertainty about future disease progression was a predominant factor, for those with both low and high perceptions of risk. Wheelchair dependence was perceived as a serious outcome, primarily because of lack of independence and a shrinking social world (Boeije & Janssens, 2004) and provides some understanding for the current study where so many participants were fearful of the possibility of needing a wheelchair and disease progression in the life journey, feeling like a burden to their family and worrying constantly about the future and what might happen. One would have thought the advent of higher efficacy medications to treat RRMS may have had some effect on these emotions, but for many that is not the case, fear continues to be a constant battle. It is a hard task for MS HCPs and MS Nurses today to change the stereotypical representation of PwMS being wheelchair bound and misunderstandings surrounding what RRMS actually is and how the disease course can be significantly altered with modern treatments abound.

Elements of facing fear expressed by the current study participants included the sub-subthemes of fear of medication side effects, fear of symptoms/relapses, fear of disease progression/disability and fear of the wheelchair.

Fear of symptoms/relapses

For PwMS, symptom changes can be overwhelming and almost feel akin to receiving a diagnosis of MS all over again, facing an acutely uncertain future much like an “emotional yo-yo” (Blundell-Jones, Walsh, & Isaac, 2014). Several study participants voiced a fear of symptoms striking at any time and relapses occurring

suddenly, blindness in particular. Rudi had a tendency to relapse rapidly and severely, and as the mother of 4 young children, this induced fear of relapses, and what her children may witness.

I can relapse very quickly...when the paralysis comes...it happens very quickly...they've seen that happen and it's been quite distressing, especially for my two young girls...the other week I fell and lost my balance, I lost my speech. Rudi line 582

For Joy, sudden blindness from optic neuritis (a common presentation of MS involving demyelination of the optic nerve) induced deep fear and a second relapse causing dyslexia left her terrified, again. For Susan, a hospital admission with a severe relapse left her fearful of what may happen in the future and if she would recover.

I was completely blind...for periods of time...terrifying, really terrifying and they couldn't work out what caused it...and it happened again and terrified...absolutely terrified. Joy line 123

So I came into hospital and I stayed the night...I was very scared and I was crying...I couldn't sleep...I said to the nurse "I'm very, very scared, I don't know what's going on". Susan line 280

Fear of DMTs and side effects

The physiological look of fear on some of the faces of PwRRMS during the interviews in relation to some DMT side effects has never left me. Once again, there were strong physiological reactions talking about how dangerous they felt some of the DMTs are, as well as possible unknown effects in the future. This concept will be discussed in greater depth in theme 7, "The DMT Dance", but also belongs as part of the story of fear in this particular theme as well. The most dramatic of these fear reactions were Piper and Joy, who had very strong feelings. After a relapse, Piper's neurologist wished to increase her treatment to a new DMT known to cause PML, but she was adamant she was not having it, nor the new and experimental HSCT

because of perceived high mortality. Joy was also equally adamant she wasn't taking a DMT which had recently been associated with deaths in others living with RRMS.

That PML thing keeps popping up ...what does scare me with that is how do you know it's that or an MS symptom causing it?...I'd rather be in a wheelchair than dead...Piper line 1362

(later when talking about HSCT) I think the risk is too great...I get that these people are in a real state of bother...they're struggling...but I just think I'd rather be, like I said, I'd rather be in a wheelchair than dead, I just think the risk is too great. Piper line 1960

(my neurologist) wanted me to go onto a drug that was about at the time...which had only killed about three people...it had only killed three people! So I said "you've got to be kidding". Joy line 820

Ruby had been offered a stronger DMT after her disease had progressed rapidly, but Ruby declined due to fear about the significant side effects. A couple of years later during our interview, Ruby wished she had taken the opportunity earlier, crying as she recalled her lost opportunity, lost to fear.

I really wish I'd listened to him (neurologist), I was just so scared, he said it could lead to other autoimmune things...and I think it was just pure fear, pure fear...going...I've got two young kids and the risk of cancers...I just didn't know if it was worth the risk...my fear of the PM...? What was it called, PML? That was massive...like every time you have that injection, you just go...(sobbing). Ruby line 511

Fear of progressing/disability

Although this subtheme has similarities with fear of the wheelchair, it is more general and involves disability in all forms, rather than the specific fear of a wheelchair itself. Some study participants met others with more severe disability at clinic visits or at MSA, and many became fearful that this might also be their future.

Being lonely and isolated as a result of disability weighed heavily on their minds and the possibility of a bleak future was ever strong, especially when confronted with the reality of other PwMS.

Margot attended exercise sessions at the local MSA and observed people living with progressive and more serious forms of MS on many occasions. She talked to them and realised many were socially isolated, raising with her a fear deep inside that this may one day happen to her as well.

A lot of them (people with progressive MS) I think are isolated and a lot of them are lonely...it's very isolating...people become very isolated which is a real shame because then it's hard to...how would you make friends if you're isolated at home with disability? who are you going to meet?...I think that would be very hard. Margot line 2517

Griff was a family friend of a celebrity with progressive MS who featured in many MSA fundraising campaigns for MS. As one of only a few people Griff knew with MS at the time, he was fearful for his own future with disability.

(I knew) the picture boy for the MSS for years so I'd been exposed to MS for at least 15-20 years with him...so it was a pretty scary image to measure myself against him...so I did have an understanding at least of how much damage it could do. Griff line 511

Will had personal experience of what severe disability in MS looked like, and he became immediately fearful at diagnosis that this could be his future with disability as well.

A friend of mine's stepfather has MS...he's in a wheelchair and he's flat ninety five per cent of the day...the first thought in my mind when I was diagnosed was what happened to him. Will line 16

Fear of “the wheelchair”

When confronted with a diagnosis of RRMS, many study participants jumped straight to imagining life in a wheelchair, an expectation which is common in the community and based on the natural historical progress of the disease. Before modern day DMTs and treatments, the risk of requiring a walking aid to walk half a block was quoted as 50% at 15 years from MS onset (Weinshenker, 1994). Nowadays the risk of needing assistance to ambulate in the future has not been quantified, the common switching between medications and the heterogeneity of RRMS making predicting future scenarios difficult. This fear of the wheelchair commonly settles with education and guidance from MS trained neurologists and MS Nurses, but for some participants in the current study, abject fear was the resulting emotion, terrifying and paralysing in intensity. Fear of the wheelchair could strike at any time, during relapses or with new symptoms, at the sight of another PwMS, or sometimes, with no specific trigger at all.

Rudi considered her future and the possibility of being in a wheelchair during a severe relapse, where she lost all motor function in her legs as well as the power of speech. The episodic disability of this relapse induced fear that one day the symptoms may be permanent.

The worst case scenario is I will be in a wheelchair...and that will be a very, very black day for me, or a black time if it does happen...afterwards I thought how's this going to affect my life...I might be in a wheelchair next year...and those sorts of thoughts...and that's why I used to get down quite quickly with my relapses because it's almost like a little bit of a taste of what may be reality. Rudi line 856

Paul disliked the MSA education material and resources because he felt that there was an undue focus on wheelchairs in MS, unnecessarily inducing fear in PwRRMS. Paul became emotional as he recalled how he felt reading this information.

I hate the MSL stuff because it's all wheelchair shit you know...it's all worse case stuff...I don't want to be in a wheelchair. Paul line 880

Susan's fear of the wheelchair was directly related to the fact that she felt that level of disability would take away any chance of her finding a partner to share her life with. Susan was tearful as she recalled her feelings at that time.

I'm very, very scared...well if it's MS am I going to be in a wheelchair, or what's going to happen...will I meet someone...who's going to look after me...you know, will I be a burden? Susan line 335

I always thought it (MS) was bad...that people would look...Oh no...I don't want to...to be with her cause she might end up in a wheelchair...I might have to look after her or they'll leave...that's what I thought. Susan line 855

Davina was terrified at her diagnosis, because her uncle's MS had rendered him wheelchair dependant at a young age and was looked upon by the family with shame. The family used to tell people he had a head injury from falling of a ladder, denying MS. The fear of the reality of a wheelchair in MS was personal for Davina.

I felt terrified, absolutely terrified because I had no idea what was happening to me...and my mother was frightened...because on top of all of this, I had an uncle who had MS and who was wheelchair bound . Davina line 360

Post traumatic stress disorder (PTSD) is a disabling condition typically characterised by the re-experiencing of a traumatic event and experiencing intense fear, helplessness or horror (APA 2013, p. 467). The prevalence of PTSD in MS was first postulated as being approximately 15% in a study sample of 58 participants (Chalfant, Bryant, & Fulcher, 2004). However, this finding was not replicated in a larger study of 232 participants where PTSD prevalence was reported as approximately 5% (Ostacoli et al., 2013). Interestingly, there was no relationship found between the presence of this mental health disorder and the severity of the disease. There are some peculiarities in PTSD in MS, as it is not related to a single event in the past but rather to the course of the degenerative condition, and the intrusive PTSD symptoms are typically orientated to the future, such as fear of the wheelchair, relapses and progression (Ostacoli et al., 2013). In the current study, no participants were formally diagnosed with PTSD, however intense physiological

reactions to talking about fear of future disability and wheelchairs figured strongly for Paul, Davina, Will and Susan.

The mere thought of MS can strike fear in people, even without any knowledge of the disease (Lysandropolous et al., 2015). Previous studies have demonstrated fear as an emotion central to the MS journey, but more recent studies on these specific phenomena in RRMS are lacking. A qualitative study, which interviewed ten women with SPMS, described how the women felt fear due to uncertainty about the future, fear intruding as the participants felt they did not know what was happening to their physical bodies (Olsson et al., 2008). A larger study interviewed 27 PwMS and used IPA methodology to reveal that fear of the future was prominent for PwMS, and in particular, fear of mobility loss, becoming a burden to family members and placement in a nursing home (Finlayson, van Denend, & DalMonte, 2005). Although the authors did not specify the type of MS in their inclusion criteria, participants needed to have MS for more than 15 years and be aged over 55 years, suggesting some elements of progressive MS and possibly influencing the fact that nursing home placement figured in fear. This nursing home fear was not evident in the present study, perhaps due to earlier disease stage of the participants or the presence of more effective patient education and DMTs in the modern era.

Fear is often induced by the vagueness of symptoms pre-diagnosis, and the uncertainty of the cause of MS post-diagnosis and the possible disease trajectory (Thorne et al., 2004). A study from Thorne and colleagues (2004) used focus groups/individual interviews and phenomenological methodology with a group of 12 PwMS and introduced the concept of “fear points” in the MS journey. “Fear points” are modifiable moments where patients receive either support or obstruction to their fear (Thorne et al., 2004). If timely, relevant and accurate information and validation of their experience is provided at these vulnerable times, the MS HCP/MS Nurse can modify these experiences significantly for PwMS (Thorne et al., 2004). “Fear points” will be different for each individual, but if carefully looked for and assessed by MS HCPs and MS Nurses, appropriate referrals may prevent future escalation of emotions and improve QOL. For some participants in the current study, fear resolved over time, but for others it never completely resolved. Fear sometimes turned to more chronic worrying, or expressed itself in other ways such as anxiety and

depression. Sometimes it was addressed with counselling and psychological interventions and sometimes it was shelved temporarily only to resurface at a later time. But fear in some form, at some time, featured in almost every participant's life story.

Theoretical foundations from fear studies can also help MS HCPs understand that perhaps some degree of fear may be helpful in clinical care. Looking at a positive aspect to the fear story, the seminal work of the "fear drive model" assumes that the emotional response of fear can function as a drive to mediate belief change and behaviour change (Leventhal, Meyer, & Nerenz, 1980). At times during the RRMS journey, our patients need to change beliefs and to change behaviour in order to adhere to evidence-based MS wellness prescriptions such as smoking cessation, adherence to DMT regimes, adherence to safety monitoring programs and follow-up appointments. A careful assessment by the MS HCP/MS Nurse is crucial in determining the impact of fear on an individual patient and whether referral to appropriate resources is required.

Weary from worry and anxiety

Worry is carrying tomorrow's load with today's strength

Carrying two days at once and moving tomorrow ahead of time

Worry does not empty tomorrow of its sorry

It empties today of its strength

Corrie ten Boom

Worry is negative thinking arising from anxiety; it is a longer-term feeling than fear and has been described as an active anticipation of possible negative outcomes (Vasey, Crnic, & Carter, 1994). For the purposes of coding clearly and consistently for data analysis in this study, worry was conceptualised as different to fear and was defined as both a noun and a verb "being troubled or feeling troubled over actual or potential problems" (Oxford dictionary, 2017). Anxiety disorders are listed in the Diagnostic and Statistical Manual of Mental Health disorders, fifth edition (DSM-V), (APA, 2013) as a diagnosable mental health illness, of which I am not authorised to

diagnose as an registered nurse. However, I do have the skills to assess for the presence of anxiety and to refer to appropriate HCPs for further assessment and advice. For the purposes of this study, anxiety was based on DSM-V descriptions; challenging a person's control, consisting of a mix of symptoms such as fatigue, impaired concentration, irritability, difficulty sleeping and impacting on day to day activities for a prolonged period of time, and conceptualised as excessive worry.

Previous studies have demonstrated high levels of worry in PwMS, and a link between worry and anxiety, separate but unique related psychological constructs (Bruce & Arnett, 2009). A quantitative survey based study of 50 patients (of mixed RRMS and SPMS) demonstrated that 36% of participants experienced worry in the elevated range and also that worry was associated with depression and anxiety (Bruce & Arnett, 2009). The authors report that indeed, the very nature of MS (uncertainty, symptoms, threat of relapse) may create an optimal environment for excessive worry, supporting the findings in the present study where some degree of worry interjected the lives of all participants at some time. The concept of worry in MS as an independent construct certainly requires further exploration and research, particularly as excessive uncontrollable worry can also progress to a more serious generalised anxiety disorders (Bruce & Arnett, 2009) or other anxiety and depressive disorders (Thornton, Tedman, Rigby, Bashorth, & Young, 2006).

In the current study worry took on several forms, and sometimes the participants worried about themselves, but just as often they worried about their loved ones and how RRMS was affecting the family unit as a whole. Almost all participants worried about something directly related to MS at one time or another, with worry about becoming a burden in the future a common worry. The chronic worriers could then go on to feel anxiety, either acutely or more long term, and for this reason (as a linked concept) anxiety has also been included in this sub theme.

In the midst of a severe motor function relapse, Rudi felt at her most vulnerable, feeling anxiety herself, but also feeling that she was the cause of anxiety for her young daughter. Rudi was worried about hurting her children if a relapse came on suddenly whilst she was driving and caused an accident.

I went through a really bad period with anxiety, to the point where I nearly gave up driving...because it happens so quickly (relapse)...so I thought...I'm going to hurt my children or I'm going to hurt someone else...I suppose it's going to be always in the back of your mind...I mean I was to the point where I used to drive with no-one in the car and see how long it would take me to stop by pulling the handbrake on...working on things to keep my children in the safest place possible. Rudi line 702

In the first year after his diagnosis, Paul spent hours at night researching on the internet everything he could about MS, his GP suggesting that he might need some professional help and counselling because the worrying and need for information became excessive.

And you know at night ...and this is why the GP sent me off to the psychologist, I don't have very good sleep at all, I sort of just lay there and I sort of get on the phone or ipad and read all this stuff (on MS) for hours at night, every night...the first year after diagnosis was very hard...I was...you know...anxiety...and you know, no matter how you try, and rationalise it, you can't, you just can't beat the fact that you're a human being and that emotions are part of...you know, being alive. Paul line 477

Davina was learning to cope with her new diagnosis of RRMS and became pregnant shortly afterwards, causing her worry and anxiety over how she was going to balance both the new disease and motherhood.

It was a huge shock and I was such an anxious person to start with, so dealing with a diagnosis and then being a very young mother...I also had a very anxious pregnancy because I didn't know how. Davina line 539

Worry about being a burden to the family

Worry about being a burden, either in the present or in the future, and worrying about what MS was threatening to do to their family unit and loved ones was common to almost all participants at some point of their RRMS journey. This sub-

subtheme also focuses on the participants worrying about family members being worried about their RRMS.

It has been suggested that one of the greatest challenges for children whose parents have MS is balancing caring for the parent with restraint in expressing their own feelings to protect their parent and avoiding burdening them with their own sadness of MS (Moberg, Larsen, & Brodsgaard, 2016). For Rudi, her children witnessing her last severe relapse has been a constant cause of worry for her, sometimes much more than the worry she has for herself physically. Rudi sought psychological counselling for her daughter to help manage the anxiety her daughter feels.

(When my last relapse happened) the children were hysterical...the kids, so they were in tears and so...so...that's really tough...I find that tougher than the physical side of things sometimes...they shouldn't have to go through that at such a young age...(my daughter) she takes too much of it on board. Rudi line 625

After a serious fall and fractures a few years before, Kate's mother worried constantly about Kate falling again and being on her own, sometimes frustrating Kate as she struggled to get to one phone with limited mobility.

If I don't answer the phone then she'll ring the mobile and if I don't get to that in time, she'll ring again and it's whole panic stations, she thinks something's happened to me...I know she worries but it doesn't help. Kate line 2398

Ruby worries for her sister, that her sister feels left out of the family unit as there is so much fussing over Ruby. The situation of Ruby requiring frequent assistance with home and childcare because of her significant MS symptoms also causes stress for her retired parents as well.

MS has changed our family dynamics...I mean Mum and Dad were stressed about me...I think my sister feels a bit left out (Ruby cries)...it would be nice if it wasn't all about me. Ruby line 1147

Worry for PwMS regarding affording MS healthcare and medications has figured prominently in an overseas study (Jones & Amtmann, 2014), however this theme did not present in the current study. This could be due to the fact that the Australian government has subsidised access for residents prescribed DMTs to treat RRMS, providing them at a greatly reduced cost.

Existing with anxiety

As previously discussed in chapter 2, anxiety is more prevalent in the MS population than in the general population (Wood et al., 2013; Feinstein et al., 2014) and has been strongly associated with lower QOL scores across all levels of illness severity, from mild impairment to severe (Ionescu et al., 2012). Anxiety is also more prevalent in females than males in PwMS (Theaudin et al., 2016). Several participants in the current study reported feeling anxious at many stages of their RRMS journey and often felt that they were left to cope with anxiety on their own.

High levels of anxiety have been associated with an emotional preoccupation of MS, and focusing on the emotional consequences of the disease (Roy-Bellina et al., 2010; Tan-Kristanto & Kiriopoulos, 2015) rather than physical symptoms. Susan demonstrated this in the present study when she described a time in her life when she felt being completely mentally overtaken by MS, to the point where she couldn't concentrate anything else in her life, not her family, not her work and not her usual sources of happiness. Paul described spending many nights lying awake, feeling anxious and researching MS on the internet, despite having very little physical disability at the time.

Interestingly, negative life events, problems in family life and social functioning can also be significantly associated with anxiety (Liu et al., 2009). Stress in childhood has been explored as potentially being a risk factor to developing MS in later life (Nielson et al., 2014). Childhood stress was present in the life stories of Joy, Will, Margot, Rudi, Davina, Evie, and Griff, for varying reasons including loss of parents, divorce, alcoholism, moving to foreign countries and childhood illness. A nationwide cohort study from Denmark found that there was an increased risk of MS amongst persons exposed to stressful life events before the age of 18, especially long term

stress (such as parental divorce) rather than acute events of significance (such as the death of a parent or sibling) (Nielsen et al., 2014). Others have also found that exposure to abuse and neglect in childhood increased MS risk (Spitzer et al., 2012). In regards to stress influencing MS activity, there is substantial evidence that disease activity is increased under stress (Saul et al., 2016), but this particular study looked at stressful life events in the 12 months preceding diagnosis, not in earlier childhood.

A systematic review exploring predictors of anxiety found that positive reinterpretation, social emotional support and humour predicted an improvement in anxiety symptoms (Butler et al., 2016). In the current study this was demonstrated repeatedly as study participants recounted stories of anxiety followed by seeking assistance and at times, psychological help. Anxiety is most highly associated with depression, low self efficacy, stress, emotion focused coping, pain, fatigue and QOL, factors that may be amenable to intervention if identified and actioned by MS HCPs (Butler et al., 2016). Furthermore, a prospective study has shown that depression can strongly predict anxiety and anxiety can predict later depression (Brown et al., 2009), continued revisiting of both of these issues by MS HCPs longitudinally could have an immense impact in preventing future problems.

Depression and Despair

Depression...I knew what that felt like...there was nothing...it's nothingness...a feeling of nothingness...I know this sounds strange but it's the only way I can describe the feeling. Evie line 270

Dealing with depression

As already discussed in chapter 2, for people living with MS the lifetime prevalence rate of a depressive disorder has been reported as greater than 50% (Hoang et al., 2016). As with anxiety disorders, depressive disorders are a diagnosable mental health illness under the DSM-V (APA, 2013), following listed criteria including depressed mood, loss of interest and enjoyment in usual activities, reduced energy, reduced self esteem and confidence, ideas of guilt and unworthiness, pessimistic thoughts, disturbed sleep and appetite and ideas of self harm (APA, 2013). For the

purposes of this study, depression was coded if it seemed reasonable in the descriptors the participants used to express their feelings, or if the participants used the term themselves (which occurred in the great majority of cases). “Feeling depressed” is a common phrase people use to describe many emotions, but I only included it in the coding if there was supporting evidence from the study participant that it was more serious than a fleeting emotion (such as a formal diagnosis or a story of prolonged depression with symptoms such as those described above). Despair was defined as a noun, the complete loss or absence of hope; and as a verb, to be without hope (Oxford dictionary, 2017). Both depression and despair have been conceptualised under the same subtheme, as they often paired together in the participant’s narratives. However, the accounts of the participant’s stories for depression and despair will be kept separate.

A British study exploring patient’s feelings when transitioning from RRMS to SPMS, used thematic analysis to interview nine PwMS and seven HCPs. The researcher found that shock and devastation is common in response to being reclassified as SPMS, and is a significant psychological blow (O’Loughlin, 2015). Participants in the study emphasised the importance of being able to debrief with an MS Nurse after discussions on this topic so that they have ample opportunity to ask questions and reconfigure the news in a hopeful manner (O’Loughlin, 2015). In the current study, this experience was shared by Davina who pinpoints the day she was told that she would one day transition to SPMS, as the day her battle with depression began. Davina was reviewed by a psychologist and diagnosed as being moderately depressed, but failed to follow-up or seek further care, she had a fear that she would be medicated and didn’t want that for herself following years of working in the health system herself.

When something does happen it hits me like a steam train and I go down to the depths of depression...like I won’t get back up again...I think I’m consistently just a little bit depressed...I think it after I was told that it could convert to progressive...and then the interferons would make that feeling of desperateness...hopelessness...it would make it a hundred times worse. Davina line 1068

Piper was formally diagnosed with depression at different stages of her life journey, both before and after her RRMS diagnosis. Despite the negative impact depression was having on her life, she was not keen to seek help until her husband demanded it.

I sort of probably had a bit...a bout of depression...I was treated with a counsellor...in hindsight you could see a pattern from younger and it was only that my husband said to me if you don't do something about it...this marriage is over...that it sort of pushed me. Piper line 279

Susan was single for many years, deeply concerned that she would not find a life partner who would accept her RRMS. Living alone with RRMS at times of major life events often triggered symptoms of what Susan termed as depression.

(Buying a house) was another turning point for me because I was again...depressed...thinking I'm doing it on my own and what if something happens again? Susan line 633

After her first MSA meeting, where she met several young people living with significant disability and progressive MS, Jane refused to go to any more meetings and to avoid the feelings of sadness she was experiencing, which Jane referred to in her life history as depression.

We were just sitting there crying and I thought I don't want to go back to this because it's just too depressing...because they don't work, they don't study, they're at home in a wheelchair and they're not going anywhere...and it's just too depressing. Jane line 211

The interferon injections were also a constant source of what Jane refers to as depression, not just the fact she was self injecting, but that she always felt so much worse after the injections. Jane ceased treatment after a couple of years, finding it preferable to be on no treatment and risk relapses rather than feel depressed.

(being on Rebif®) you just had to inject all the time and it's just depressing...I used to hate it...and I thought I might as well just give up and do nothing...and it was just really depressing. Jane line 372

After his neurologist sought special permission for compassionate use of an expensive DMT so he could have it at no cost, Will was tormented about doing the right thing and battling his feelings of depression. His life went into a downward spiral for several months.

It's probably the greatest thing anyone has ever done for me...but then I threw it all back in his face...depression set in pretty bad...I just wasn't feeling any better...I didn't contact them (MS team) so I went unmedicated...I quit my job...I hadn't told my family at this point about my diagnosis. Will line 880

Rudi felt that because she has been through so much in her life, from a troubled childhood living with a single mother diagnosed with bipolar disorder to the stillbirth of her third son, that it was time for life to be fair to her. Rudi often felt the demons of depression and worked hard to fight them.

I do tend to crash and burn emotionally because things are just taken from you...I suppose that's when I get down cause I think it's not fair...I think because I've been through so much in the past that you know how hard I have to fight and you look at it and you feel tired just thinking about it...when you've had to fight all of your life. Rudi line 1690

Face to face with despair and hopelessness

It has been suggested in chronic illness literature that despair and hopelessness actually help move towards hope for patients, as awareness of the future and consequences become clearer (Morse & Penrod, 1999). It has also been suggested that maintaining hope is a balancing act between hope, hopelessness and despair, with patients often passing through despair when moving toward hope or hopelessness in a study of living with another chronic illness, acquired immune deficiency /human immunodeficiency syndrome (Kylma, 2005). Moore (2005) has

placed hopelessness at the centre of despair, with despair occupying the bigger picture and hopelessness one component of it. Threats to hope (and thereby opens to hopelessness and despair) include pain and other uncontrolled symptoms, spiritual distress, fatigue, anxiety, social isolation and loneliness (Fitzgerald Miller, 2007), all potential threats when living with RRMS. Interestingly, perceptions of hopelessness from those seen by the patient as “powerful”, such as HCPs and family, may also threaten hope (Fitzgerald Miller, 2007).

Davina described times of feeling hopelessness and the angst she felt at never ending darkness. For several years after her diagnosis, Susan struggled with managing her feelings around RRMS, often taking two steps forward and one step back and never feeling emotionally in control as life went on around her.

I've had times of hopelessness, people say to me you're not your disease and I'm not...but...sometimes it becomes my focus and I can't think past it because hope to me is looking to my future, that's hope. Davina line 1523.

Hopelessness is dark and it's lonely...and it's never ending darkness and misery...hopelessness feels like it's never going to end, that nothing's ever going to fix it. Davina line 1539

I felt like I'm here but I'm not here...I felt numb...I thought I can't feel like this...I can't think like this. Susan line 481

Joy suffered debilitating bouts of deafness and blindness, the aftermath of coping with sensory loss took her to the depths of despair.

It was horrific...it nearly broke me (tearing up)...and I went into a downhill spiral emotionally...(and later)...I deteriorated from there...so the visual thing would come and go it was just really, really hard and I'm trying to hold down a job and I'm saying to my husband I'm so sick I have to, I have to give up work I'm so sick, I can't work and he was just like 'absolutely not' ...I was heartbroken. Joy line 855

Choosing to keep thoughts of despair and hopelessness to themselves was sometimes the chosen path, no matter how much support was around them at the time. Will discussed his feelings, keeping his friends away from what was happening after the diagnosis of RRMS was made. He made this conscious decision to distance his friends from his diagnosis of MS because of a family friend who was wheelchair bound and severely disabled.

I had a breakdown to be honest...and no-one saw it, not even my best friends, I hid it from everybody...it was just the worst and again, looked back at my friends stepfather...and that's all I could think of. Will line 700

Depression, despair and loss of hope in MS can be serious and life threatening issues. Loss in MS goes beyond loss of ambulation and function and also incorporates the loss of future plans and dreams, pre-morbid roles and significant relationships (Gedik et al., 2017). Thoughts of death and self-harm are prevalent in MS, with data suggesting that over a quarter of PwMS (type not specified) contemplate suicide (Feinstein et al., 2012) and that young males in the first five years of diagnosis are the most at risk (Feinstein, 2011). A recent study of 3,823 MS patients used a systematically collected questionnaire during routine clinic visits to capture the frequency of thoughts of death in patients with epilepsy and MS (Dickstein et al., 2015). A prevalence rate of 15% in the MS cohort was reported (slightly higher than epilepsy), associated factors being depression, male and unmarried, medical comorbidities and poor QOL (Dickstein et al., 2015).

Exploring suicidal thinking in MS, researchers used questionnaires and semi structured interviews to talk to 16 PwMS (type not specified) who all expressed suicide ideation, but not suicidal intent (Gaskill, Foley, Kolzet, & Picone, 2011). Fear of burdening their family was one of the most common reasons participants gave for thinking about suicide as a way of reducing family tension. They also identified issues of feeling a loss of control, loss of femininity/masculinity, hopelessness, feeling lonely and symptoms of MS; all amplified if they were in distress (acute symptoms, pain) exacerbating the feeling of being a burden (Gaskill et al., 2011). Despite most participants in the current study expressing concerns about burdening their families, no participants in the current study spoke directly about

suicidal thoughts. Will discussed having several emotional “breakdowns” during the course of his life journey living with RRMS, during his long diagnostic process and hospitalisation and then again a few months following his diagnosis of RRMS.

Struggling with the saboteurs

A saboteur destroys, damages or obstructs (Oxford dictionary, 2017). Saboteurs are the unwelcome demons that threaten happiness and downplay moments of joy for PwRRMS. These saboteurs were different for each individual, but could have a significant negative impact on living with RRMS. The saboteurs I identified as subthemes were “Coping with uncertainty”, “I’m never free of MS” and “Social isolation”.

Coping with uncertainty

When a person’s actual present and future is characterised by uncertainty, a person’s sense of feeling whole is threatened (Olsson et al., 2008). Uncertainty in chronic illness has been well recognised (Mishel & Braden, 1988; Mishel, 1990) and it is not surprising that the uncertain and ambiguous nature of MS creates the “perfect setting for uncertainty to thrive” (Tams, Prangnell, & Daisley, 2016). Uncertainty can take several forms in MS, including symptom uncertainty, medical uncertainty and daily living uncertainty (Gray & Arnett, 2014). This is further hampered by a lack of pattern manifestation in terms of remission and relapses (McReynolds, Koch, & Rumrill, 1999), so it becomes difficult to control and predict. Eventually being diagnosed with MS and piecing together the puzzle doesn’t do away with the concept of uncertainty, in many ways the uncertainty has only just begun.

Mishel (1990), a nurse researcher and theorist, spent many years studying uncertainty in illness theory. Mishel (1990) defines illness uncertainty as being multifactorial and encompassing doubts and unpredictability’s relating to symptoms, diagnosis, treatments, relationships, prognosis and future planning. All of these components are features in the RRMS journey and impact directly on PwRRMS, sometimes on a daily basis and in multiple ways. Every participant in the current study felt the wrath of unpredictability at some time in their life, with the inability to

plan for a “normal” future, presenting as a constant stumbling block. Coming to terms with uncertainty in MS and the inability for long term planning is problematic for many PwMS (Finlayson et al., 2005) and, as previously explored, can lead to other demons, such as anxiety, fear, despair and depression breaking through the barriers to take control.

Of all the saboteurs, coping and living with the uncertainty of such an unpredictable and incurable disease caused challenges for most of the study participants. They told of stories about the uncertainty of where MS will target next, how bad a relapse might be and how their individual disease may ultimately progress. Many found the concept of being diagnosed with a disease with no definite prognosis difficult to live with and coming to terms with uncertainty was a daily battle for them. Kate was the mother of a two year old child when she was diagnosed and uncertainty caused some challenges in planning life.

RRMS...is unpredictable...and scary...extremely scary because you don't know what's going to happen...Kate line 24

I had a two and a half year old son at the time (of diagnosis)...it was scary...You couldn't plan your life because you were always worried about a relapse...going on a holiday...I was scared and always at the back of my mind was what would happen...what am I going to do? Kate line 1248

Knowing the DMTS could reduce relapses, but not stop them altogether impacted both Jane and Piper, the uncertainty always a factor.

You just think it's a very difficult disease because you never know what's going to happen...you can't judge anything. Jane line 745

I'm still going to relapse at some point really...aren't I...I could relapse more often on one of them (medications)...you don't know. Piper line 1393

I'm never free of RRMS

Caring for chronic illness takes planning, time and motivation by the patient (Katon et al., 2010) and can be hampered by constant intrusion to everyday lives (Larsen, 2016). Integrating illness into daily life includes skills of modifying lifestyle and seeking normalcy through balancing activities and illness needs (Schulman-Green et al., 2012). Some participants discussed how RRMS is always with them, which is one of the realities of living with a chronic illness. This seemed to be most prevalent in the time after diagnosis when thinking about MS took up so much time and energy. Life enjoyment was sabotaged by the continuous preoccupation with RRMS, and this could happen at any stage. For Paul, it was constantly on his mind, and he felt that he didn't need to share that burden with others.

There wasn't a moment that would go by where I wasn't thinking about MS...I've always got it in the back of my mind...don't get too comfortable and think that everything's going to be OK...be prepared. Paul line 852

(on non-disclosure to his close friends) I'm reminded enough of it as it is...I don't need to...other people to...I don't need any more, that's enough, you know...everyday you don't go without thinking about it...it's impacted my life in that way, in a big way. Paul line 1024

Between relapses, Rudi kept a lot of her symptoms to herself and frequently hid how she was feeling, reluctant to let others know that RRMS is always with her, even when she appears well and back to “normal”. Similarly, Will refused to be a burden to his wife, he worried that he wouldn't be seen as the strong man he wanted to be seen as and often hid symptoms from his wife so that she won't have cause for worry. However, sensory loss in his hands and the loss of the feeling of intimacy when holding hands with his wife, are reminders that he is never free of RRMS.

I don't think (my husband) realises that I have something every day...because I don't tell people...oh I had pins and needles today...or I'm a bit tired today...I get sick of talking about MS. Rudi line 1413

I hid it from my family and I do it for the simple fact that...my wife's pretty fragile...we've got responsibilities...I need to be that strong person...I wouldn't want anybody to have to go through how I feel on a daily basis. Will line 64

I hide the aspirin packet so my wife doesn't see it because I don't want her worrying about it...she's got a baby to look after...I know how hard it is to deal with all of this and all of that...My hands are very numb you know, things like having my wedding ring on, I don't know if I've got it on or not, I can't feel it, which is sad...I've never said this to my wife because my wife always wants to hold my hand and I don't know if I'm holding it or not. Will line 100

Social Isolation

Social isolation refers to the absence of social relationships and social networks (Umberson & Montez, 2010) and has been reported to be a risk factor for suicide in MS (Feinstein, 2002; Pompili, 2012). Seminal work in chronic illness suggests there are health risks of social isolation and loneliness (Charmaz, 1983). There is a paucity of literature exploring social isolation and MS, but there have been reports in health policy literature, which suggest that both the quality and quantity of social relationships affect mental health, health behaviours, physical health and mortality risk (Umberson & Montez, 2010). Prospective studies of mortality have shown that individuals with low levels of social relationships were more likely to die than those with greater social relationships (House, Umberson, & Landis, 1988). In adults with medical conditions, social relationships also reduce mortality risk, confirmed in a study of coronary artery disease (Brummett et al., 2001).

The daily grind of social isolation could be a constant saboteur to mental health and how the participants saw themselves. Griff became a stay at home father after losing his job because of his MS symptoms and has never returned to the workforce. Now that his children are older, he finds himself frequently alone and struggling with social isolation.

The social consequences of social isolation...I was never allowed to be completely "in" with the mothers groups, with the playgroups...the kids start high school and

the first thing they tell you is we don't want to see you...my days are spent wastefully...social contact is what you're trying to establish so people have...you know, community to operate in...well I don't have those links anymore...it's not going to be easy for me to return to the workforce...who'd want me anyway? Griff line 707

Recognising the demons to battle

What we know about some of these demons (fear, anxiety, depression, PTSD) and MS is that they can be fatal. Of course, MS and MS treatments can also be fatal, but that situation is far less prevalent than demons such as depression, which can induce suicide (Feinstein et al., 2014). The demons of fear, worry, anxiety, depression, despair and social isolation can be interlinked in many ways, for example depression and anxiety often go hand in hand to sabotage mental health, predictive of each other in MS (Brown et al., 2009). Worry can lead to anxiety, anxiety can lead to panic and depression can lead to despair and hopelessness. These negative emotions can then also interfere with RRMS treatment, with people suffering mood and anxiety disorders in RRMS being five times more likely to non-adhere to their DMT (Bruce et al., 2010). MS Nurses have an important role to play in assessing and monitoring for signs of these demons, as trusted confidantes by PwRRMS, they often can discuss these issues and advocate for PwRRMS to ensure early referral to appropriate services (Porten & Carrucan-Wood, 2017).

The following theme of “Surplus Suffering” explores a novel concept in MS care, which may inadvertently contribute to some of the demons experienced by people living with RRMS. The concept of Surplus Suffering is suffering over and above that experienced by the disease of RRMS itself and represents an area of MS care with no existing specific literature.

Theme 4: “ Surplus Suffering”

Only through the experience of trial and suffering can the soul be strengthened, vision cleared, ambition inspired and success achieved.

The world is full of suffering; it is also full of overcoming it.

Helen Keller (1880-1968)

The **central organising concept** for the theme of “Surplus Suffering” is suffering inflicted by others onto the PwRRMS over and above that imposed by the condition itself.

Eric Cassell, a physician who has explored the concept of patient suffering in medicine for decades, has defined suffering as “the distress that is brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person” (Cassell, 1991, p. 4). Suffering affects the entire person, extending past the physical to emotional, social, spiritual, existential and financial domains and often not fitting neatly into current biomedical paradigms (Epstein & Back, 2015). Many people living with chronic illness suffer as they experience their illness, but it is the broader significance of the suffering beyond physical discomfort which can cause the loss of self for many people with chronic illness (Charmaz, 1983). Indeed, consequences of suffering spread and accumulate through one’s life and can prevent patients moving forward into the present, stealing joy and limiting social worlds (Charmaz, 1999). Suffering is important for MS HCPs to consider because it can lead to some of the demons discussed in the previous chapter, especially isolation, hopelessness and vulnerability (Reed, 2003) and involve a loss of dignity and alienation (Coulehan, 2011).

It has been argued by Cassell and others that little attention or discussion has been given to the problem of suffering and patient emotions in medical education, research or practice despite the relief of suffering being considered one of the primary ends of medicine by both patients and the general public (Cassell, 2004; Kenny et al., 1997; Shapiro, 2011). Furthermore, suffering is ultimately highly personal, the presence and degree of the suffering can only be known to the sufferer

(Cassell, 2004). If suffering is not relieved, there is a threat to the person's integrity and a loss of part of that person as their suffering continues (Cassell, 2004). This degree of suffering and loss to self was evident during the current study. Several participants whose physical, mental and emotional suffering continued with them for many years after the precipitating event, felt an intense impact on their present sense of self and their life living with RRMS. This will be highlighted throughout the remainder of this theme with the use of participant comments, crystallising their experience of Surplus Suffering.

Medical models of suffering tend to concentrate on fixing, curing and eliminating illness compared to the nursing perspective which tends to look at the broader paradigm of the quality of a life lived (Ferrell & Coyle, 2008). As nurses play a fundamental role in the caring of those who suffer, and are present for people as they struggle through illness, the relief of suffering is at the core of nurse's work (Ferrell & Coyle, 2008). Suffering is a universal human experience and nurses commonly encounter pain and suffering at all levels when caring for their patients (Davitz & Pendleton, 1969; Reed et al., 2003). Nurse researcher Morse (2001) has identified two stages of suffering: *enduring suffering* which occurs when the sufferer brackets their emotions so that they continue on in everyday life, not expressing the negative emotions and *emotional suffering* which is a distressing state where emotions are unconstrained. Individuals can move between the two types of suffering depending on their circumstances and context (Deal, 2011). Participants of the current study reported experiences of both enduring and emotional suffering.

Surplus Suffering as a concept was first described by James and Clarke (2001) as they explored the experience of Portuguese immigrant women adjusting to life in a new country and the extra suffering inflicted on them as a result of seeking healing in a western health care system where disagreement arose between their old culture and the new health care system (James & Clarke, 2001). In that particular study, Surplus Suffering was conceptualised as the women suffering over and above the signs and symptoms that brought them to medical care in the first place (James & Clarke, 2001). Further work in Surplus Suffering by Clarke and Fletcher (2005) explored experiences of parents when their child was living with cancer, interviewing 29 parents and discovering that "problems in the system" and carelessness, unkindness

and mistakes led to increased suffering for children and their families. In this work, the authors conceptualised Surplus Suffering as the extra, unnecessary suffering that can result from the HCPs and the health care system, in addition to the inherent physical suffering already resulting from cancer and its treatment (Clarke & Fletcher, 2005). Clarke went on to explore further themes of “Surplus Suffering” as a key component in studies of people living with Asperger’s syndrome (Clarke & van Amerom, 2007), parenting a child with mental health issues (Clarke, 2012) and childhood mental health issues (Clarke, 2013).

Whilst listening to the stories of many of the participants I interviewed in the current study, at times I was struck by the realisation that the medical/health system had let these PwRRMS down in some way and induced additional distress on top of the burden of living with RRMS. By this I mean suffering in addition to that caused by disease onset, disease symptoms and disease related disability and in addition to the considerable mental health and emotional burdens discussed in the previous theme, *Battling the Demons*. Very sadly, the stories of additional distress experienced by the participants in the current study sometimes involved compromised care from their HCPs, neurologists and nurses, exacerbating the disease-related suffering these PwRRMS were already experiencing. For other study participants, it was the additional emotional pain inflicted by those they loved or trusted, such as family or friends or sometimes by strangers. During the study interviews I was struggling to find a way to describe some of the similar feelings and experiences I was hearing from the participants (and later coding and analysing) that effectively described the concept of what I initially termed “added distress” or “compromised care”. When I unexpectedly came across the work of Clarke at a qualitative research conference in May 2017, the concept of Surplus Suffering fit the data exceptionally well and truly captured the essence of the stories I had been told. Unfortunately, I realised at that moment that Surplus Suffering was alive and happening in the field of RRMS.

Surplus Suffering reminded me of the seminal work by Charmaz (1999, P.365) of suffering and chronic illness:

“When in agony suffering is immediate and relentless. Suffering can also be insidious. It steals in and it spreads out. It is of the self and it is social. As suffering

spreads out it shapes social relations and limits social worlds. Such suffering means work - for chronically ill people, caregivers and co-workers.”

The notion that suffering is dangerous, stealing in and spreading out and affecting many others in its path was highlighted in the stories of study participants. Surplus Suffering presented a risk to the health and livelihood of the affected study participants until it was discussed, assessed and positively managed. The significance of suffering in chronic illness has been well documented by nurse researchers (Morse & Carter, 1996; Charmaz, 1999); suffering shapes stories and meaning and poses existential problems of identity and self as one lives with chronic illness (Charmaz, 1999). Often MS Nurses will hear stories from patients of positive and negative experiences they have had with other HCPs leading up to, and after, their diagnosis of RRMS. Even if Surplus Suffering was not inflicted under their care, the MS Nurse could possibly be dealing with the impact of previous Surplus Suffering on the PwRRMS in current consultations. This could in turn influence learning and education, adherence to medication/lifestyle recommendations, trust, loyalty and likeliness to partner with us as HCPs in future care. It is something MS Nurses need to explore and assess at the beginning of their professional healthcare journey with a PwRRMS. Everyone’s journey is unique, not all PwRRMS will have stories of Surplus Suffering to tell, but many may well.

Towards understanding and a definition of Surplus Suffering in RRMS

From the study participants’ interviews and stories, and from the literature on the phenomena of suffering, I have adapted a definition of Surplus Suffering from the work of James and Clarke (2001), Clarke and Fletcher (2005), Clarke & Amerom (2007) and Clarke (2012, 2013) to fit a conceptual model of living with RRMS:

Surplus Suffering is suffering caused to PwRRMS over and above suffering from the existing physical, emotional and mental burdens of the disease. Surplus Suffering in RRMS is caused by the actions of others; including HCPs, the healthcare system, family, friends or community.

Surplus Suffering inflicted by HCPs in clinical care

The most moving story I listened to during the interviews was the multifaceted story of Surplus Suffering incurred by Joy for most of her childhood and then continuing into her adult life. As a small child Joy endured mysterious burning sensations which interrupted her sleeping patterns and stopped her from enjoying play with other children in her small country town. Joy's Surplus Suffering began when her parents never believed Joy's pain and neither did doctors when her mother eventually took her to be assessed. The Surplus Suffering lay in the emotional pain in this case of being ignored, rather than the physical pain. Additionally, Joy's mother had been labelled as having Munchausen syndrome, a form of factitious disorder listed in the DSM-V (APA, 2013) where people exaggerate or create symptoms to seek medical attention and assume the patient role. Growing up in a small rural community this was a difficult label for Joy to avoid. Her pleas for help were not taken seriously and intense pain and sensory symptoms were not investigated further. Even when Joy suffered a form of sudden dyslexia at age 16 and in just a few months plummeted from an A level student to failing school, she was still not believed; not by parents, not by teachers nor by HCPs. This pattern stayed with Joy into her adult life as she suffered various neurological complaints over the years (such as blindness, deafness, stroke-like symptoms) but was never investigated properly by her HCPs, often refusing her requests for further specialist referrals or investigative testing.

The doctors really weren't interested, they just didn't believe me...they thought I was a fruit loop, they thought I was crazy. Joy line 360

They just thought I was crazy and they weren't remotely interested and it didn't help that my mother...they treated her like she was a Munchausen's mother...they thought she was crazy, so I went to the doctor and said "I'm sick"...they thought...they believed this is the child of the Munchausen's mother, well of course she's going to be a hypochondriac...I didn't even get any tests or anything. Joy line 369

I went deaf and my right leg dropped and right arm...but again he wouldn't send me for tests to see if I'd had a stroke...and I thought you're frigging joking! My right

side had dropped and you're not willing to do any tests on me? I just...despair...it nearly broke me. Joy line 403

Kate, highly educated and with experience in the medical and scientific field, sought neurological medical attention after sudden episodes of blindness could not be explained. Over 25 years prior to our study interview, Kate recalled her first visit with the neurologist when she was told her likely diagnosis was MS. Kate had no knowledge of the disease at that point in time and struggled greatly with the abrupt delivery of the diagnosis, leading to extreme Surplus Suffering in the many years since. There was no follow-up education and no chance to ask more questions at that consultation.

He says "you probably have MS"...he turns around and goes to me "and you may end up in a wheelchair and you will probably be blind in five years time"...I looked at him and thought, five years...I said I'm only going to be twenty seven and I'm going to be blind? And I was a mess...he gave me antidepressants to get over it and I thought...Oh, this can't be happening to me. Kate, line 243

Davina's experience of Surplus Suffering was also the result of the news of her diagnosis when it was revealed to Davina at the foot of her bed in a full hospital room shared by others. The doctor was presumably unaware of her family history. Davina had an uncle who had been hidden away from family and society with his MS, his physical disability instead explained to others as being the result of an accident and head injury. Davina was left devastated with no offer of follow-up care at that point and cried during the interview as she recalled this experience.

He stood at the end of the bed and said it's probably 99 percent definitively MS because you fit the age, your sex and your symptoms are very textbook...so I suggest to you that you think of your future and perhaps if children was something you were looking forward to, it might be something you think about now, because better to be a disabled younger mother than a disabled older mother...I was distraught...there was no-one to go to really. Davina line 471

In the area of power, dominance and medical interaction, the doctor-patient relationship has traditionally been viewed as an area where doctors exercise power over patients (Pilnick & Dingwall, 2011). In recent years this has been addressed in medical training programs, but research on whether there is a positive impact on a more patient centred approach having a positive impact on health outcomes has not been established (Jaen et al., 2010; Lee & Lin, 2010). One extreme model of the doctor-patient relationship is paternalism, where the doctor makes all the decisions without patient input (Goodyear-Smith & Buetow, 2001). In some ways, recent advances in medicine (such as the introduction of the more efficacious RRMS DMTs in the last decade) discards the whole person and concentrates on a list of scan results and blood tests (Aitini et al., 2014). This feels especially true of RRMS where the new DMTs dictate careful and prolonged scan and results monitoring, perhaps at the expense of a closer doctor-patient relationship. MS HCPs must be mindful to maintain a balanced, individualised and holistic approach. Relationships between doctors and patients with MS are particularly complex (Burnfield, 1984).

However, more recently it has been suggested that proper disclosure with effective communication requires discernment, tact, timing, flexibility, responsibility and sustained attention to the particular needs of the patient as a person in their own, unique context (Krahn, 2014). Studies have also shown that getting clear information can help reduce patient anxiety and distress with suspected MS, at all stages of the process (Heesen et al., 2004; Kopke et al., 2012). This means that the consultation where a diagnosis of MS is revealed should be planned thoughtfully with adequate time for preparation, a discussion of the likely diagnosis and planned treatment options, sources of support for afterwards, time for questions from the patient and a planned date for a follow-up appointment.

The paternalistic delivery of diagnosis and prognosis experienced by both Kate and Davina affected them negatively for many years. Kate immediately decided not to consult further with that particular neurologist and was fortunate to find a new specialist she was able to talk to about her concerns, listen to her questions and consider her feelings. However, she still felt anger and resentment for many years after her encounter. A gentler approach with Kate that took into consideration her specific context of being a 22 year old balancing terrifying symptoms, full time

work, mothering and part time university study may have ameliorated many years of Surplus Suffering and given Kate opportunities to manage her feelings. Davina still retains the emotional scars of the day her diagnosis was revealed to her, crying and emotional as she recalled the story from almost three decades ago. Similarly for Davina, realisation from the doctor of her previous life experience with MS in a close family member may have resulted in a gentler, more compassionate delivery of her RRMS diagnosis.

Studies have shown the importance of the physician-patient relationship to patients and the effect this relationship has on long-term adherence to therapies and lifestyle prescriptions (Koudriavtseva et al., 2012). In a disease such as RRMS, regular and consistent adherence to DMTs are essential to gain disease control and prevent future disability (Bruce & Lynch, 2011). A recent study of 97 people with “mild” MS using mixed methods of interviews and questionnaires, explored the physician-patient relationship and determined that patients with MS sought a close relationship with their doctor and more disease related information. On the other hand, sources of dissatisfaction included poor management of diagnosis, unavailability and poor accessibility, low levels of psychosocial support and a lack of information (Koudriavtseva et al., 2012). Furthermore, Mead and Bower (2002) identified five dimensions essential in a patient centred approach; a biopsychological perspective, viewing the patient as a person, sharing power and responsibility, practicing therapeutic alliance and also viewing the doctor as a person. Unfortunately, in the stories of Joy, Kate, Davina and Paul, they all believed that their biopsychological position was ignored, they were not viewed as individuals, they were given no power or access to shared decision making and no exposure to therapeutic partnership. Their care (in the stories discussed in this theme) was not patient centred and lacked information and support.

Surplus Suffering inflicted by brush-off

The concept of brush-off was explored in the first theme Piecing Together the Puzzle as study participants reported feeling ignored or dismissed by HCPs in the early days of their quest to identify the cause of their symptoms, in the lead up to a diagnosis of RRMS. As part of piecing together the puzzle, the concept of brush off was anchored

strongly in that theme. However, it is definitely also a form of Surplus Suffering and also belongs in this theme to tell a story of the emotional pain induced by the refusal of HCPs to take symptoms seriously, to investigate symptoms further or to trivialise symptoms. All of the participant stories and quotes from feeling brushed off as a part of Piecing Together the Puzzle also belong here in Surplus Suffering. Rather than repeat them, I will acknowledge their strong links as a form of Surplus Suffering, and also add some other instances where brush off figured strongly in participant stories.

Participants Davina and Susan have both served long careers as HCPs, and were impacted by Surplus Suffering directly from the nurses looking after them during inpatient hospital stays during severe relapses of MS. Both of these cases happened many years prior to the study interviews, but were still as real and distressing to Davina and Susan when I interviewed them. They have never forgotten what they felt as being abandoned by fellow health professionals when they needed them the most, the Surplus Suffering exacerbated by the fact this was from a profession they valued as caring and kind.

Davina worked at the same hospital where she was admitted as an inpatient and tells how the nurses secluded her in the furthest room from the nurse's station, causing her to feel isolated and alone at a time of intense vulnerability. Recalling her memories of what happened induced distress and she cried as she remembered how she felt.

They put me in the end room and the nursing staff on the neurology ward avoided me because I don't think they wanted to face me, that was very, very obvious...how do you treat someone who has just been given the worst news of their life...of which they didn't understand either. Davina line 511

When Susan was an inpatient following a severe relapse, she recalls feeling desperate for support in the middle of the night but received no compassion or guidance from the nurses looking after her.

I was scared and I was crying...and the nurses kept coming in and doing obs...I couldn't sleep and I said to the nurse, I'm very, very scared...I don't know what's going on" ...there was no support. Susan, crying, line 280

As explored in Piecing Together the Puzzle, Susan's GP would not refer her on for tests or to see a specialist despite her neurological symptoms and requests. Although the GP has since apologised to Susan, the impact of the Surplus Suffering from his disbelief of her symptoms remained with her and were expressed during the study interview.

To acknowledge what I was feeling that's all I wanted...and I was angry when it all started with my GP not listening to me...I accept his apology but he needs to listen to his patients, people know their own body. Susan line 1008

Surplus suffering inflicted by HCPs in research care

Paul's story has significant implications for poor clinical research conduct but also for compromised care and Surplus Suffering. Paul had been carrying around the emotional scars from a consultation encounter with a neurologist, not telling anyone else about it until our interview, and carrying the burden of Surplus Suffering for several years. At the time of the Surplus Suffering encounter, Paul was already under the care of a neurologist he trusted and who had recently diagnosed him with RRMS (after several years of Piecing Together the Puzzle) and was about to start his first DMT in a few weeks. In the wait time before his next follow-up appointment he suffered a further relapse and was admitted to the emergency room of a local hospital. He then saw a different neurologist who provided emergency treatment and advised a follow-up appointment to check Paul's progress a week later. As Paul had very little experience with the medical and hospital system, he was unsure of the correct etiquette in this situation and agreed to attend the appointment. Upon arrival to his consult with the emergency room neurologist, Paul was ushered through to another room, unfortunately apart from his wife who had accompanied him. The neurologist asked if he would like to begin a DMT soon, Paul answered that he would, and within minutes Paul recalls that he was signed up to a new clinical drug trial without explanation and without the chance for him to ask why. The neurologist

told him that the nurse would explain it all to him later. Unfamiliar with MS clinical care and procedures, Paul felt bullied into signing the papers and assumed that he would be given better explanations later. However, this did not happen, leaving Paul feeling angry and taken advantage of.

I said “what’s going to, what’s this all about? and he says “Oh well, we can go over all of this later on but what I want to know is to see if you would like to start treatment today or in the near future?” ...and I said “well, you know, obviously I want to get onto something, but what does that mean? ” And he says “Oh well, OK, I’ll take you out to the nurse out the back and we’ll get you enrolled in this trial” ...and I’m thinking...what is this? what is this?...And so, ten minute consult without anything...what the hell is going on?” ...he stood up...he went and stood at the door, just under ten minutes to usher me in and out...it was quite horrific in hindsight. Paul line 250

Not once through that whole episode did he do any neurological test, you know, tapping a knee and all that sort of stuff...and that would at least be baseline stuff that you would be doing? ...I was worried about what sort of results were coming out of this thing...you’ve got to treat these things very seriously. Paul line 371

Despite his misgivings, Paul completed the twelve-month trial commitment as he didn’t want his efforts and time already spent to be in vain. I asked Paul why he continued in the trial and returned for follow-up visits when he felt so violated. Paul recalled how his background in science encouraged him to complete the research trial for altruistic reasons (for others rather than himself) and he was pleased that he did so, despite the personal cost to his piece of mind continuing to be regularly exposed to the neurologist who he believed was the cause of his Surplus Suffering. This was made easier by the fact that Paul rarely ever came across him at research visits; ancillary research staff seeing Paul for most of the trial assessments.

I wouldn’t have gone through it other than thinking you know...if I can help in some way because bloody hell, I don’t want anyone else to...or I would want other people to be helped as well. Paul line 408

As a researcher in clinical trials for many years I was horrified by Paul's story, but more than that, I was affected by the degree of Surplus Suffering this act of disregard for clinical guidelines had on Paul. He tensed up when discussing it, his fists became small balls, he became red in the face and the anger surfaced as he became emotional recalling the day the Surplus Suffering began. Paul's basic right to autonomy was violated, he was not provided with the appropriate information to make an informed choice. In fact, all four of the general principles of international research ethics were violated in some way: beneficence (the welfare of the patient comes first), non-maleficence (do no harm), autonomy (independence, in charge of self) and justice (fairness to patients).

What's happening? Unravelling the cause of Surplus Suffering inflicted by healthcare and preventing Surplus Suffering

All of these encounters have shown areas where HCPs have let their patients down in some way and even though most likely (and hopefully) this has not been intentional, the Surplus Suffering has been felt for years and sometimes decades afterwards. A research study looked at the evidence for quality care encounters alleviating patient suffering (Arman & Rehnsfeldt, 2007). The authors found, that similar to other research, healthcare encounters may actually increase suffering rather than alleviate it (Arman & Rehnsfeldt 2007; Clarke & Fletcher, 2005; Wiman & Wikblad, 2004). Findings also showed that the basis for this suffering was essentially neglect; patients were not seen as whole human beings and their suffering was not noticed by the HCPs. The stories described above certainly fit this category and highlight situations where kindness and compassion from medical and nursing staff could have potentially changed the journey for these PwRRMS.

Compassion has been defined as understanding or being aware of another person's suffering and acting to end this suffering (Crawford et al., 2013) and has been described as an important part of the ethos of nursing (Bradshaw, 2011). Papadopoulos and Ali (2016) explored compassion in nurses and other HCPs in an integrative review and found several overarching themes as the main components of compassion. These included being empathetic, recognising and ending suffering,

being caring, communicating with patients, being competent, connecting to and relating to patients, and involving the patient in their care.

Similarly, “turning toward” is a concept in medicine which involves recognising suffering, becoming curious about the patient’s experience and intentionally becoming more present and engaged (Epstein & Back, 2015). Turning toward is about being authentic, emotionally available and engaged, intentionally tending to the immediacy of the patients experience even when the suffering is horrific and troubling. Expressing loyalty, honesty, shared humanness and non-abandonment to patients can be shown through caring actions, taking an extra minute or two, calling a worried relative, choosing words carefully and caring gestures (Epstein & Back, 2015) and can be long remembered by the patient after the visit.

Suffering occurs when an individual feels voiceless, when their suffering is unheard or when they cannot give the words around an experience (Ferrell & Coyle, 2008). When nurses ask questions and act as confidants for patients, they can aid relief from suffering and reduce physical, emotional, social and spiritual distress (Ferrell & Coyle, 2008). Several participants who recalled experiences of Surplus Suffering in the study interviews contacted me afterwards to say that they felt better for having told “secrets” about their previous care and that they now felt more optimistic about the future. Paul told me that he could now “let go” and move on from his previous bad experience of research in MS care (which he felt was now due to his “good” research experience in the current study) and Joy was equally as happy to have been able to tell her complete story to someone who listened and engaged. I feel humbled that this research study was able to be a catalyst for such positive change. The degree of (often silent) Surplus Suffering experienced by these individuals was distressing at times to listen to, but helping participants to regain some optimism and trust in MS HCPs is extremely fulfilling. I felt that the simple act of telling me their life history and exploring their feelings helped each participant to move forward with positivity and hope, despite this not being a specified aim of the study.

Surplus Suffering inflicted by family, friends and community

In a seminal paper on the lived experience of RRMS, Miller (1997) reported a theme of conflict arising as a result of RRMS in two ways; the first was conflict with HCPs, particularly physicians regarding the diagnosis of RRMS or explaining the disease, as described in the three subthemes discussed above. The second area of conflict involved study participants reporting considerable conflict within their own family (Miller, 1997), a concept that was also experienced by some of the participants in the current study.

Joy continued to suffer greatly, not just from the Surplus Suffering from HCPs already discussed, but also from people she loved. When she was 16 years old and suddenly became blind to typed text (a form of dyslexia) she was not believed by her family or teachers.

No-one believed me, my teachers didn't believe me, my parents didn't believe me, I wasn't taken to the doctor, no-one believed me, no-one cared, no-one did anything about it, nothing...you are lazy, stupid, ridiculous. Joy line 57

Joy's second husband worked in the healthcare sector, his championing her search for a diagnosis and health care connections had been integral to Joy finally being diagnosed with RRMS after decades of undiagnosed symptoms. However, he showed no compassion in relation to Joy's RRMS symptoms and disability. Joy recalls him forcing her to take more medication when she was already showing signs of drug toxicity, something she feels that he would have identified as a HCP. It took Joy some time to realise what was making her feel so sick, finally getting herself to hospital and being diagnosed with valproate toxicity (a drug used to treat epilepsy as well as nerve pain) from overdose.

Over a number of years I ended up going on Copaxone® injections as well as Epilum...I ended up having this huge, huge reaction, I blew up to three times my normal size...Epilum toxic and the Copaxone®. Joy line 694

He did this twice during our marriage...but I figured out it had to be medication induced...He would put the tablets in my mouth and I would pretend to swallow them and then I'd spit them out...that's what got me better and then I would drive myself to the hospital...I don't think he necessarily wanted me to die...I don't know...I will never know. Joy line 743

On a separate occasion Joy's husband forced her to continue to work as she battled a severe relapse, not allowing her to take sick leave (which would have been unpaid) and pushing her to breaking point.

I'm so sick and I can't work and he was..."absolutely not, you have to go to work" ...I was just heartbroken, I kept going but my legs went on me and I started walking with a cane because I was really struggling to walk...and then I lost my job because I wasn't doing my job, so while my husband was screaming at me "you have to go to work", I lost my job, so I couldn't go to work. Joy line 859

The impact of Surplus Suffering from Davina's immediate and extended family brought tears to her eyes as she recalled the unkindness inflicted by her family over many years. This happened initially at diagnosis when her mother and father's families argued openly over whose fault it was genetically that she had developed RRMS. This caused extra angst at a time when Davina desperately needed support. Later, her (now ex) husband did not engage with Davina and she felt at the time that there really wasn't anyone else to go to or confide in. He treated Davina and her RRMS symptoms with contempt and also encouraged their children to do the same. Additionally, Davina's sister-in-law accused her of taking away attention from other family members because of her RRMS.

The problem is... because my husband didn't want to know, he never shared it with them (our children)...he never was supportive of me...so then it became them against me...so if I lost it or I got really tired, I've got MS or whatever, don't stress me so much, they'd turn around and say "Oh, don't pull that MS card again" ...he would never defend me, he'd never say "don't you speak like that to your mother, she's got a condition" ...and that went on for years. Davina line 1264

She (my sister-in-law) said to me that you use your MS as a crutch and said your parents give you so much more attention and provide far more to you than they do to your brother...and out of that came the greatest reign of jealousy...how could someone say that to me? Davina line 1778

MS Nurses managing Surplus Suffering

The three important questions that arise from this data and discussion are firstly, how can MS Nurses ensure that they aren't the perpetrator of Surplus Suffering? Secondly, how can Surplus Suffering in the PwRRMS be managed in a way that may lead to healing and enhanced nursing and medical care for the future? And thirdly, how can MS Nurses educate others (HCPs and family/friends/community) on how to avoid inflicting Surplus Suffering on PwRRMS?

Empathic nursing and “going the extra mile” may be the key to setting up better outcomes for the PwMS in the future (Davies, 2014). The word empathy comes from the Greek *empathia* meaning physical affection or passion, but shares its roots with *pathos*, which means suffering (Stueber, 2011). Unlike sympathy, empathy goes beyond merely acknowledging suffering. When a nurse truly practices empathy with a patient, they share the patient's struggle and feel their pain (Davies, 2014), allowing the nurse to interact on the same emotional level as the patient and helping to establish trust (Ward, Cody, Schaal, & Hojat, 2012). Four components of empathy have been conceptualised by Morse's group in a model to provide insight into developing and expressing empathy (Morse, Bottorff, Anderson, O'Brien, & Solberg, 1992). This includes consideration of moral empathy (unconditional acceptance of another human being when encountering their suffering), cognitive empathy (sensing what another human is thinking), behavioural empathy (nonverbal communication to convey understanding such as a smile or head nod) and emotive empathy (perceiving and sharing the patient's feelings) (Morse et al., 1992). These empathic qualities should be mindfully considered by MS Nurses at every step of the life journey for PwRRMS.

By embracing holistic care and practicing empathy with PwRRMS, the MS Nurse is in the ideal position to establish a relationship of trust, taking into consideration the

vulnerable state of the person who may have experienced Surplus Suffering in the past and may continue to live with it. Discussing past hurts, past compromised care, past disappointments and perceived let-downs can help build a bridge to the future based on common goals and realistic expectations, improving care effectiveness. This does not mean that the MS Nurse ridicules or supports past care or injustices, but that they listen closely to the patient stories, reflect and validate the patient's feelings to enhance mutual respect and understanding. Patients can also find meaning in suffering through personal growth (Pollack & Sands, 1997), if we, as engaged MS Nurses are courageous enough to guide them.

The challenge for MS Nurses is to foster an atmosphere where patients realise that finding meaning in their suffering is a possibility and they may gain skills to help them in current and future situations (Pollack & Sands, 1997). MS Nurses cannot always alleviate suffering, but can listen, support, show kindness and compassion (Deal, 2011) and create a safe, empathetic environment in which patients can heal and gain strength. As Helen Keller reminded us in the opening quote to this theme, suffering can strengthen the soul, and as MS Nurses, part of our mission is to find strength and lend strength until the patient finds their own. To help patients understand the place of Surplus Suffering and to help them to heal.

The following theme of "High (In)Visibility" explores some of the reasons why Surplus Suffering may have occurred in the first place; the occurrence of many invisible symptoms in RRMS, symptoms which cannot be easily seen or understood.

Theme 5:” High (In)Visibility”

*But you look so well, are you sure that's what you have?
Of course I'm sure, I didn't make this up for attention
Attention I don't want and don't need
Maybe if I just hide in the corner and work hard you won't notice
You'll forget
And then I'll never have to try and explain
I'll never have to tell you I'm not the same
That I'm different to you
That I'm different to me
So I hide, I keep secrets
I hide symptoms I can't really make clear
I pretend, I pretend I am the normal person you think I am
I am normal
But if I am normal, why do I feel so wretched
So strange, so unknown to me*

*I wish I could take you on a journey
A journey through my body
Through the sensations, the weird noises
The sharpness of pain and the prickles
The feeling of not being able to move even though I do move
Of looking normal to you but feeling like a log to me
Of fogginess and clouds
Of tiredness and misunderstandings
Not quite here, not quiet there
Not quite anywhere
TB*

For the purposes of this study, I conceptualised invisible symptoms as symptoms which cannot be seen by others. Invisible symptoms are very commonly experienced by PwMS (Ben-Zacharia, 2011) and were experienced by all participants in the current study at some time in their life journey with RRMS. Invisible symptoms in

RRMS are numerous and include fatigue, mental health issues (including mild depression and anxiety), sensory symptoms and pain (pins and needles, tingling, burning), mild cognitive dysfunction (thinking and memory issues), mild sexual dysfunction, mild bladder and bowel issues (urge incontinence, constipation) and visual disturbances (blurred vision, colour loss). I have used the descriptor of “mild” in some of these invisible symptoms, because there are more noticeable features by others in the case of moderate to severe classifications. Additionally, invisible symptoms represent an extra layer of invisibility and complexity because PwMS reluctantly discuss them and MS HCPs may not enquire about them (Lysandropoulos et al., 2015). This may be related to lack of time in a consultation, inability by the patient to express the symptom or to understand its connection with RRMS, or perceived inability to treat the invisible symptoms by the HCP.

The *central organising concept* of this theme is the presence of invisible symptoms and their impact upon life with RRMS. Invisible symptoms may cause chaos with activities of daily living and may also cause misunderstandings with others, but on the other hand they can also provide a refuge from chronic illness and the struggles that MS brings. The fact that invisible symptoms are invisible can have both undesired *and* desired effects, sometimes leading to conflicting feelings in the same person about the same or other invisible symptoms. Some study participants suffered greatly from the effects of invisible symptoms in their lives, but other participants held on to the welcome cloak of invisibility protecting them.

There are three subthemes to High (In)Visibility; striving to make the invisible visible (please see me), reverse stigma (when my MS isn't enough for you) and invisibility as a welcome cloak (the downside has an upside). The subthemes are all linked by concepts of invisibility but all had different effects on the lives of the study participants, clarified further by sub-subthemes.

Understanding the impact of invisible symptoms

Invisible symptoms are not peculiar to RRMS, it is well documented that invisible symptoms exist in many other chronic diseases, such as mental illness (Jackson, 2015), systemic lupus erythematosus (Brennan, 2016), fibromyalgia (Cunningham &

Jillings, 2006; Parsa et al., 2015), Parkinson's disease (Hermanns et al., 2013) and heart failure (Whitehead et al., 2017) to name but a few. It has been suggested that in living with invisible symptoms, PwMS may feel that they are not being seen heard or met properly in the social environment (Lohne et al., 2010). Most people would identify a PwRRMS as someone who has significant overt disability and possibly using a wheelchair to ambulate. The idea of a PwRRMS functioning at a high level with no outward signs of disability at all, but claiming to have significant unseen symptoms, may cause issues for the understanding of MS in the wider community.

In a German MS registry study report (involving over 18,000 PwMS of all MS types) 20% of PwMS lost work capacity due to invisible symptoms despite being able to mobilise independently (Stuke et al., 2009). The impact of MS on quality of life is also emphasised by the high number of persons in the registry who suffered from invisible symptoms (notably fatigue, cognition difficulties and mood disorders), both in the early and the late stages of MS (Stuke et al., 2009). The invisible symptoms of MS, often combined with the difficulty in communicating these invisible symptoms to others, can often cause inattention towards the disease and ignorance (Grytten & Maeside, 2006). It must also be remembered by HCPs that invisible symptoms can often be more distressing to PwMS than visible symptoms (White, White, & Russell, 2008), even if they are not brought up and discussed.

Study participants discussed both positive and negative qualities about living with invisible symptoms, some aspects were complicated for them to understand and often involved more than just the symptoms. For example, Kate was appreciative that she could keep her symptoms of RRMS invisible at work where she had not widely disclosed her diagnosis, but what she wasn't counting on was the fact that her DMT side effects were threatening to give the secret away. The side effects from her interferon treatment, including flu like side effects, temperatures and fatigue led to people at work wondering "why is she so sick all of the time?". Kate couldn't explain to them the reasons why as she did not wish to disclose her diagnosis. Rudi lamented that her husband didn't realise that she suffered invisible symptoms everyday and preferred to keep it to herself; she didn't wish to talk about invisible symptoms as she felt this gave them and her RRMS some sense of control. Paul gave an example of an invisible symptom he found it difficult to explain to others, he

didn't really understand it himself, but he felt it everyday for months before the symptom remitted.

*It's like a cloud...I was sitting on a cloud...I don't understand...it's really hard to describe...a very, very weird feeling and I could sense there is something not right.
Paul line 78*

Balancing whether to tell or not to tell others about invisible symptoms was individual for each participant and each decision had consequences, either for telling, or against telling. On the one hand, participants wished to have invisible symptoms understood, but on the other hand, to disclose the invisible symptoms might mean disclosing the diagnosis of RRMS as well, which was a big step for some. Others disclosed the invisible symptoms but had their experiences devalued as their RRMS was deemed to be not severe enough. Some participants were glad their RRMS symptoms were (mostly) invisible as they could continue hiding their diagnosis whilst getting on with life. The subthemes of High (In)Visibility will explore these concepts in more detail.

Striving to make the invisible visible

Research into another autoimmune illness with predominantly invisible symptoms, systemic lupus erythematosus (SLE or lupus), revealed that others were disbelieving of the diagnosis because the participants looked so well and normal, leading to feelings of psychological invalidation and loneliness for the person living with the disease (Brennan & Creaven, 2016). The researchers also discovered that this lack of meaningful sympathy extended past family and friends to include HCPs and GPs and these experiences may then have deterred participants from disclosing their diagnosis to others or from seeking support afterwards (Brennan and Creaven, 2016). As discussed in the preceding two themes Battling the Demons and Surplus Suffering, similar situations also applied to PwRRMS, with several participants in the current study experiencing invalidation from HCPs and GPs, and for some participants such as Piper and Joy, this was a repeated occurrence. Several participants in the current study also experienced similar feelings of disbelief, invalidation and loneliness from family, friends, work colleagues and the community.

Please see me

Living with an invisible chronic illness raises questions of illness validity where no evidence can be seen by others (Moore, 2013) and is challenged significantly if the disclosure of the illness produces no visible support (Moss & Dyck, 2002). Doubts regarding symptom severity can be raised by family, friends, work colleagues and also by doctors and other HCPs, significantly impacting on identity and self for the PwMS (Skar et al., 2014). In addition, the lack of proof for such invisible symptoms as fatigue and sensory dysfunction can lead to others punishing the PwRRMS for being lazy, malingering and lacking credibility (MacAllister et al., 2009). Many participants in the current study were the recipient of doubts by others on the severity of their invisible symptoms, were not believed or brushed off and felt unsupported in their claims.

Struggling to come to terms with the diagnosis of RRMS diagnosis herself, Susan wished her friends and family could better understand her invisible symptoms, so that they could truly understand her difficulty. Susan took them along to her initial education meetings at MSA, believing that if they attended and learnt about the disease that they might be able to relate to her invisible symptoms such as severe fatigue and sensory loss.

I took a couple of girlfriends and Mum...just so they could understand what was going on because...they see me as I'm OK they don't know what's going on inside...so I wanted them to understand. Susan line 498

Evie disclosed her diagnosis of RRMS in the workplace early on in her journey and had worked with the same group of work colleagues in a senior role for many years. She organised for someone else with RRMS to come into her workplace to talk about what it was like to live with invisible symptoms in an attempt for her work colleagues to appreciate the daily struggles she encountered. Evie felt it helped to provide greater understanding of her situation in her workplace, and it was beneficial that a stranger (rather than herself) did this introduction.

I wanted them to see somebody else other than me. They see me, they see me well, but they don't see me, they've never seen me bad. I wanted them to see something different to me...and they were absolutely floored...most of that I have suffered at some point and some I go through on a daily basis. Evie line 26

Margot cleverly devised a way of protecting herself in crowds when she was affected by invisible symptoms such as dizziness, finding a way to alert others to stay clear and keep herself safe from being knocked over or falling.

People (in crowds) don't know you might be a bit rocky, so you have to be very careful...I take that (a walking stick) with me and it made such a difference, even though I wasn't using it to help me...people thought straight away, oh there's something wrong with her...I'll be careful around her, which is great...that was a very good tool...so even though it wasn't assisting me walking, it let other people know. Margot line 1969

For Davina, a constant struggle was having her invisible symptoms seen and appreciated by others, she wished there was some outward physical sign to alert them of her severe fatigue.

The hardest part for me is when I don't feel a hundred percent...I wished I suddenly developed little green spots or something would happen to me where people would say "Oh, she's not great". Davina line 786

Exposing the "secret one"

Sexuality, in particular, is an invisible symptom which has been significantly neglected in literature and is often neglected in MS consultations (Esmail, Munro & Gibson, 2007). Griff openly discussed what he referred to as "the secret one", the invisible symptom "nobody wants to really talk about", sexual dysfunction in MS. Griff discussed how the concept of sexual dysfunction is hard for HCPs to hear, hard to talk about by patients, hard to treat by doctors and leads to "hushed tones" in MS circles and in Griff's case, led to more questions than answers. Over the years Griff had unsuccessfully sought out treatment and assessment for sexual dysfunction. Griff

felt that but has been left to deal with it on his own, and felt that his neurologist was not skilled in assisting with this symptom or referring him to the appropriate resources and personnel to help.

Nobody ever wants to really deal with that (sexual dysfunction), not even me...I don't want to deal with it either, (doctors) don't want to talk about it...a young fellow me (a fellow person living with RRMS) at a meet and greet came up to and said "what about sex?"...it's all in hushed tones and it's industry wide I think, nobody wants to deal with this...how you express it to your partner, how you even tell yourself that you're not a bad person? Griff line 575

Sadly, Griff is not alone, prevalence reports indicate that 40-80% of PwMS report changes in sexuality (Foley, 2010; McCabe, 2004; Redelman, 2009). Sexual dysfunction has been found to be associated with depression and reduced QOL and to have implications related to relationships, fertility, pregnancy and parenting (Delaney & Donovan, 2017). Additionally, it has been suggested that MS HCPs often wait for patients to initiate discussions about sexual dysfunction rather than bringing up the issue themselves (Gromisch et al., 2016), perhaps restricted by time in a consultation or by inability to actually help with the issue. This is an area that needs immediate action by MS HCPs to improve assessment, reporting and treatment of sexual dysfunction in MS. Interestingly, despite the reported high prevalence of sexual dysfunction in males and females with MS, no other study participants discussed sexual dysfunction in the study interviews. This may have been for several reasons, such as time constraints, embarrassment at discussing sexual health with a stranger, importance placed on other issues they wished to discuss first or the fact that it was not a concern for them personally, or the fact that it is the "secret one", even in the arena of research.

When my MS isn't enough: reverse stigma of RRMS

MS has been described as an "invisible employer who hides their needs as a patient" and can lead to feelings of silence, belittling and ignorance (Lohne et al., 2010). Many participants in the current study with predominantly invisible symptoms of MS felt that their disabilities were less important than others with more obvious and

disabling MS symptoms such as people using a wheelchair or with poor speech. And yet they struggled each day, trying to lead a normal life whilst managing debilitating invisible symptoms. The dichotomy about how the PwRRMS feels on the inside with invisible symptoms, against how the PwRRMS appears on the outside as physically normal, can be difficult to cope with.

One of the surprises to me investigating invisible symptoms with the study participants, revolved around the concept of reverse stigma, the idea that as someone with RRMS, their MS wasn't severe enough to be considered legitimate or to secure empathy and understanding from others. So, rather than suffering from the stigma of a disabling disease, this was just the opposite, it was stigma in reverse. This could happen for two reasons, being compared to progressive forms of MS and RRMS being viewed as insignificant against it, or being "fobbed off" as unimportant when trying to give insight into invisible symptoms to others, because they looked well and healthy and not unwell and sick. Both reasons had the same effect, loss of confidence and self esteem for the PwRRMS.

Seminal work from Goffman (1963) exploring stigma in illness, reports that ignorance from others is an assimilative technique to establish sameness and common identity amongst a group. In the case of participants in the current study, it had the opposite effect and left them feeling vulnerable and isolated. Experiencing others refusing to acknowledge MS is a violation of self and imposes alienation (Grytten & Maeside, 2006). A previous study in RRMS has also reported that PwMS have been discriminated against for being "too healthy" and have taken advantage of the sick role to secure benefit for themselves (Miller, 1997).

I'm not enough of MS for you, devaluing the impact

There appeared to be two distinct sides to stigma in MS described by study participants; one of being ignored, or the MS symptoms being devalued or undervalued ("reverse stigma") and the other of having MS over-emphasised and over-acknowledged (Grytten & Maeside, 2006). Findings from the current study support reverse stigma as being particularly applicable to RRMS, whereas the latter possibly applies to more progressive forms of the disease displaying more overt

disability, and was not reported by any participants in the current study. Grytten and Maeside (2006) also reported that PwMS experienced minimalisation of their illness by others, even amongst friends.

Margot struggled with the “filthy looks” people gave her as she parked in the disabled car spot close to the local shopping centre and then proceeded to walk once she disembarked from the car. For months Margot carefully avoided parking in the disabled parking bay, she struggled with her invisible symptoms of fatigue and pain, sometimes overwhelming her on shopping trips and making it difficult to walk long distances, but she did persevere. One day Margot gave up the fight, put her disabled parking sticker on the dashboard and parked in the disabled bay, only to be confronted with looks from strangers that she felt conveyed a message to her of “ fancy parking there, you’re not even disabled”. Margot went back to struggling after that for some time, parking long distances away from the shops rather than risk perceived judgement from strangers again. In recent times though, Margot has come to terms with the situation and puts herself first.

Davina struggled with acceptance of her invisible symptoms from others, particularly hurtful was that her husband and children often did not believe the severity of her invisible MS symptoms and openly made fun of her. Davina just wanted to be seen, believed and understood.

(I didn't tell my four kids much) I didn't want to burden them I suppose...but because my husband didn't want to know, he never shared it with them...never was supportive of me...so then it became them against me... if I was...really tired...he would never defend me and that went on for years...and then they'd make a joke of me...he (ex husband) would undermine me. Davina line 1263

Recently one of Davina's now adult children recently contacted her after watching a documentary about MS on television. As Davina recalled the conversation, tears fell down her cheeks as it meant such much to her that finally, her RRMS was visible to at least one member of her immediate family.

She (daughter) said... "I just watched this documentary on someone who'd just been diagnosed with MS and I was unaware of what you must have gone through" ...so it's been really hard...it meant that maybe she'd started thinking a little bit about it. Davina line 1298

Interestingly, two participants, Susan and Davina, who reported lack of understanding of invisible symptoms from close friends, both worked in the healthcare profession, as did their friends who failed to understand the difficulties they were under fighting invisible symptoms. Perhaps their exposure to more serious conditions in healthcare desensitised them to the suffering of their friend, the PwRRMS. Davina was particularly surprised that her HCP friends would question her invisible symptoms and devalue her severe fatigue levels.

My (HCP) friends would turn around and say "Oh, what's wrong with you, you can't keep up anymore, you're getting old?" ...and they do it til this day...how dare they...and then they'll try and make me feel better by saying "oh, everybody gets tired" ...but I said, I don't get tired, it's more than that and it can hit me really suddenly and I go down like a pack of cards. Davina line 794

For Susan, although she felt that she has already educated her friends about the invisible symptoms of RRMS, she felt they still didn't fully understand the impact that invisible symptoms of RRMS could have.

People, they don't understand...they see you as you're OK because mine's only mild, but inside...in here, it's hard to accept and hard to make other people understand how you're feeling...it was hard to talk to friends about and if I did say anything, they'd say "Susan, you're OK, look at other people, you're very lucky" ...so I went OK...but I was really sad and thought...well, what about me? Susan line 670

Jane was fundraising for MS awareness and research in an endurance bicycle event. The riders were to cycle a long distance in extreme heat and the day prior to the event Jane expressed her concern to the organisers that fatigue and Uhthoff's phenomenon (when the body overheats and old MS symptoms reappear from previous nerve damage) would be a problem for those with MS in completing the

course. Jane requested an earlier start time to avoid the midday heat for herself and the fellow MS riders taking part, but this request was refused. Jane was then forced to leave the ride without even starting it, causing her to lose the significant amount of fundraising money she had been promised to take part in the event. Jane felt that she had been shamed for speaking up and verbalising her issues, her invisible RRMS symptoms. The irony of the situation is overwhelming, raising awareness of MS and MS symptoms in a fundraising event, only to have her own invisible MS symptoms overlooked and devalued by the very group that should have the greatest understanding.

They thought I was being demanding...it was so disappointing...I said...I have MS...I know what it's like. I had to leave the trip early, it wasn't possible to do...very disappointing, people had sponsored me and I had to tell them I couldn't do the ride for these reasons...I raised a lot of money but I didn't do the ride like I said I was going to...it was so disappointing. Jane line 798

A “pretender to the throne”

Griff's tale of reverse stigma is as poignant as it is astonishing. As a newly diagnosed, vulnerable man diagnosed in his forties with RRMS, he was navigating his first MSA meeting and getting to know more about MS and the invisible symptoms he had been battling silently for many years. After the seminar there was a chance to meet other PwMS. Griff was surprised when the mother of a severely disabled and wheelchair bound young lady came over to Griff and verbally “attacked” him, accusing him of not having MS and not being serious. This public humiliation threatened his newfound confidence, and although he understood the reasons behind the reverse stigma, the emotional scars are still borne by Griff today. He felt like, and still feels like, a “pretender to the throne” of MS.

Compared to so many other people, I am light years ahead...which brings its own problems in fact...I coin the phrase “pretender to the throne” ...when I was at a welcome to your disease meeting, there was a girl...probably early twenties...and in one of those wheelchairs you never really get out of...her Mum's with her and absolutely distraught, saw me and maybe 3 other people chatting...we have much

lower damage...and she came over and attacked us...I was upset at the time but I wasn't cranky at her...I'd hate to think what she was going through...(she) had a go at me because "what are you? You haven't got MS!"...that's always been at the back of my mind, that I'm a bit of a "pretender to the throne". Griff line 532

Invisibility as a welcome cloak: the downside has an upside

Many people living with chronic illness don't look so different from those healthy people around them, and it can be a huge burden to make the invisible visible (Siouta et al., 2016). Some PwRRMS decide to keep the diagnosis private and the invisibility of many MS symptoms suits them very well. Previous studies regarding living with MS have noted that PwMS often wish to deal with their disease privately (Clair, 2003) and this may be due to several reasons including stigma, embarrassment and (perceived) career advancement. Several participants in the current study were able to continue working and functioning at a pre-RRMS symptoms level and were able to keep their diagnosis of RRMS hidden from those they did not wish to disclose to. However, not disclosing their illness could also expose the PwRRMS to real threats of physical and emotional well being rendering PwMS "damned if they do, damned if they don't" in regards to disease disclosure (Vickers, 1997). If they were not sure what to do, participants in the current study tended to err on the side of caution by withholding the diagnosis and practicing information control. For some participants such as Kate, Paul and Jane, this was the great benefit of invisibility; there was definitely an upside to the downside. Keeping a diagnosis of RRMS concealed from a public that knows little about the disease of RRMS has been previously reported (Miller, 1997) and this may help the PwRRMS retain the identity they wish others to see and avoid being labelled.

The presence of invisible symptoms could also be seen as a blessing to some participants. At times the invisibility of MS symptoms was an added bonus and seen in a more positive light, especially when there was reluctance to disclose the MS diagnosis to others, such as in the workplace or to extended family or friends. This is a form of information control, not just in deciding disclosure just after diagnosis, but continually along the life journey living with RRMS. The presence of invisible symptoms allowed decision making by the PwRRMS, who received what

information, how and when was then up to each individual. Will wished to control what his family sees of the disease, especially his wife as she is caring for a new baby. Piper also keeps her symptoms from her children, acting as she always has and pushing herself to live and look as normally as possible.

The invisible stuff...I hide it from my family...my wife's pretty fragile, we've got two children, we've got responsibilities...I need to be that strong person. I don't want her worrying about it...she'll see what's going on...she just leaves it alone because she knows that's how I deal with it...I keep it to myself. Will line 64

My kids don't see the impact of MS, I guess they don't see it because I just...if I...stopped every time there was something wrong I would do nothing basically and I'm not like that...I'm a do-er...the kids I guess don't see, a lot of people don't see it...all the symptoms anyway because of my way of day to day living...I will do it...I will push myself and I will do it. Piper line 838

Not disclosing the diagnosis and not being “called out” on it led to feelings of success in keeping MS hidden, success mainly due to the predominantly invisible symptoms. Paul and Kate were both successful in controlling who knew about their diagnosis of RRMS in the workplace; Paul also kept the diagnosis secret from his many friends and extended family.

Nobody else knows, I much prefer to keep it that way...my wife's parents don't know, only my Mum and Dad and my brother know...(I haven't disclosed to any friends) I doubt they would think they could catch it...but I don't know. Paul line 1004

(I was offered a new job and the Boss knew I wasn't well) but due to invisible symptoms he said “no-one needs to know, you can do the job”...and I thought, why not? I'd hide my relapses and treatment and it worked quite well. Kate line 590

MS Nurses can educate PwRRMS that it is helpful to have a few close confidants they can talk to about their symptoms (invisible and visible) and how they are feeling, openly and honestly. The confidant can also help advise on sensitive issues such as disclosure and can provide a “sounding board” for feelings. Having a

sounding board to practice with can also help improve communication skills and provide systems to make it easier to explain invisible symptoms to others. This is especially important at the beginning of the journey and many MS clinics will advise new patients to bring someone trusted with them to the first few appointments for this reason. Becoming skilled at explaining invisible symptoms will take time and practice, but is possible with the right guidance.

MS Nurses also need to become skilled at assessing for invisible symptoms in PwRRMS and providing opportunities for open discussion and education. Setting time aside to discuss fatigue, cognition, pain and sensory symptoms, mental health issues, sexual dysfunction, bladder and bowel issues are just as important to the PwRRMS as scan results, DMT prescriptions and laboratory tests. Discussing invisible symptoms provides the words, phrases and framework to talk to others about the symptoms and the difficulties they face. PwRRMS then learn the terminology and they discover that the symptoms are understood by others, there are reasons for the symptoms and that they are considered genuine. This instils confidence in managing the life journey with RRMS.

This final theme of High (In)Visibility concludes chapter 6 of the thesis, Walking the Low Road. The skills that have been learnt and practiced by the study participants and the things they have learnt about themselves and others along the life journey so far has prepared them well as they embark on “Taming the Beast”, the next and opening theme to the following chapter , “Finding the High Road”. This really marks the start of a brighter future and a time of much personal growth and development. This is the time when PwRRMS begin feel a sense of taking control of their lives, living with RRMS, not living against RRMS.

CHAPTER 7- “FINDING THE HIGH ROAD”

The following chapter “Finding the High Road” outlines the final three themes from the data analysis and explores a distinctly different overall feeling from the previous chapter Walking the Low Road, where despite some occasional glimpses of brightness, there was more a sense of confusion, of negativity, of unanswered questions and of battle. Finding the High Road feels exactly like the metaphor it is taken from, taking a turn in the road for a higher path, to be able to reach higher ground and look down on the muddy waters below. A journey of self-discovery, of finding previously unknown talents and gifts, of packing a personal “toolkit” to live the best life possible with RRMS. A time of immense personal growth and achievement, sometimes noticed by others and sometimes not. But always active, always engaging, are the choices in Finding the High Road.

The three themes making up Finding the High Road and their related subthemes and sub-subthemes are listed below in Table 5. The only subtheme in this chapter requiring elucidation is the sub-subtheme “decisions driven by fear” which is placed under the main theme of “The DMT Dance”. This sub-subtheme also relates to the concept of fear, which was introduced in the third theme Battling the Demons in the previous chapter. However, I have included decisions driven by fear in this chapter and theme because it is part of the negotiation of successfully completing The DMT Dance and an important element of perhaps later reaching “decisions driven by hope”. This sub-subtheme also forms an opposing force to decisions driven by hope and for this reason I felt DMT decisions driven by fear and decisions driven by hope belonged *together* for clarity and understanding, both being key components of The DMT Dance.

Table 7. Summary of themes six to eight of the study findings; demonstrating central organising concepts, subthemes and sub-subthemes developed from the study data.

Theme	Central organising concept summary	Subtheme	Sub-subtheme
6. Taming the Beast	Finding tools and packing a toolkit to live with and manage RRMS, the different ways that PwRRMS regain control of their life	Finding my North Star Getting a handle on RRMS symptoms and relapses Maintaining physical and mental health and wellness Choosing my medical A-Team Harnessing support from family, friends, organisations and workplaces Riding high on resilience	
7. The DMT Dance	Negotiating and coping with the medication therapies to treat RRMS	The hardyards: making decisions about DMTs and adherence Switching to a better life	<ul style="list-style-type: none"> • decisions driven by fear (“I’d rather be in a wheelchair than dead”) • decisions driven by hope
8. Holding Hands with Hope	Hope and positivity about reaching happier times and the beginnings (or totality) of acceptance of RRMS into life and how looking to the future with hope brings its own peace and rewards	Hope in its many forms Purposeful positivity	<ul style="list-style-type: none"> • functional hope • restorative hope • curative hope • defiant hope • optimism and a positive outlook • searching for meaning • harnessing a sense of humour • faith, religion and spirituality • giving back and being involved

Theme 6: “Taming the Beast”

*Now I have arrived
Armed in my combat gear
I'm taking you on
Gone is my negativity, my fear
This time I'm ready
I've read the rules of the fight
This time I'll take you
I'll show you my might
I've gained so much
I've lived and I've learned
I'm a new person now
Full of positivity I've yearned
TB*

The theme of “Taming the Beast” represents a turning point for PwRRMS, a time where they start to conquer the demons they have battled since suffering their first RRMS symptoms, a time where they have gained some experience living with the disease and now have some knowledge about what RRMS actually is, and is not. It is a time for positive change, for the beginnings of acceptance, sourcing the best support, sharing tips, gaining confidence and for recognising the incredible things they have achieved since Piecing Together the Puzzle, working on (Re)defining Me now that I have RRMS, Battling the Demons, managing Surplus Suffering and learning how to live with High (In)Visibility. Taming the Beast brings life firmly into the foreground, working to be a person living with RRMS, not an RRMS person. Evolution is key to this theme, as the nature of RRMS means that change is always potentially around the corner and nothing is static. Adapting to change and living with uncertainty has become a major life achievement.

The **central organising concept** for this theme is packing a metaphorical “toolkit” to live with and manage RRMS, the different ways the study participants found to regain control of their life. Taming the Beast comprises six subthemes: finding my North Star, getting a handle on MS symptoms and relapses, maintaining physical and

mental health and wellness, choosing my medical A-Team, harnessing support from family, friends, organisations and workplaces, and riding high on resilience. Several sub-subthemes will add further clarity and explanation to these subthemes.

Finding My North Star

This subtheme goes beyond the “getting acquainted with MS” subtheme of (Re)defining Me now that I have MS discussed, in the second theme of the previous chapter. Finding my North Star is after the settling in period, where the initial shock or devastation of the diagnosis and the thirst for knowledge or running away from knowledge has advanced into more of an acceptance of RRMS. This subtheme has a positive feel, in recognition of the qualities this stage has invoked in the participants, finding new meaning in life and finding a place where both the person and RRMS can cohabit the same body. For some participants, these feelings of regaining control were still very new and developing, and for others the sense of control had been well established for years prior to the interviews, yet was always constantly evolving.

The North Star, or Polaris, is the brightest star in Ursula Minor. The North Star does not appear to move in the sky to the naked eye, remaining fixed above the North Pole to mark the way due North (Hirsch, Kett, & Trefil, 2002). The North Star in the sky guiding and lighting the path due North captures the sense of PwRRMS finding their inner light and a way to move forward in life living with RRMS. Even though RRMS was ever changing, the study participants could find their way to their fixed point of control, their North Star, to keep travelling in a positive direction.

The turmoil and upset explored and discussed in the earlier themes started to settle as education and learning brought confidence, as symptom mysteries unravelled, DMTs were commenced and disease control started to become a reality. Although a difficult concept for MS Nurses to explain to patients, the simple notion of *time* assisting assimilation with the disease is real. Study participants Paul and Davina describe how time can be the friend PwRRMS need, how time helps PwRRMS to understand that life can be about more than RRMS, especially with some tools.

As time rolls on and nothing happens, you tend to become a little more complacent I guess...I'm always a bit cautious, so just a little more planning involved with things. Paul line 937

I'm comfortable in my own skin now, I think I've accepted wisdom that comes with age rather than worrying...I have got a wonderful partner, best friend...we have our own quietness. Davina line 1746

Research has identified that several key skills are beneficial to successfully adjusting to life living with RRMS. These include positivity, perceived control over life situations, self-efficacy in disease management, optimism, hope, benefit finding and spirituality (Dennison et al., 2009). Additionally, patterns such as developing strategies to combat difficulties, making extra time to manage daily needs and avoiding making MS the life focus, begin to develop as confidence and experience living with MS grows (Dennison et al., 2010). Several study participants incorporated some of these skills into their new existence living with RRMS and chose to change their feelings and attitudes about RRMS as a conscious and deliberate choice. I conceptualised this as slowly progressing in Taming the Beast. Joy contemplates how she chose to look at RRMS in a new light rather than being bitter and angry about feeling different to others.

That was my gift...it actually was my gift at birth to be given this brain that didn't function the same as other people's, so I just didn't see the world the way other people saw it...and it gave me something more to work with...I am blessed. Joy line 2009

Similarly, Rudi describes how she purposefully changed her attitude to see RRMS as a gift in her life and a facilitator for positive change, the chance to finally travel and see the world.

As a mother you just get on with it...as hard as it is. I got really angry and obviously went through the stages of grief...but by the end of it I actually think of it as a gift because it's made me live my life differently...it's made me start to travel whereas I

would have put that off...I just have a different outlook on life...I tend to care less about things now so I view it as a gift...MS is not such a bad thing. Rudi line 835

After initially struggling with what he termed depression for many months, and not adhering to his DMT or treatment plan, Will realised he needed to actively make some changes to his life to successfully live with RRMS. His life turned around as a result and he learnt what he needed to do for himself to secure happiness, finding his North Star.

From that point I just said nothing's going to stop me, I'm sick of being that guy that just goes home...I never used to go out I used to go home from work and go to sleep...I just said I'm not going to go home and sulk on my own, get up and live in circles...so I joined a sporting team, I'd go and play poker with my friends...I just lived this active life. Will line 1151

A recent study explored the experiences of 10 PwMS after being diagnosed with MS (unfortunately the MS subtype was not defined) and reappraising their lives (Flensener & Rudolfsson, 2016). The authors explored feelings about changing from a healthy, strong body before MS, to experiencing altered bodily functions and the possibility of changes to life activity. Much like the concept of Finding my North Star in the current study, Flesner and Rudolfsson's (2016) work revealed that PwMS "learn to fly with broken wings" by getting to know their new foreign body and "building a new living space" for the body to function. Building a new living space took time, requiring adjustment, reappraising and creating new meaning in life, and was sometimes uncomfortable. Many participants in the current study displayed features of these themes as they partnered with RRMS in a new life, learning to fly with broken wings over time.

Susan suffered greatly in the early years of her RRMS diagnosis, and being a HCP herself, she was frustrated that she couldn't seem to make sense of her new MS world and make positive progress. For many years she was sad, lonely and deeply fearful of what her future life was going to be. Being single, she felt intensely alone and that nobody would want to partner her in life with RRMS. One day after a

relapse that all changed, Susan decided enough was enough. It was time to find her North Star.

What I was looking for was to help myself to be able to understand these little demons...to then thinking you are good enough...don't listen to them...to be strong and I could also help others...to just accept it, to embrace it because it doesn't mean the end...that was a new beginning for me. Susan line 773

MS doesn't make you the person...that's not you, there were other things before that and there's going to be more things, that's just there and you deal with it. Susan line 1299

Coming to terms with the occasional need for wheelchair assistance if her mobility was impaired by a relapse or severe fatigue was a huge stumbling block for Margot, steadfastly refusing her husband's attempts to try a wheelchair so that she could still enjoy outings and travel. But, once she tried it, she was amazed at the difference it made to both their lives and how easy things became now that the stress and worry about possible falls was taken out of the picture. Finding her North Star to include the occasional use of the wheelchair or walking stick with relapses or severe fatigue brought new perspectives for Margot.

It was a real mental block (tearing up)...it's really hard to do...it's the elephant in the room. The thing is it was so stupid...you do become more accepting...but it was fantastic. Margot line 1533

I thought I can't believe I didn't do this sooner, it was the best thing...it was the initial embarrassment but once I sat the first time...this is fantastic...now I'll take my wheelchair and the girls will wheel me around shopping. Margot line 1701

Starting to see unexpected benefits from situations that previously caused angst can be a positive catalyst for change as well. Rudi turned the dismay she felt at not being able to work due to her severe MS relapses into a positive as she was able to spend more time with her four young children.

Whilst it (our lifestyle) may not be extravagant, I'm just doing a lot more and loving it...loving it...I look at this as I'm lucky because I get to spend this time with my children...whilst it was tough financially, we adapted, as you do. Rudi line 950

Evie took a different approach, yet one that firmly changed her future path to one of positivity for not just herself, but for others with RRMS. She began talking to others as an MS advocate and sharing her story to change public perceptions about RRMS, improving her own outlook on MS along the way. Evie's North Star was all about others and less about herself.

If I'm going to have it I may as well do something with it...that was the way I saw it...I want to help others and make a difference, I want people to see people who aren't disabled by MS...it's not all doom and gloom. You shouldn't focus on what you can't do, it's what you can do, what you want to do...yeah it's going to feel like shit sometimes and you're going to get angry and upset, but you need to pare that back and take a different perspective. Evie line 1210

As study participants were able to look back on their journey with RRMS, their MS experience generally gave them confidence about how they viewed the disease in the future. As discussed in the literature, over time, PwMS tend to develop expectations about their disease path, and often with minimal input from MS HCPs in regards to prognosis (Dennison, McCloy-Smith, Bradbury, & Galea, 2016). As confidence grows, PwMS begin to make more decisions, to make plans and to become more actively engaged as their knowledge increases and they regain a sense of control over what is happening (Clair, 2003). Taking on a more active role in treatment decisions is something that PwMS tend to opt for as they become more educated and engaged as the life journey with MS continues (Heesen et al., 2004). This prepares them for new challenges on the life journey, guides them in finding their new North Star and allows them to start building positivity and hope, which will be discussed in greater depth in Theme 8, "Holding Hands with Hope".

Getting a handle on MS symptoms and relapses

The course of RRMS is characterised by unpredictable relapses interspersed with periods of remission from disease activity (Halper, 2007a). Relapses can either be mild and barely noticed by the PwRRMS, cause a myriad of sensory and motor symptoms, or be catastrophic in their effect causing paralysis, blindness and gait disturbances. Although most people living with RRMS usually recover from early relapses, some residual effects can remain and over time, relapse recovery tends to lessen (Mills, Mirza, & Mao-Drayer, 2017). To add to the mix of confusion and unpredictability for people learning to live with RRMS, “pseudo” relapses which feel like a new relapse coming on but are not inflammatory in nature, can occur in the setting of infection or changes in body temperature (such as with exercise or overheating) and can be very frightening to the PwRRMS (Mills et al., 2017). Working out the difference between true relapses and “pseudo” relapses takes time and experience, none of which are accessible to the patient in the early stages of living with RRMS. For most participants in the current study, coming to terms with various RRMS symptoms and managing relapses was initially difficult for them, but as time passed and with education and experience, their confidence in managing MS symptoms and relapses grew as they began Taming the Beast.

After initially being worried about new onset symptoms and not understanding the meaning of them, Piper gradually set up a system of communication between her local GP and her MS clinic, which was located several hours drive away from her rural town. Relapses became a nuisance rather than the cause for deep concern, which she had felt in the early days.

They're just a nuisance...I get a build up of things...you go to the doctors...I do converse with my neurologist which is really good and so between here and there, they get this agreement...you just hope they are not as bad or severe as before. Piper line 1240

Piper's husband set up an excel spreadsheet for her, with separate columns to score her symptoms daily in an attempt to help Piper try and work out what triggers her symptoms, her bad days or high fatigue days and hopefully avoid those triggers in

the future to improve her quality of life. It is his way of providing support and has been key for Piper to uncover ways of managing her own MS symptoms and Taming the Beast.

Everyday I fill out a spreadsheet with all my meds, and symptoms, give myself a pain score, how many hours I've slept, exercise, diet...we've even got the weather...so the idea is we'll see a graph and there might be some pattern. Piper line 1522

Becoming experienced and educated in RRMS provided Kate with the plan she needed to instil confidence that she could manage her relapses, whenever and wherever they occurred, which was important as she planned to travel overseas. Kate felt as if she had regained some control over RRMS.

Being relapse free for four years was fantastic because you could plan your life...I felt a lot better and my doctor gave me his mobile number, steroids to take and told me what to do...so I thought I felt a lot better knowing that I had a backup plan. Kate line 1247

For study participants Rudi, Margot, and Joy, the initial (undiagnosed) relapses became less of a worry for them once they knew that it was MS and not something they viewed as more sinister such as a stroke or brain tumour. This was particularly so for Rudi, who suffered rapid onset and serious relapses which often resulted in admissions to hospital.

Everyone else got panicky around me but I know it's the MS so I don't...I don't feel highly stressed...I know I'm not dying, I'm not having a stroke...I tend to cope better than everyone else around me. Rudi line 252

For Margot, letting go of household chores that worsened her MS symptoms has made a positive impact on her general health and fatigue levels. This has been an effective tactic in Taming the Beast.

I've pulled back on domestic duties, I don't do cleaning anymore...I think you just let things go really, but it's not that important...I accept things a lot more...I'll walk past dust in the hallway...it's not important...I've become more patient with MS. Margot line 952

Kate suffers terribly with pain from spasticity, a condition caused by nerve damage from MS where her leg muscles become tight and painful. A new drug has recently become available internationally, which has had good results reported in reducing spasticity symptoms. Although she is yet to try the medication, Kate is on a crusade to bring the new drug to Australia because no treatments she has tried so far have given any relief. Kate is determined to bring this quality of life-sapping MS symptom under control, even if it means organising her own treatment to engage in Taming the Beast.

I need it, I desperately need it...I don't need it in three years time I need it now...I've called the PBS...this is the problem and I need to do something about it...you have to be on everyone's back...I put that on the backburner until next week when I get another burst of energy. I really do feel like I have to be my own advocate. Kate line 2158

Rudi suffered from severe bouts of fatigue, particularly after relapses. Rudi had to find a way to deal with this debilitating symptom so that she could reclaim her life as a busy and engaged mother of four children. Balancing rest and life enabled Rudi to get a handle on her MS symptoms and to take on Taming the Beast.

I do recover...when the symptoms disperse, it's very draining...it's like I've been hit with a truck...very tired...I go straight to bed basically cause there's nothing else I can do, and I will sleep...usually I recover pretty well. Rudi line 1087

There's periods where I would have to go to bed...because I feel like I've been hit with a truck...I've learnt...I can play hard but I also have to rest hard...because I've done it before where I just keep going and pushing and pushing and I crash and burn...so I've found I just have to balance. Rudi line 1769

Maintaining physical and mental health and wellness

MS poses challenges to both physical and mental health and wellbeing, and increasing disability over the course of the disease is associated with increasing burden and transformation of life plans (Rommer, Suhnel, Konig, & Zettl, 2017). Indeed, the adjustment process in RRMS does not conclude when early stage PwRRMS get used to their MS symptoms, it continues as future disease status changes occur, as their life journey goes on (Dennison et al., 2010). Learning to manage health and wellbeing is therefore an important part of the life journey with RRMS and one which is in a constant state of flux depending on symptoms, relapses, medication side effects, as well as general life, work and family commitments and responsibilities. It has been reported that after diagnosis, PwMS often say they won't be able to cope in certain situations or with certain symptoms, but longitudinally as life progresses and the changes happen, they do learn to cope and often very well (Dennison et al., 2010). This pattern was displayed by most participants in the current study, capturing the concepts of Taming the Beast, so vital not just to coping with the disease, but for thriving with RRMS. Maintaining physical and mental health and wellness is an important step in this process.

The "Shifting Models Perspective" (Paterson, 2001) believes that people choose to have a predominant focus of either wellness or illness in the foreground of their lives and that encounters and experiences are selected which will support their preferred perspective. During the time of Piecing Together the Puzzle discussed in theme 1, study participants demonstrated that a perspective of illness lay in the foreground leading up to RRMS diagnosis, with the tests, many consultations, hospital visits and uncertainty. As time progresses after diagnosis, symptoms dissipate, relapses come under control and PwRRMS generally become more settled, their focus often starts to shift from the initial illness in the foreground to one of wellness in the foreground. Holding the burden of illness in the background sustains a sense of well being, and many study participants concentrated on a wellness plan for physical and mental health.

As mentioned in theme 2, (Re)defining Me Now That I Have RRMS in the subtheme dare to compare, Will took the view that he wished to stay away from others with

RRMS during his DMT treatment in the day admission ward of the hospital where he underwent his monthly infusions. Will chose to look after his mental health and commit to mental wellness, deliberately sitting with patients being treated for cancer, rather than his fellow MS colleagues. Staying away from others with MS and out of the so-called “cripple club” (Dennison et al., 2010) distanced Will from MS stereotypes and helped him place his RRMS in the background. Will also chose not to read up on RRMS or engage with education programs for the same reason.

I don't want to read the bad sides of MS because I can't influence them and I can't change the way they feel...I don't need to hear it...I know some people are geared to go out there and really advocate, be positive and speak about their problems...that doesn't work for me. Will line 301

Will's attitude to others with MS was in the minority for the study participants, most of whom embraced being with others with RRMS, talking with them, sharing tips in Taming the Beast and looking forward to their treatment infusions for this reason. Margot looked forward to the monthly infusions of her DMT in the hospital day admission ward and was disappointed when her DMT changed to an oral medication and she no longer spent time with people living with RRMS. It had become an important part of her mental health wellness strategy.

In the hospital you met other people with MS, which was fantastic...because people had little tips, they had stories...you'd exchange how long you'd been diagnosed, what your reactions were...and there were people from all walks of life. Margot line 503

An important facilitator for resilience in MS is physical wellness including exercise, stress reduction and energy management (Silverman, Molton, Alschuler, Ehde, & Jensen, 2015). Studies have shown that continuing physical exercise behaviour over time predicts a continuation of enhanced QOL for PwMS (Dennison et al., 2009). The most dramatic turnaround from illness to health and wellness in the current study was from Joy, who described how she felt in the aftermath of her husband's death when her RRMS symptoms were at their worst and she attended his funeral

aided by two walking sticks, making a decision that day to reclaim wellness to the forefront of her life and take back control.

At my husband's funeral I made an absolute heartfelt decision that I would get better no matter what...something switched on...when my husband died...I had to choose life...this resurgence wants to do what I wanted it to do, there must be another pathway...I started fighting for my own health...I felt like I had the power to control my health...I made it true...I was suddenly aggressively and passionately seeking wellness and I have done ever since...I took back control of my life...the disease doesn't control me, I control my body. Joy line 983

Making the active decision in Taming the Beast by becoming healthier physically was more than just a decision to move forward for many of the study participants, it was also an act of defiance, challenging the very essence of what RRMS takes away in physicality and mental health to do the physical activity which is threatened by the disease. Many study participants described how maintaining or commencing acts of physical health, exercise and sports helped them to feel better, stronger and more connected in both physical and mental wellbeing. Piper was proud that she pushed through her symptoms to maintain her physical health.

Just get out there and do stuff while you can and I do that everyday, I like going for walks or runs...I do it because I can...I've got my own gym...even when I am fatigued with MS I still do it, I will still do my walk, it actually makes me feel better...if you move you'll be amazed at the difference. Piper line 990

Margot has recently started gym work and has already felt the benefit, feeling stronger physically. Rudi and Evie have also found that physical activity has helped regain control with specific symptoms, as well as being a mental health boost of positivity for Evie.

Since I've finished work I haven't had many falls at all because I've started going to the gym. I had an assessment and program done and now I go twice a week which has been the best thing...my legs are stronger. Margot line 1341

I do regular yoga...I started playing team sports...I'm absolutely loving it, whilst I could be more active, I have consistency...and I paddleboard to help with the balance. Rudi line 993

I've gone back to gym now, my muscles needed it...keeping fit and healthy...just to remind myself that I was being more defiant...you can knock me down but I'm going to get up. Evie line 1358

Susan embraces the holistic view of improving both her physical and mental health and also in educating others living with MS and sharing her tips to living life better with RRMS.

I always tell others with MS just try and do all the good things like eating good food and exercising...the whole wellness thing is what you need, MS medications are part of that but exercising, eating well, rest, seeing friends...that's what makes you healthier in mind and body...you have to be healthier up here too. Susan line 1305

Choosing my medical A-Team

The subtheme of “Choosing my Medical A-Team” is all about the PwRRMS gaining some control in Taming the Beast by selecting members of the health care team to be on their side, to take charge of their own care, to engage with self-management strategies and to make decisions about who makes them comfortable and who they trust to manage living with RRMS. Often when symptoms first strike, patients are referred for consults and tests to people they have never met before and they don't have choice in who they see, especially so if they are referred by GPs or present through emergency rooms. After diagnosis and the settling in period however, it appears important for PwMS to choose their A-Team for the long life journey ahead with a chronic neurological condition. It has been reported that PwMS choosing their own doctors and health care teams helps the PwMS to take charge, a concept which is extremely important to moving forward and gaining some control (Clair, 2003).

Several participants described scenarios where their MS HCP, in particular the neurologist or MS Nurse, went “over and above” what was required to advocate for

them, securing trust and instilling confidence in the care they were receiving. Will was unable to gain financial assistance from the government for the expensive DMT he needed due to residency issues. The medication cost was almost the same amount as his earnings at the time. Will became very emotional as he recalled the day his neurologist advocated for him and sought compassionate use for the medication, meaning it would be provided at no cost to him.

He said don't worry about it, you focus on what you have to do and we'll work out the rest...since that day I still make sure I come to him because he's just the best. Will line 672

I broke down in front of him...I don't know what to say...it's probably the greatest thing anyone has ever done for me. Will line 877

After many years and failed attempts to secure a diagnosis for his intermittent symptoms while Piecing Together the Puzzle, Paul was referred to a neurologist who gave him plenty of time, spending two hours with him on the first consult and finally providing a diagnosis and treatment plan.

My neurologist was brilliant...he had a number of MS patients...he had a massive checklist he was going through, the first consultation I had with him would have been over two hours and he was wanting to solve this...he later retired but not before sending me to the best MS Neurologist...he's the one in Australia that you want to be with and he organised all that for me...he was wonderful. Paul line 112

The family doctor or general practitioner (GP) can often be the first consult when PwMS develop their first symptoms (Giovannoni et al., 2016) and an important part of the health care team during the lifetime living with a chronic illness. A systematic review has shown that being under the care of an empathic family doctor improves patient adherence to medical advice, decreases anxiety and distress, improves clinical outcomes and improves patient enablement (Derksen, Bensing, & Lagro-Janssen, 2013). Paul was also fortunate to secure a GP who supported him at every opportunity, becoming an important member of his Medical A-Team.

My GP, she's another one who spends hours with you, she's learning from me about MS, so whenever she's at conferences she tries to go up and find out a little bit more with neurologists, she's told me she's loving having me because I'm the only one that she's got. Paul line 481

MS Nurses have been perceived by patients as being ideally situated to discuss practical and emotional issues relating to MS (Dennison et al., 2016). MS Nurses play an integral role in helping patients and families come to terms with diagnosis (White, 2012) and across the entire disease trajectory providing expert information, relapse intervention and decision support (Mynors, Bowen, & Doncaster, 2016). MS Nurses cover many domains, including advocacy, empowerment, disease expertise and education (Halper & Harris, 2016) and have an important role in preventing unnecessary emergency and hospital admissions (Quinn et al., 2014). Rudi and Ruby both valued the support of MS Nurses who advocated regularly for them and were both interested and available as members of their A-Team.

I've got a great GP, she's advocated on my behalf, I've had her great support and the whole MS clinic has been great...if I ring and say I need to see someone, they know I'm sick and they will get me in...the MS Nurse, the fact that I can ring her, that's awesome because you probably have more contact with them than you do with the doctor and she can answer your questions. Rudi line 1871

My neurologist, he's just beautiful, he loves what he does and the MS Nurse...she takes the edge off going, I've never met a more efficient woman in my life...the nurses are divine and it's a comfortable environment. Ruby line 494

Harnessing support from family, friends, organisations and workplaces

Social support systems can vary greatly between countries and cultures but mostly comprise of family, friends and HCPs (Rosland et al., 2013), as well as organisations, societies and work places. Immediate family, significant others and close friends also play an important role as the first line of support, especially true for spouses of PwMS who are often sharing the burden of MS on a daily basis (Aymerich, Guillamon, & Jovell, 2009). When appropriate support is provided it can

be positive and affirmative for the PwMS, however, sometimes social isolation can occur as family and friends may withdraw from the ill person, especially if they feel there is nothing they can offer in terms of help (Reade, White, White, & Russell, 2012). As discussed in earlier themes, for Davina and Joy sadly this was the case many times during their lives with RRMS as those dearest to them withdrew their love and support, refusing to acknowledge the impact of RRMS in their lives. However, for the majority of the participants in the current study, family and friend support was present in abundance and became a welcome refuge from RRMS and an important factor in Taming the Beast.

Ruby and Paul described how their immediate families rallied around and provided support when they needed it the most.

My husband's become a pro at managing it now, I'm very blessed...Mum and Dad bought a house around the corner and my sister wants to move closer...Mum and Dad are just there which is a godsend with the children and this has brought us closer together for sure. Ruby line 1122

My family first and foremost got me through that first year...my parents are just out of this world, but my wife is just the best. Paul line 861

I try and give my wife time off MS, let me look after the kids for a while, but she's like no, we'll do everything as a family...I'm very, very lucky. Paul line 947

For Susan, after many years of worrying and searching for a partner who would accept both her and RRMS into their life, she was fortunate to find someone who was willing to partner wholly with her in living with RRMS.

He was beautiful...such a gentle soul and I told him about my MS and he was so accepting of it and he said that doesn't worry me, he was so loving, he was very supportive...I'll do it with you...and then I forgot about my MS, it wasn't the focus any more when I had been focusing on that for the last whatever many years before I met him...I was more. Susan line 884

Simply holding the belief that others will provide appropriate support has been shown to increase patients perceived ability to cope with chronic illness and to lower their stress levels (Uchino, Cacioppo, & Kiecolt-Glaser, 1996) and actually receiving support from loved ones can be an integral part of the illness journey (Kiecolt-Glaser & Newton, 2001). MS focused research has repeatedly demonstrated that greater social support is associated with better mental health outcomes (Koelmel et al., 2016) and that the presence of social support can protect against stress and improve the sense of purpose for PwMS (Bambara, Turner, Williams, & Haselkorn, 2011; Kirchner & Lara, 2011; Krokavcova et al., 2008). Additionally, social relationships are known to play an important role in stress and coping (Wirth & Bussing, 2016), factors that are absolutely vital for PwMS in the unpredictable RRMS journey ahead.

High quality social interactions have been shown to lead to higher levels of life satisfaction and also lower levels of depression and anxiety in a study using a mixed methods questionnaire in 103 PwMS, most of whom were living with RRMS (Reade et al., 2012). Supporting these findings is a recent Iranian study which demonstrated that increased social support for PwMS was also positively associated with more effective coping strategies and also enhanced psychological well being, both so important for quality of life living with MS (Farran, Anmar, & Darwish, 2016). In order to be effective, it appears that social support needs to be of high quality, worthwhile and appropriately applied to times of need for the PwMS. Examples of social support that did not fit these categories in the current study included Jane's mother providing her with MS information at diagnosis which was well meaning, but outdated and wheelchair-focused, and Paul's mother "canoodling" him with worry and over emphasising MS. However, the great majority of participants in the current study described situations where family and friends provided much needed support and encouragement at just the right time, were consistent in their support and greatly assisted them in Taming the Beast. In Piper's case, her social world widened significantly after her diagnosis and she took every opportunity to participate in life, laughing as she recalled the toll her new social life took on her.

I've met another girl and she's become a good friend of mine...she was the one who recommended the neurologist...we sort of catch up nearly every other week and have coffee...her experience with MS has been different but it's actually nice to have someone who understands. Piper line 695

I'm probably doing more than ever...my social life is more than I can take...I've had that many weekends away...I'm actually a little tired of it! Piper line 683

A study exploring stigma in MS found that PwMS were sometimes ignored in social situations and interpersonal relationships, described as “polite inattention” towards the illness (Grytten & Maseide, 2006). Kate felt a sense of losing friendships when her friends learned of her diagnosis with RRMS. However, Kate also felt that the worthwhile friendships were able to withstand her life with RRMS and she takes comfort in the strength of these current friendships.

Your real friends stick by you...friends that I've come to learn were more like acquaintances...the minute you get sick and you can't do things that you used to do...they are no longer your friends...you're in the too-hard basket...good friends make the effort, they make the effort to come and we have developed strong friendships. Kate line 1994

Rudi felt the support from her country town environment, where everybody pitches in to help those who need it.

I'm very lucky, I couldn't have had more support and friends...in small towns people are so willing to help...people that you're friends with, but you don't really associate with...give me a call...I'll pick kids up, can I cook you something? So, I'm very fortunate. Rudi line 1721

MS Societies and organisations can be an important source of social and emotional support and can be vital in strengthening morale for PwMS as they adapt to their disease (Ebrahimi et al., 2017). Additionally, connecting with social support from other PwMS is an important positive coping behaviour (Rommer et al., 2016). Several participants in the current study reinforced the importance of sharing stories

and being supported by others with RRMS, people who truly understood how they were feeling and the battles they were facing. This could happen in organisations such as MS Australia, or more informally at MS clinics and infusion centres where PwRRMS tend to gather together at common times for consultations and treatments.

The MS Society is brilliant, I love them...I used to love the blogs but I can't handle the negative...I'm quite a positive person. Ruby line 995

Natalizumab (Tysabri®) is a DMT infusion that needs to be given regularly every four weeks in a hospital clinic, usually for a period of several years if all progresses well. Patients would often be scheduled to receive their next infusion on the same day four weeks later, leading to meeting up with the same fellow patients regularly. For some study participants such as Margot and Griff, this led to strong friendships being forged and a sense of support from others living with RRMS and having the same treatment. Griff also valued the chance to see other diseases he viewed as worse off than his own, appreciating the perspective this brought to his life.

You had a common thing, MS...I made friends there and it was nice... different experiences rather than just yourself, the Tysabri® days were fun and I still keep in contact. Margot line 506

Tysabri® became my social world...it was a big part of my social life...one of the great pleasures was actually keeping the disease in perspective, I'm sitting there with people having their cancer drugs as well...you've got to just do it...it was such a good social environment. Griff line 958

Work places and work colleagues can also provide support at difficult times, providing understanding during sudden relapses or on “bad days” when MS symptoms were overwhelming. Having the ability to choose to work days and hours to assist with fatigue management was seen by several participants as being a great advantage in Taming the Beast. Rudi was able to chose hours that suited her RRMS symptoms best and allowed her a rest time in the afternoon prior to collecting children from school.

Now I'm back working twelve hours a week I chose the hours and the days...this just landed in my lap so I was lucky and it was the right time... and while it's not the most stimulating job, it's a job and this is good for now. Rudi line 955

For both Ruby and Susan, having their immediate work manager understand their unique needs has led to them feeling supported at work and able to continue balancing work and life with RRMS.

I've just asked next year to have part time reduced hours to have a day off in the week...my body's really craving to move...my boss has been really good so far...work's been really supportive, so I feel blessed to be in that work environment. Ruby line 657

They looked after me and understood...I was very grateful, very blessed...two days on, one day off, two days on...and I rested and felt healthy. Susan line 591

Riding High on Resilience

Resilience can be defined as the human capacity to persist, to bounce back and to flourish when faced with stressors (Bonnano, 2004). More formally, resilience is the capacity of an individual to successfully maintain or regain their mental health in the face of significant adversity or risk (Stewart & Yuen, 2011). In disability and illness, resilience has been identified as an important contributor to QOL (Terrill et al., 2014; Silverman et al., 2015). Moreover, in the case of RRMS, the very nature of the unpredictability of the disease can present unique challenges in resilience right through the life trajectory (Silverman et al., 2017). For all of these reasons it is imperative that MS HCPs are aware of the benefits of resilience for PwRRMS and that they themselves acquire skills to enhance and develop resilience for patients under their care.

After only the first few interviews in this life history series, I was humbled by the stories of resilience I was hearing from the study participants. This pattern continued throughout all of the interviews and was one of the study highlights for me personally. I have consulted thousands of patients over the years of my nursing

career, and even more intensely since working in the field of MS, but, I questioned myself, have I ever asked a patient to talk to me about previous life difficulties and how they overcame them? Had I ever asked a patient with MS to relate stories from their life that told me about some of their life challenges and how they managed them? To my great embarrassment I could not recall ever asking that particular question. But very quickly during this research study I became acutely aware of how important resilience was for PwRRMS to Tame the Beast and what an essential part of the life journey with RRMS that resilience occupied.

The stories of past resilience in the lives of the study participants differed of course, but the common thread they all had was overcoming difficulty and moving forward in life, sometimes even managing to thrive along the way. Some stories were incredibly sad, comprising of very harsh and neglected childhoods and family situations. Will had endured a home situation of an absent father and a mother who died from alcoholism when he was thirteen, Joy had overcome a lifetime of abandonment and neglect to be thriving, and Davina and Evie had both survived bullying during school years and traumatic home situations from their fathers. Margot and Kate were the children of ethnic parents who moved to Australia, without speaking English, and later becoming translators for their parents and taking on family responsibility beyond their years. Ruby, Piper and Susan also suffered issues with infertility, and Rudi was to suffer incredible grief as her full term son was stillborn. Surviving these traumas provided a strong base and an individually acquired skill set for their later battles with RRMS.

During a particularly dark time in her RRMS life journey, Joy was desperate to reconnect with her old, happier self and spent time trying to recall a time when she felt carefree and happy. She wanted to use these memories to conjure up a new direction for herself and in the process, Joy provided an excellent example of harnessing resilience and moving forward to conquer demons.

I thought about when I felt most alive and full of joy and it was when I was in my twenties, I used to wear stilettos and I really enjoyed it...the joy part is around the high heels I hadn't worn them for years, I had to wear flat shoes (because of instability walking from MS)...so I thought, well, let's give this a try. So I bought

four inch high heels...I felt amazing, I felt amazing...I was walking better and I was much more conscious of the way I walked and carried myself...I adjusted my gait for wearing the high heels and then I walked towards the mirror with confidence, I was so empowered and I felt so strong, so joyful. I felt like I got my whole life back...I would walk downtown, dance all night long...that was a special time. Joy line 1151

Although most of the study participants did not outwardly recognise their great achievements in resilience, several participants did recognise that previous challenges had helped them gain valuable life skills to help navigate life with RRMS. Piper and Margot both did realise that their special challenges had given them resilience to shape their lives today.

People don't see all the symptoms because of my day to day living...even if I'm having a bad day with MS I know now that I am in control of my thoughts and I can change that thought process...I think I've become more resilient along the way. Piper line 1772

I think having MS was the big thing that impacted on my life...I think growing up in an ethnic background with parents who didn't speak English for a long time...you are growing up in two different cultures...I think it gave me resilience...and a bit more empathy for people. Margot line 1424

Rudi also recognised that the hardships she has endured throughout her life have also helped her to deal with life so far and this resilience will help with whatever the life journey is going to bring for her.

We've been through a fair bit...I think so very much...and I look at that as a gift as well...and you know people had it worse than me, but people had it better...it does give you resilience, not that it's any easier, but it gives you something to be able to get through it and get back on track. Rudi line 1275

I had Max, not in my wildest dreams did I think that would ever happen (his stillbirth)...so yeah, it's been tough but...you obviously carry some sort of strength...the death of my son changed everything. Rudi line 1320

Resilience is a learnable behaviour (Manning, 2015) and interventions can be created for patients to provide training in resilience enhancement, important for the entire life trajectory with MS (Mealer et al., 2012). A recent study explored the impact of resilience in chronic illness and on later life disability (Manning, 2015). This research supported the observation that high levels of resilience can protect against the negative impact of disability in later life and that teaching resilience from the beginning of the journey can have a profound effect in protecting against chronic illness and disability in a normal aging population (Manning, 2015). The message for MS Nurses is to take every opportunity to develop resilience in PwRRMS, as the benefits may be life long and may even lessen later disability.

It is also important for MS Nurses to be aware that resilience is dynamic, it is under constant negotiation and is often contextual (Ferguson & Walker, 2014). A recent three year longitudinal study of 31 adolescents with chronic illness found that a key component of living with chronic illness was the desire to live life as “normally” as possible, as highlighted in the second study theme (Re)defining Me Now That I Have RRMS; even in the face of challenges, and to focus on opportunities and optimism (Ferguson & Walker, 2014). Similarly, participants in the current study were keen to focus on the positive aspects of the situations they found themselves in instead of focusing on the negative, although this was sometimes a struggle for the participants to remain positive as some hardships were particularly difficult to deal with (death of a child, childhood parental neglect). Participants were able to describe how they faced challenges, developed new ways of looking at the problems and continually moved forward with the help of family, friends and community.

MS Nurses have an important role in helping families through both the diagnosis of RRMS and living life with RRMS, being in a unique position to facilitate normalising the response to extreme events (such as diagnosis and relapses or medication changes), ideally by providing narratives of families in similar situations (Chesla and Leonard, 2017). Talking about stories of how other families successfully overcame difficult or challenging periods instils confidence and practical information to consider for the PwMS and is an important educational role for MS HCPs. Of course, no two families are exactly the same, but knowing others have survived such challenges can be immensely helpful for those navigating difficult times and can also

be helpful for novice clinicians and HCPs to enhance their own learning and development (Chesla & Leonard, 2017).

Sharing experiences and narratives through reflection also helps to strengthen resilience in people living with chronic illness, showing the possibility of mastery in a situation and fostering connectedness between the HCP and the patient (Kralik, Van Loon, & Visentin, 2006). However, it is important to remember that this is contextual for the PwRRMS and is not a one-off discussion, and PwRRMS may need additional resilience assessments and education at each clinic visit. It is important to reassess scenarios with patients and not assume they are at the same level of resilience as the last clinic visit. They may have shown high levels of resilience at the last appointment, but the nature of living with a chronic and evolving illness such as RRMS means that they may also have lost some momentum along the way with life and may need a reminder of the importance of fostering and developing resilience.

Approaches MS Nurses can use to nurture and build resilience in their patients include discussing the importance of maintaining social connections both within and outside the MS community, using strategies such as using humour, discussing ways to creating a normalcy in their life, the benefits of maintaining a positive outlook, methods of practicing self compassion, and the importance of planning ahead and managing commitments (Silverman et al., 2017). Almost all of the participants in the current study reported using at least one of these techniques to help when Taming the Beast and many participants used several techniques. Harnessing resilience is an important and valuable skill in the life story of PwRRMS, and a skill that can be developed with the help of the MS Nurse.

Theme 7- “The DMT Dance”

Shall we dance?

The first dance of the night is with me

Alone and fragile

Scared about the first steps and where my feet shall go

Some lessons, some guidance, a show

I start to feel a little more confident

But still not ready

The waltz commences, regardless of me

Stepping on toes

Feeling clumsy I suppose

I start to learn the steps

I sail through the air

I continue my lessons, I practice, I step this way and that

Life has more in store than I imagine

I change my dancing partners

This one feels more comfortable

These steps I know

My confidence starts to show

I can salsa, I can two-step, I can sway

I am now a dancing master, but in my own way

TB

The **central organising concept** of “The DMT Dance” consists of negotiating and coping with medication therapies to treat RRMS, the DMTs. There are two distinct subthemes within this concept, the first subtheme “The hard yards: making decisions about DMTs and adherence”, further subdivided into DMT decisions driven by fear and DMT decisions driven by hope, and the second subtheme switching to a better life.

Although the past 25 years has seen the development of the first effective treatments for RRMS with DMTs, there is still no curative treatment for RRMS (Torkildsen, Myhr, & Bo, 2016), meaning that relapses on therapy are still possible (Anderson &

Philbrick, 2014). Nowadays it is widely accepted that early treatment with a DMT will reduce both MS relapses and MRI activity, which will ultimately delay disease progression (Smith, Cohen, & Hua, 2017; Comi et al., 2017). Whilst DMTs have improved the disease course of RRMS dramatically, they have also added a layer of complexity to RRMS care (Comi et al., 2017). Managing DMTs provides challenges for both patients and MS HCPs and requires close communication to improve clinical outcomes and QOL for PwRRMS (Tintore et al., 2017).

The current focus in RRMS care is on both early diagnosis and prompt commencement of a DMT in order to modify the disease course and result in better outcomes for PwRRMS (Kobelt, Eriksson, Phillips, & Berg, 2017). That seems straightforward, but PwRRMS and their HCPs are faced with complex decisions regarding which treatments will be most effective and appropriate for them (Bottomley, Lloyd, Bennett, & Adlard, 2017). As discussed in previous themes, this is often at a time when *Piecing Together the Puzzle*, *(Re)Defining MS* now that I have RRMS and *Battling the Demons* have led to increased vulnerability and distress for the PwRRMS, further impacting on DMT decision making. Assessing the relative benefits and risks for individuals of each DMT can be confusing and complicated for the PwRRMS. Additionally, potential side effects (risks) of some DMTs can be very serious, adding further worry, stress and uncertainty about treatment decisions. These serious side effects include progressive multifocal leukoencephalopathy (PML), an incurable brain infection which has contributed to many deaths in PwRRMS (Chataway & Miller, 2013) and also autoimmune blood and kidney conditions which have also led to fatality in PwRRMS (Coles et al., 2012). There is also preparation needed at the start of the DMT journey regarding family planning and pregnancy, as most DMTs have pregnancy related risks and considerations (Wingerchuk & Carter, 2014). With many PwRRMS diagnosed and commencing treatment during their child-bearing years, this is an important factor in *The DMT Dance*.

Evidence from clinical trials and from daily clinical practice has demonstrated that not all patients respond satisfactorily to a given DMT, the response to medications and their effects are highly individual (Comi et al., 2017). Switching between DMTs is common in RRMS, particularly if the patient does not respond well to the medication (e.g. experiences a relapse or has new lesions on the MRI) or experiences

significant side effects (Costello, Thrower, & Giesser, 2015; Giovannoni et al., 2016). This often leads to a PwRRMS experiencing several different DMTs during their lifetime, all with their own particular set of risks and benefits. This scenario was referred to by Ruby in the current study as starting “*the wave of medicines*” (Ruby, line 110).

In Australia, the first DMT to treat RRMS was Betaferon® and was registered in 1995 (Broadley et al., 2014b). This injectable interferon was followed in 1998 by two more interferons (Avonex® and Rebif®) and in 1999 by another class of drug, glatiramer acetate (Copaxone®) (Broadley et al., 2014b). All of these DMTs required PwRRMS to learn how to self inject the medication at various intervals ranging from daily to weekly administration. The first infusible (by intravenous infusion or “drip”) medication was natalizumab (Tysabri®), being registered in 2006 and the first long awaited oral medication to treat the disease, fingolimod (Gilenya®), was registered in Australia in 2011 (Broadley et al., 2014c). Fast forward to 2018 and there are currently 12 DMT choices for PwRRMS registered with the Therapeutic Goods Administration (TGA) in Australia. Currently, all of these DMTs are available at a heavily government subsidised cost on the Pharmaceutical Benefits Scheme (PBS).

There are variable modes of administration between the DMTs ranging from subcutaneous injections just beneath the skin, to oral tablets to intravenous infusions that need to be administered in a hospital or clinic setting. This results in truly individualised MS care where the best drug can be selected for the right patient at the right time, without having to consider step-wise approaches, insurance company preferences or other ‘red-tape’ which may govern DMT prescribing in many other countries. Australia is one of only a few of countries in the world with so many effective treatments available first line and at a low cost to the patient (Broadley et al., 2014c). Many other regions, such as some areas in Europe and the USA, can have restricted access to DMTs or restricted government or company reimbursement (Wilsdon, Barron, Mitchell-Heggs, & Ginoza, 2014; Comi et al., 2017), causing DMTs to be out of reach financially for some PwRRMS. For example, some insurance companies in the USA require a PwRRMS to experience treatment failure on a DMT before being permitted to start a more highly efficacious drug (Owens,

2013), thereby missing the early time in RRMS when the anti-inflammatory effects of the drug may be the greatest (Hauser, Chan, & Oksenberg, 2013). In an ideal world where the evidence points to the need for early and effective treatments in RRMS, there would be DMT treatment access for all PwRRMS and the full range of DMTs available to PwRRMS and supported by national bodies, regulatory authorities and reimbursement agencies (Giovannoni et al., 2016).

The hard yards: making decisions about DMTs and understanding adherence

As the course of RRMS is heterogeneous, a confident prediction of long term individual prognosis of RRMS on a particular DMT is not yet possible (Wingerchuk & Carter, 2014). This can be frustrating and confusing for patients as they are faced with making DMT decisions when the long term benefits are unclear and the degree of side effects and risks they may experience are also uncertain. A recent UK study found that most patients with RRMS wished to be part of the decision making process regarding their DMT and that shared decision making underpinned effective disease management, especially when supplemented by MS Nurse support (Colhoun, Wilkinson, Izat, White, Pull, & Roberts, 2015). However, there is very little literature available exploring how PwRRMS make decisions about the best DMT to suit their situation, their beliefs, their values, their disease state and their lifestyle or how they balance treatment risks and benefits. By taking into account factors such as patient preferences, lifestyle, how patients view risks and benefits, personal tolerance, acceptance of side effects and the time commitment required for treatment and safety monitoring, shared decision making between the MS HCP team and the PwRRMS can be made.

People living with a chronic medical illness must balance the probability of current side effects with treatment with the probability of long-term benefits (Bruce et al., 2016). For a disease such as RRMS where disease remission and return to baseline or 'normal' functioning occurs between relapses, it can be very difficult to reconcile the side effects from DMTs that make patients feel unwell with the fact that they often feel better without any treatment. Jarmolowicz et al. (2016) reports that side effects can often make patients feel much worse in the present moment, causing the patient to consider balancing their current QOL (reduced by the taking DMT now) with the

potential of reduced QOL in the future (reduced by *not* taking DMT now). Unlike drugs such as analgesics where an immediate benefit may be felt, DMTs in chronic disease are preventative medications to reduce the probability of negative future effects with no immediate observable benefits (Jarmolowicz et al., 2016). Additionally, DMTs do not typically improve acute symptoms in RRMS and so PwRRMS do not usually experience observable improvement while taking the medication (Bruce et al., 2016).

Adherence has been defined by the World Health Organisation (WHO) as “the extent to which a person’s behaviour - taking medication, following a diet and/or executing lifestyle changes - corresponds with agreed recommendations from the HCP” (WHO, 2003). Studies have shown that DMT adherence in RRMS is particularly problematic, with up to 25% of PwRRMS non-adherent to their DMT (Devonshire et al., 2011). No medication is going to be effective in controlling a disease if the patient is non-adherent, as former US Surgeon General C.Evert Koop stated, “drugs don’t work in people who don’t take them” (Osterberg & Blaschke, 2005). Maintaining DMT adherence in MS has been described as comprising of three actions: those of acceptance (the patient accepting that therapy is needed), persistence (continuing to take the treatment over time) and compliance (taking the treatment as prescribed at the right time and right dose) (Remington et al., 2013). This subtheme will define adherence as taking the prescribed DMT as directed by the MS HCP.

Recognising adherence and non-adherence to DMTs is a crucial part of the MS HCP role (Costello et al., 2008). The Global Adherence Project (GAP) was a worldwide study of 2,648 participants, the goal of which was to evaluate the degree to which patients with RRMS adhered to dosing schedules for DMTs as outlined by their neurologist (Devonshire et al., 2011). Several factors were found to relate to greater DMT adherence: being female, the ease of administration, satisfaction with therapy, treatment at a designated MS centre and the presence of family support. Of further importance in the GAP study was that adherent patients reported higher QOL scores than non-adherent patients. This finding is significant for MS HCPs, as it suggests that by targeting strategies to improve DMT adherence, there may also be indirect improvement in patient QOL.

Adherence to DMTs in RRMS can be difficult to quantify and the specific combination of factors influencing an individual patient's likelihood to adhere to a DMT can be difficult to determine (Remington et al., 2013). Patients who are non-adherent to DMTs usually follow one of two patterns; either missing doses and taking the DMT less frequently than prescribed (Wicks et al., 2015) or by abandoning therapy completely, usually within the first six months (Rio et al., 2005). Adding to the complexity of adherence or non-adherence on DMTs, there may also be a wide range of emotional and cognitive factors present which are specific to RRMS (Wicks et al., 2010), with mood and anxiety disorders prevalent in the disease (Feinstein, 2011; Feinstein et al., 2014).

Increasing the complexity of DMT decisions further for PwRRMS, is the fact that the more highly efficacious (more effective) therapies have rare, but potentially serious side effects and unfortunately, the safest therapies have much lower rates of efficacy (are less effective) in controlling RRMS (Smith et al., 2017). Very little is known about how patients decide between oral (tablet) therapies and parental (injection or infusion) therapies, or how patients 'trade off' the convenience of oral therapies against treatment frequencies or side effects of the other medications (Lynd et al., 2016; Utz et al., 2014; Wilson et al., 2015). Additionally, not all patients respond satisfactorily to DMTs and a 'one-size fits all' approach is not attainable in RRMS (Comi et al., 2017). Ideally, the best treatment option would be the safest treatment that eliminates disease activity (Hauser, 2013), but the identity of this DMT is not known at the beginning of the RRMS journey. This is currently an area of intense research interest and hopefully biomarkers (measures such as blood tests or scans which can determine responses to a medication) will be able to shed light on this in the future (Hegen, Auer, & Deisenhammer, 2016).

Understanding how the PwRRMS makes decisions about which DMT will suit them best is vital for MS HCPs to understand, but there is limited literature to provide guidance and support for MS HCPs in this regard. A recent study of 189 PwRRMS in Canada used focus groups and individual interviews to determine attributes of DMTs that were most important to patients. The researchers concluded that overall, the most important attributes were the avoidance of side effects and the improvement

of symptoms (Lynd et al., 2016). Unfortunately, both of these attributes cannot be guaranteed for patients with the current DMTs. As the adherence data discussed above has suggested, actually taking the DMT as prescribed is a particular problem area in RRMS, and an area where the MS Nurse and other MS HCPs can target understanding to enhance adherence in the future. Unravelling how these decisions are affected by other factors is poorly understood, however participants in the current study shed some light on how these decisions were driven, some decisions appeared to be driven by fear and some decisions driven by hope.

DMT decisions driven by fear: “I’d rather be in a wheelchair than dead”

As discussed briefly in theme 3 Battling the Demons under the subthemes of facing fear and weary with worry; fear and worry can be major barriers contributing to adherence issues in RRMS, especially fear of medication administration and worrying about potential side effects (Anderson & Philbrick, 2014). This fear and worry can be further impacted by mental health issues in RRMS (for example depression and anxiety) leading to negative cycles that threaten DMT adherence (Anderson & Philbrick, 2014). Indeed, fear and worry can sometimes influence a patient’s decision to take any form of DMT, with some PwRRMS preferring to stay unmedicated and take the risk of further relapses and possible disease progression over what they perceive as unacceptable potential side effects. A one percent risk of a serious side effect can reduce patient preference for a particular DMT fivefold (Wilson et al., 2015).

A recent study using focus groups in PwRRMS found that patients who opted out of DMT entirely felt that this was mainly due to side effects they experienced, feeling that their present QOL was more important to them than future disease progression (Mortensen & Rasmussen, 2017). In the current study, this was the case for Joy, who adamantly refused to take the advice of her neurologist and commence a DMT. Joy suffered greatly from side effects on earlier DMTs, at one stage needing hospitalisation from medication toxicity. This experience made Joy reluctant to try a new DMT, preferring to feel well in the present moment and take a risk with possible disease progression in the future.

I don't see any point on going on a drug that could potentially kill me...I don't see any point on going on a drug that's not going to cure me and when it doesn't really alleviate the symptoms. Joy line 1651

I don't believe that medication is the answer for me...if they can't come up with a cure then, really...I'm not going to take something that may make me sicker. Joy line 1687

The Health Belief Model (HBM) looks at anticipated gains and losses balancing present and future QOL (Rosenstock, Strecher, & Becker, 1988). Using the HBM, health behaviour can be determined by personal perceptions about the perceived susceptibility and seriousness of a disease together with the perceived threat and benefits from a given behaviour, that is, in order for an individual to take a certain medicine, potential gains must be considered greater than losses (Mortensen & Rasmussen, 2017). Adding complexity to this theory in RRMS is the uncertainty of the disease and the lack of prognosticative ability in the future (Wilson et al., 2015) and if the chosen DMT will have the desired effect at all. On a background of fear and worry, there is no definitive answer that can be given to a patient on what their individual risk might be for a given DMT, and for some, the fear is too great. Piper had researched the newer DMTs in preparation for a change to a DMT with improved effectiveness, but was unconvinced this was the right move for her. She preferred to take her chances with the disease than mindfully expose her body to potential fatal side effects.

With the newer, unproven medications, I just think the risk is too great...I get that these people are in a real state of bother, they're probably prepared to give anything a go...but I just think I'd rather be in a wheelchair than dead...I just think the risk is too great. Piper line 1960

The list of reasons to be fearful about starting a DMT, often outlined in great detail by MS neurologists and MS Nurses when considering DMTs (and supported by product brochures and internet research) can sometimes be more frightening for the PwRRMS than the disease itself. This is particularly so in recent years with the advent of more efficacious (effective) therapies with more potent side effect profiles

and where deaths have been reported in PwRRMS receiving the various DMTs. The introduction in Australia in 2006 of the monthly intravenous infusion natalizumab (referred to in the interviews by patients as the trade named Tysabri®) was exciting because at that time it was the most highly effective treatment for RRMS and showed long term benefit (Smith, Cohen, & Hua, 2017). However the occurrence of a potentially life threatening brain infection called PML (Chataway & Miller, 2013) forced the drug off the market shortly afterward. Natalizumab was reintroduced to the market a year later, with a safety warning about PML which necessitated special safety monitoring when using the drug. As of December 2017, there had been 756 reports worldwide of PML associated with natalizumab therapy, with 25% of the cases being fatal (Biogen, 2018).

In more recent years, PML has also been associated with some of the other DMTs (fingolimod and dimethyl fumarate), although not in numbers as high and as predictable as with natalizumab (Faulkner, 2015). Several participants in the current study openly discussed PML as a great fear for their current and future treatment. Piper was adamant in choosing possible disease worsening from RRMS over potential death from PML.

And that PML keeps popping up and I don't like the sound of that...and what does scare me about it is how do you know it's PML or an MS symptom? And it's not curable. Piper line 1362

A blood test called the JCV test can measure for a specific antibody and give an indication of whether a PwRRMS has a higher risk of contracting PML on natalizumab treatment (Torkildsen et al., 2016). For Rudi, knowing that she was JCV positive influenced her decision to refuse treatment with natalizumab (referred to by Rudi as Tysabri®) and to risk further disease progression on her current oral DMT, which had so far been not been able to control her relapses.

One medication they're considering is Tysabri and I refuse to go on because I carry the JC virus, they tested me for that and I'm just not willing to (take that risk). Rudi line 501

Participants also experienced fear when changing treatments after many years on the same DMT, even if it was perceived by the MS HCP as a change for “good”; such as changing from an injectable therapy to an oral therapy. This was the case for Davina, after many years of struggling with the side effects of a weekly self-administered intramuscular injection, to contemplating a daily oral medication. The fact that it was a change at all was frightening for Davina, even if there were benefits expected from the treatment switch by her MS HCP.

Changing treatments...that was really hard, I'm not good with change...so to change a medical treatment was really scary because I'm going on the hearsay of someone who knows more about it...but hasn't actually received it...so I had to think a lot about that...it's a bit of an unknown, I don't know if I'm going to have problems in the future. Davina line 1423

Having a son before her diagnosis of RRMS, Kate made the decision not to expand her family and have another child after her diagnosis, even though she did once wish to have more children. From a science background, Kate was deeply concerned about the possible effects of the DMTs she had previously taken on a foetus, especially as Kate had needed less conventional and more toxic treatment options in the time before many of the modern DMTs had become available.

Being on all of these drugs, I thought...I'm not going to have a child that's going to turn out to be sick. I've got no idea what these drugs are doing to me...and what they're going to do to a baby. Kate line 1393

There are very few qualitative studies addressing patient perspectives in regards to preferences in selecting a DMT in RRMS. However, a recent study explored patient perspectives on DMT choice by interviewing ten PwRRMS and using hermeneutical phenomenological methodology to analyse the findings (van Capelle et al., 2017). Researchers found themes of “constant confrontation with the disease” voiced by study participants who felt frightened at the prospect of having to use medication with possible side effects for the rest of their lives, reflecting similar themes of participants in the current study. Emotional fear as a theme was also described by van Capelle (2017), including a fear of injections and the act of injecting oneself

making the patients feel ‘different’ to others. These themes were also supported by current study participants, most notably Jane, who felt that her need to self inject her interferon DMT curtailed her ability to travel freely with the medications to remote countries (as she loved to do) and left her feeling disappointed and ‘different’ to others.

I can't do this now...you have to inject three times a week and it's just a pain, you're travelling with syringes and everyone thinks you're a drug addict, and I absolutely hated it...it was really, really depressing...I thought I may as well just give up and do nothing. Jane line 338

DMT decisions driven by hope

For other study participants, their choice of DMT, and indeed their choice to remain adherent to the medication, was driven more by a positive sense of hope for future good health rather than by fear of DMTs or potential side effects. Adhering to one's DMT is also an important way that PwRRMS can take control of their disease (Settle et al., 2016). This appeared to be a conscious choice for Paul in the current study, who performed considerable scientific research to decide on the DMT he thought would give him the best result in the long term.

I was happy to go on Gilenya because at the time there was going to be some neuroprotective effect and it looked like a better option than 2 pills and possibly being sick all day...I was happy going on Gilenya at that point. Paul line 635

A little later on in his life story, Paul suffered a further MRI relapse with a new lesion in a delicate area of the brain, of which he was considerably fearful. With a science and physics background, Paul introduced the concept of “front end loading” which I had never heard applied to DMT decision making before our study interview. “Front end loading” is an industry or economic term involving developing strategic information to address risk and to make decisions to commit resources early in a project in order to maximise the potential for success (Morrow, 2012). In Paul's case, he was using the term to describe how he preferred to use one of the newer high efficacy DMTs now before he deteriorated, rather than continuing the moderate

efficacy DMT he was currently prescribed and risking further disease progress. His neurologist did not agree to change treatments at this time and preferred that he stay on his current therapy with close supervision. Paul argued that with an unpredictable disease such as RRMS it was better to “front load” and possibly stop the disease and he was willing to risk the potential serious side effects, which he felt were manageable with his level of education and understanding of what they meant. With a young family, an exciting new job and a love of the outdoors, Paul argued that he had a lot to lose not escalating his DMT to a higher level and would continue to seek out support to change therapies with another neurologist.

I've developed a new MS brain lesion and I'm not real happy about that. My thoughts on how I want to proceed with all this are...front load risk, I would much prefer to have it out and discuss with my neurologist again. I don't want to be at a stage where it is something they think about, you know, around the world at the moment they're using it as a front line...I'm aware that there's lots of therapies. Paul line 522

The best drug on the market is alemtuzumab, I mean, it does come with a lot of risks, but they're even more manageable than MS is...so if I take a thyroid medication for the rest of my life, that's great...a better outcome. Paul line 600

After experiencing significant deterioration in her physical condition over a short period of time, Ruby placed hope in her new DMT (alemtuzumab, also known as Lemtrada®) to be able to improve her mobility and prevent further decline so that she could enjoy her two small children and participate more actively in family life.

I hope from the alemtuzumab (the DMT) to be able to walk...I don't feel so weak...I hope so...this time last week I couldn't even strengthen my own body to come up so this week I woke up and I can actually get up by myself...it's no marathon, but for me it's pretty good, so fingers crossed. Ruby line 598

I was really excited about Lemtrada®...so hopefully it will start working and I'll be really happy. Ruby line 868

Several participants in the current study described nursing support as an integral part of successfully managing their DMT and a reason for their DMT adherence at various stages of undergoing DMT therapy (such as complying with blood tests and other safety monitoring). This was particularly so for those study participants diagnosed for longer than ten years, who only had access to the self-injectable medications in the beginning of their treatment journey and relied on nursing support to teach them the injection techniques and injection site management. Margot had an MS Nurse visit her to introduce her to the injectable DMT in the comfort of her own home and surroundings.

A nurse actually came out and showed me how to do the injections which was fantastic, she showed me how to do it and she made it so easy. Margot line 475

Hope in a DMT refers to more than just statistics of how well a DMT works to control RRMS, hope also refers to feeling positive and confident about adhering to treatment, with family and nursing support being an important factor in commencing, continuing or changing DMT (van Capelle 2017). In the current climate of so much choice, complicated therapies, monitoring programs, and evidence for using early, effective DMTs, MS Nurses are more integral than ever to managing RRMS by implementing patient-centric programmes and supporting PwRRMS (Giovannoni et al., 2016).

Switching to a better life

Almost all of the study participants had stories to tell about past unhappiness on earlier DMTs, particularly as two thirds of the participants had previously been taking interferons or glatirimer acetate injections before the newer oral and infusible medications were introduced. For these study participants, they were switched to newer therapies as soon as they became available. Difficulties for patients with the early injectable medications are well documented, particularly in terms of PwRRMS suffering from skin reactions, injection site reactions, flu like symptoms and feelings of depression as side effects (Costello et al., 2008). As these side effects and patient experiences are already well documented (Miller & Jezewski 2001; Miller & Jezewski 2006), only a selection of participant comments will be presented here.

These participant stories also have a role to play for the MS HCP to consider the resilience shown by PwRRMS in overcoming challenges, as discussed in the previous theme of Taming the Beast. These insights from Davina, Will, Evie, Griff and Kate also give some background for the MS Nurse to understand why adhering to DMTs can be difficult, and how the effects can infiltrate all areas of life.

*When I started on the interferon...that feeling of desperateness, hopelessness...so if I felt like that on the day I had the injection, it would make it a hundred times worse.
Davina line 1083*

My symptoms were getting worse, depression set in pretty bad and I became non-compliant...I went unmedicated and I quit my job. Will line 884

I went onto the interferon Rebif®, God awful drug...I don't have a problem with needles, it was the reactions...site reactions made me look like a red and white checkerboard and the cold and flu symptoms, the headaches, the pains, the fevers...you just wanted to curl up basically...I didn't take the treatment properly...I wanted to do it...but...I feel fine, so I stopped it. Evie line 835

*(Injecting glatirimer acetate) I hit a vein once, or a capillary and straight into my bloodstream and I thought I was going to die...it scared the shit out of me, it knocked me flat...and I had limited sites it was getting to the stage where I was hitting scar lines...(as a consequence) my compliance was getting sloppier...because it was fucked, I hated it and the thought of having to wake up everyday and do it again.
Griff line 892*

I was on the Betaferon® which I really couldn't tolerate, it was just like getting the worst flu...I just couldn't function...I'd have my injection and the next day I'd be totally miserable and really sick...and going to work people would just be thinking ...well, why is she sick all of the time? And you just couldn't explain it to them. I've always been quite vocal about how I feel and I said to the Neurologist "I don't like this, it's making me sick, it's not making me better and I don't want it. Kate line 743

Several of the non-adherence scenarios described above were first reported to the MS Nurse rather than to the neurologist. Physicians have been found to miss indicators of poor adherence in patients (Osterberg & Blaschke, 2005), possibly due to the subject not being brought up in clinic encounters and MS patients not being keen to report non adherence to their physician themselves (Schwartz et al., 2017). Implications for HCP practice include the need to check at every clinic visit and care encounter (email, text, phone) on the status of adherence for DMTs. Often adherence is difficult when patients are faced with intolerable side effects, especially when mental health is also affected (Costello et al., 2008). The value of the MS Nurse as someone the patient can confide in about true DMT adherence and also to discuss issues they are having to maintain adherence are important aspects of the MS Nurse role (Burke et al., 2011).

It is rare that the more serious side effects reported with the use of RRMS DMTs actually do happen in clinical practice but when they do, the consequences can be horrific. Kate suffered one of the first reported anaphylactic (allergic) reactions to natalizumab (referred to by Kate as Tysabri®) and recalls the horror of that day when hope in her new DMT suddenly was taken away. After this event, Kate was switched to one of the new oral treatments and has thankfully remained well since that time.

This Tysabri® was a nightmare, after three months it was stopped, it was working really well and I was quite excited about the whole thing...I went back on it and I had an anaphylactic reaction...that was horrible...I think I was the only case at the time...that was absolutely horrific...I felt my back was itchy but before I could even finish saying anything my face swelled up and the doctor's trying to get a thing down my throat...I was just terrified. Kate line 1076

For some study participants, specifically Griff, Margot and Susan, moving on to a new DMT after suffering at the hands of their first treatments led to improvements in their quality of life. Additionally, for both Griff and Margot, starting natalizumab (referred to by the participants as Tysabri®) widened their social circles as an unexpected benefit of a DMT change as they spent a half-day at their local hospital day admission unit for the DMT infusion with other PwRRMS. These feelings about

natalizumab were in stark contrast to those study participants who had earlier refused to consider natalizumab because of the potential side effect of PML in the first subtheme decisions driven by fear. Life just felt better on this DMT for these participants, despite the reported risks.

On Tysabri®, I just felt flat afterward and then 36 hours later it was gone and I had the rest of the month to myself, it was a joy and it was a big part of my social scene. Griff line 954

I had Tysabri® for four years, that was actually really good. When I went to have the Tysabri®, you met other people with MS which was fantastic...it was sort of like a day out really. Margot line 494

For the first time in years Susan felt “normal” taking tablets rather than self injecting her DMT.

I feel more relaxed...it's just a little tablet, I take it, I don't have to get up, it doesn't hurt...the injections were hurting. It's improved, I don't have to take injections with me, to find a freezer or to have a letter on the plane about why I have syringes, so now I feel normal taking tablets, I feel better and I feel positive. Susan line 1179

Oral treatments, especially when taken once daily, have been widely reported as being preferred by the majority of patients with RRMS over injections and intravenous infusions (Utz et al., 2014; Thach et al., 2016; Mortensen & Rasmussen, 2017). A recent study in adolescents with RRMS found higher levels of DMT adherence since the introduction of oral therapies in this population than in past studies (Schwartz et al., 2017). Over half of the participants in the current study were now taking an oral DMT and were happy with the change in terms of lifestyle and ease of administration.

To enable a DMT to have the maximum impact on the course of RRMS, adherence to the prescribed regime is essential. Maintaining adherence involves developing strategies to manage side effects, successful and safe DMT commencement and monitoring safety and drug tolerance as vital aspects of the role of the MS Nurse.

When The DMT Dance moves elegantly, controlling the disease with minimal side effects, with the engagement of an educated empowered patient, a reliable support network and an approachable invested HCP team, the results can be outstanding. Switching to a better life is achievable. The treatment goal with RRMS is clear, early and effective DMTs in a shared decision making environment (Giovannoni et al., 2016), performing The DMT Dance. Although some decisions are initially decisions based on fear, that doesn't mean they will always remain so. At times, another relapse, a severe relapse or progression of disease (either by EDSS disability assessment, by reduced mobility or by MRI progression) may prompt a PwRRMS to reconsider their past DMT decisions, and the basis for these, and change their thought process and direction. As demonstrated within this theme, a major part of this revolves around decisions based on hope and switching to a better life, and merges well into the final theme from the study findings, theme 8, which is all about Holding Hands with Hope and developing purposeful positivity.

Theme 8: “ Holding Hands with Hope”

Hope summons, hope heals

Hope can see me, hope can share

Hope understands, hope feels

Hope teaches, it helps me to bear

Hope wakes with me each bright new day

Hope teaches me to think in brand new way

Hope, stay with me

Hope, help me to be

TB

Linda Morgante passed away in 2007. Linda was based in New York and was an exceptional MS Nurse researcher, author, clinician, teacher and leader (Halper, 2007b) who became well known for her belief in the concept of hope being an essential component of living well with MS. As a noted speaker and writer in MS nursing, Linda inspired and encouraged nurses from all over the world to instil hope in MS care, both in their patients and in themselves. Linda Morgante wrote, spoke, taught, lived and breathed hope.

“Hope is an essential element of life - it embodies our vision of the future, our opinion of ourselves and others, and our sense of control over the events and direction of our lives. The presence of hope for someone experiencing an illness can provide the energy necessary to promote health and well-being.” (Morgante, 2000, p.9)

Looking back over the transcripts again in preparation to explore themes of hope and positivity revealed a startling, yet irrefutable, pattern. Almost every interview with participants in this research study commenced with stories of worry, of uncertainty, of the uninvited guest of RRMS invading lives and causing havoc in many forms, and almost all interviews ended with stories of hope, of some form of acceptance, of resolve and a will to do well in the future. This should not have been wholly unexpected by me, as the participants all volunteered to be part of the study and to share their stories (suggesting a purpose to help others and an essence of positivity). Nonetheless, it was a striking feature of the study and I was left astounded.

This theme of “Holding Hands with Hope” encompasses ideas of hope, positivity, defiance, and spirituality, giving back to others and sharing stories. I also felt a sense of determination, where PwRRMS held on tightly to their newfound peace and positivity, often borne after many years of struggle. Holding Hands with Hope also reflects the way fingers intertwine to provide support, not by a single finger, but by many fingers and a thumb working together to link perfectly inside one another. It reflects touch and sensitivity and it reflects hard work to get there. These hands are not soft and protected; they are often calloused and tough. PwRRMS hold many hopes and dreams in them, for themselves, but also for others living with RRMS and progressive forms of MS, and also for the people working in the field of MS as well.

The **central organising concept** of this theme is hope and positivity, it is all about reaching happier times, of the beginnings (or totality) of acceptance of RRMS into life and how looking to the future with hope brings its own peace and rewards. Expressions of hope differed greatly between participants of course, but the essence of hope remained remarkably similar. It was palpable and it was present in every study participant I interviewed. It often left me leaving the interviews smiling and

happy, reflecting on the remarkable achievements of my informants, even if there were tears and sadness interspersed regularly during the interviews. This theme is divided into two subthemes and several sub-subthemes to provide additional clarity. The two subthemes, “hope in its many forms” (including the sub-subthemes of functional, restorative, curative and defiant hope) and “purposeful positivity” (including the sub-subthemes of optimism and a positive outlook, searching for meaning, harnessing a sense of humour, faith, religion and spirituality and giving back and being involved) provide exploration of the role of hope in the lives of PwRRMS and the various ways PwRRMS express this hope and positivity.

Despite the anguish, ambiguity and suffering that appears to be part of the life journey with RRMS discussed in the earlier themes, participants often lingered after the end of the interview to ensure I understood the entire story. The fact that happiness and hope were a very important part of that story, even if it took years for some participants to feel hope, or even if it was more of a temporary or fleeting feeling. It was still present and it was overwhelming in intensity. As the MS Nurse is a pivotal part of the team in ensuring the PwRRMS maintains a sense of hope throughout the lifetime living with the disease, understanding the role of hope in the disease is critical for MS Nurses (Morgante, 2000). I have never felt, or believed this more, than after hearing the stories of these study participants.

What is hope? Why hope?

Defining hope for this particular theme was difficult, primarily because there are so many different variations of the concept of hope, with literature spanning many, many decades. Haase and colleagues (1992, p.143) sought to clarify the concept of hope for nurses, reviewing the available hope literature at the time and defining hope as:

“Hope is an energised mental state involving feelings of uneasiness or uncertainty and characterised by a cognitive action-orientated expectation that a positive future goal or outcome is possible”.

Noted hope researcher and writer, Snyder (2002) also embraced the concept of goals as an important component of hope and emphasised the active role needed to achieve these goals. Snyder (2002, p.249) defined hope as:

“Hope is defined as the perceived capability to derive pathways to desired goals, and motivate oneself via agency thinking to use those pathways”.

As a complex concept to describe, Clarke (2003, p.164) resonated strongly with my own feelings, noting that:

“We know hope when we see it, feel it intensely when it is gone. But it is hard to describe”.

The literature surrounding hope in both chronic illness and nursing care in general is substantial and stretches back for decades. Less common is literature specifically exploring hope and MS, although recent years have seen studies emerging, particularly in areas of allied health and MS (Soundy et al., 2012; Soundy et al., 2013; Soundy et al., 2016). Herrestad and colleagues (2014) have suggested that instead of generalist work in hope, what is needed to understand hope more deeply, are in-depth and context specific hope studies. As this theme developed and the data evidence to support hope as a theme was extensive, I was keen to explore and define hope in a way that captured the very essence of hope in this specific population. Even in the absence of supporting literature, the data from the participants demonstrated that hope is important to PwRRMS, and as MS Nurses, we have an obligation to at least try and form some sort of understanding of what hope might mean for patients under our care. If we make this effort, then we can recognise hope, we can facilitate hope and also introduce strategies to inspire and coach hope in others. We can take the beginnings of hope and help mould them into achievable goals and aims and strategise pathways to reach these goals. We can partner with our patients to make hope an important, active and achievable part of their health care plan.

Dialectic relations between hope and despair have been referred to as the existential paradox of chronic illness (Barnard, 1995). The line between hope and hopelessness

can often be very fine and sometimes blurred. Several study participants spoke about hope and hopelessness in the same sentence, feeling that talking about one necessitated mentioning the other. Living the paradox means those suffering chronic illness simultaneously confront their limitations and losses at the same time as leaning towards hope and possibility. The concept of therapeutic hope in MS was explored by Slater and Yearwood (1980). The need for a positive, affirmative mental attitude in MS management by HCPs was proposed to counteract the natural tendency toward negativity in PwMS (Slater & Yearwood, 1980). We, as nurses in general, have a responsibility to notice, acknowledge, understand and verbalise the possibilities, the abilities and the skills to live with chronic illness and to develop strategies with patients to do this successfully (Chesla, 2005).

In healthcare, hope is of special interest because of the disruptive nature of illness that requires considerable healing resources for recovery to occur (Tutton, Seers, & Langstaff, 2009). For MS Nurses, understanding hope may also help to understand the individual's experience of the recovery process and identify effective support strategies. In the field of MS, hope has been described as an essential element of the life journey, and the very presence of hope may help a patient to continue functioning more successfully or to remain independent for longer, bolstering self esteem and well-being (Morgante, 2000). Every person has a perceived future and in this dimension of existence, hope lives (Cassell, 2004).

Hope research and hope theory

“In studying hope I observed the spectre of human strength. This reminds me of the rainbow that is frequently used as a symbol of hope. A rainbow is a prism that sends shards of multicoloured light in various directions. It lifts our spirits and makes us think of what is possible. Hope is the same – a personal rainbow of the mind.”
(Snyder 2002, p.269)

Stepping back from the enormity of the hope literature in academia, exploring hope theory and its origins is necessary to give insight into how our thinking about hope has evolved over the years and how hope fits into life with RRMS. Early general hope literature recognised the desire to seek goals as part of hope (Cantril, 1964;

Frank, 1975) and the concept of hope as a way of thinking, as a cognitive process, was beginning to be recognised (Snyder, Irving, & Anderson, 1991). This led to hope being defined as “a positive motivational state based on an interactively derived sense of successful agency (goal directed energy) and pathways (planning to meet goals)” (Snyder et al., 1991, p.287).

In the following years, Snyder became a leading theorist on hope, believing that having a goal is the cognitive component anchoring hope theory (Snyder, 1994), the goal providing the targets of mental action sequences (Snyder, 2002). The means to achieve goals Snyder refers to as “pathways” (Snyder, 2002); what we would recognise as actions, the plan of what we would do to achieve a goal. An important part of hope theory also rests with the motivation to reach these goals, the “agency thinking” to achieve them. Hopeful thinking necessitates both “pathways” and “agency thought”, and they often feed off each other (Snyder, 2002). Thus, for PwRRMS, hope can be inspired and sustained by developing goals, making plans on how to achieve these goals, discussing contingency plans in case of obstacles, and maintaining the motivation to see the goals through to achievement.

Snyder’s theory of hope conceptualises hope as a cognitive-motivational construction, which relies on the perception that goals can indeed be met (Snyder, 1989) and therefore, realistic. Further research by Snyder and colleagues (2006, 2014) suggests that people with high-hope (thinking characterised by specific and clear goals) are more successful at harnessing the resources needed to achieve their goals and at negotiating alternatives when obstacles appear. In contrast, people with low-hope (characterised by vague goals) tend to ruminate and rely on avoidance, and repeat cycles of goal blockage, escape and failure (Snyder, 2002).

The MS Nurse is in an ideal position to assess the hope status of the PwRRMS. Identifying exactly where the PwRRMS is positioned in terms of low and high hope potential could prove helpful to the life journey as early intervention and guidance can provide the PwRRMS with both tools and resources to successfully self-manage the condition. When considering an unpredictable disease such as RRMS, with many losses along the way, with relapses, with an uncertain prognosis and with no cure, it is easy to see how easily a lack of hope can penetrate the thinking processes for

PwRRMS, block goals and impact on goal attainment. Indeed, RRMS can erode well-being and interfere with goal pursuits on many levels (Madan & Pakenham, 2014) for example, interfering with cognition, mood and energy levels. However, if hope related pathways and agency thinking can be engaged and supported by MS HCPs, adjustment to RRMS may be improved, despite the losses (Madan & Pakenham, 2014). If MS Nurses have a basic understanding of hope theory and the importance of goals, they can help PwRRMS develop goals, articulate aspirations and strategise pathways to goal achievement and also discuss alternative routes (pathways) in the event of upheaval along the way. Additionally, as hope theory suggests that hope is a cognitive process, the high rates of cognitive deficits seen in RRMS (Chiaravolloti & DeLuca, 2008) may also have an impact on the ability of the PwRRMS to set up goals, and the agency thinking and pathways skills needed to achieve their goals. The MS Nurse can assess, intervene and help the PwRRMS in the case of issues with cognition with both goal setting and strategies to achieve goals, promoting both agency thinking and pathways.

There are very few studies investigating hope specifically in MS, however a recent Australian study surveyed 296 PwMS (two thirds with RRMS) using various hope scales in an attempt to explore concepts of MS disease adjustment and hope (Madan & Pakenham, 2014). Findings from the study suggested that greater hope was associated with better adjustment to MS. Greater hope scores also predicted better life satisfaction, positive states of mind and lower depression, consistent with the earlier work of others (Foote et al., 1990; Lynch, Kroencke, & Denney, 2001). It is interesting that even though there were several decades between the studies, they showed similar results, despite the introduction of DMTs in the interim. This suggests that concepts of hope are just as important in the present time, even though treatments and prognosis have greatly improved, essentially leading to greater levels of hope. Hope has also been identified as a potent protective resource for coping with MS (Madan & Pakenham, 2014), and a resource that the MS Nurse is perfectly positioned in the health care team to recognise and assist with (Morgante, 2000).

Hope in the nursing literature

“Hope is central to life and specifically is an essential dimension for successfully dealing with illness” (Fitzgerald Miller, 2007, p.12)

Various conceptualisations of hope have also been posed in the nursing literature. As difficult as it is to conceptualise hope into a simple and neat definition, it is an important model for nurses to understand as it underpins our views about strategies to use with patients, especially during different stages of health and illness (Fitzgerald Miller, 2007). Hope has been described in theoretical terms for decades, but recognition of hope as a concept in nursing is a more recent development (Herth, 1990), which continues to grow (Cutcliffe & Herth, 2002). Before any inductive nursing studies were undertaken, Miller (1985) explored the empirical literature on hope and identified elements of hope that can be demonstrated and taught to patients and families by nurses. These elements included radiating hope, expanding the patient’s coping skills, teaching reality surveillance, helping with setting and obtaining goals and helping to renew spirituality (Miller, 1985).

In the 1980’s, the first inductive nursing studies of hope were performed, looking at the role of hope in specific groups such as adolescents and those suffering cancer (Hinds, 1984; Owen, 1989). Hind’s study used grounded theory methodology to define hope as the degree to which an adolescent believes that tomorrow exists (Hinds, 1984). The research in cancer also used grounded theory methodology to develop a conceptual model of hope, resulting in six themes: goal setting, positive personal attributes, future redirection, meaning in life, peace and energy (Owen, 1989). Indeed many of the key elements and themes of hope as expressed by Miller, and later by Owen, were also important for participants in the current study and will be discussed at length in the two subthemes to follow.

Further work in the following two decades built upon these theories and concepts of hope with Stephenson (1991) reviewing over 50 papers to develop conceptual attributes of hope. These attributes included viewing hope as a basic human experience, providing meaning in life, being fluid in nature and not static, being multidimensional and being associated with nursing (Stephenson, 1991). All of these

attributes could be applied to the current study participants and particularly the concept of hope being fluid and not static. This has deep connections to the variable disease course of RRMS, with unpredictability and periods of remission. Several years later Morse & Doberneck (1995) reported the concept of hope as being poorly understood, despite the growing nursing research, and proceeded to interview patients themselves to gain a deeper understanding of hope. This resulted in seven universal components of hope being identified: a realistic initial assessment of the threat, envisioning alternatives and the setting of goals, bracing for negative outcomes, a realistic assessment of personal and external resources, socially mutually supportive relationships, continuous evaluation for signs to reinforce goals and a determination to endure. Whilst all of these hope components were seen in most of the current study participants, a determination to endure was also present in all of them.

There is a paucity of hope related nursing research specifically in MS. However nurse researchers in other areas of chronic illness have found that patients showing signs of higher hope (characterised by specific and clear goals) have been associated with better adjustment in spinal cord injuries (Elliott et al., 1991; Lohne, 2001) and breast cancer (Stanton, Danoffburg, & Huggins, 2002). A nursing study of hope which fits well with the life story of MS is from a study exploring hope and its meaning in patients with spinal cord injuries (Lohne, 2001). In this study of 10 people one year after their initial injury, Lohne (2001) found that every participant in the study had hope, although for some it was sometimes silent hope, which was left unexpressed. Hope was described as intensely personal, as giving inner strength and as being a motivational spark (Lohne, 2001). Lohne developed this concept of hope in later years, describing hope further as a universal and dynamic concept, which is personally significant (Lohne & Severinsson, 2006). Similarly to how Lohne described hope in spinal cord injuries, hope appears to be universal, dynamic, motivational and personally significant in RRMS as well.

Morgante (1996) provided the first insights into hope, PwMS and the role of the MS Nurse. MS Nurses can be a healing presence in the lives of their patients due to their nurturing care, empathy and support of PwRRMS (Morgante, 1996). Additionally, nurses who care for PwRRMS and their families can provide resources to inspire

hope and prevent hopelessness (Morgante, 2000), often maintaining hope whilst untangling a web of false hope (Morgante, 1996). MS Nurses are in an ideal position to develop strategies with their patients to explore personal goals, to utilise support and resources and to formulate care plans to enhance the likelihood of goal achievement, which has been demonstrated to be a vital component of hope. Hope may also help a patient with MS to continue functioning more successfully, remain independent for longer and may also have a synergistic effect on medical therapies (Morgante, 2000).

The overarching theme of Holding Hands with Hope can be further developed into two subthemes to explore these concepts in greater depth - hope in its many forms (how hope is expressed by PwRRMS and different types of hope) and purposeful positivity (actively seeking out positivity to express hope).

Hope in its many forms

Our personal ideas of hope will be shaped considerably by our own personal experiences, and no two life experiences will be exactly the same. During the interviews with participants for the current research study, I was struck at times by the different types of hope people fostered, although during the interviewing phase I had difficulty in defining exactly what these types of hope were, and how hope fit into the wider model of MS care. A recent study from the physiotherapy/rehabilitation specialty in neurological diseases and injuries has shed some light on several different types of hope that PwMS may possess and use in their MS journey, including concrete hope, hope in possibility, active hope and transcendent hope (Soundy et al., 2013). Further work by Soundy and colleagues (2016) used thematic synthesis to examine 47 studies of MS to identify expressions of hope in MS patients as hope for a cure, hope for improvement, hope for normality and hope to cope. I did not recognise all of these elements of hope in the current study participants, possibly because Soundy et al.'s. 2013 study primarily focused on spinal cord injuries and stroke, and to a lesser extent on MS. However, all of these concepts of hope helped me build a clearer picture of the types of hope I was being informed about by the participants. I was guided in some of my hope descriptors on concepts from Soundy and colleagues (2012, 2013, 2016) research work in hope, but

also extended them to be more inclusive of the personal stories I was hearing and types of hope that have not previously been reported in this population.

Previous qualitative nursing research on the experience of living with RRMS reported that PwRRMS hoped to manage and maintain function as part of their future (Miller, 1997). As Miller's study (1997) was conducted prior to the introduction of DMTs to control RRMS, it was interesting to explore if hope to maintain function would still be as important to PwRRMS today now that disability outcomes have greatly improved. The answer was a resounding yes, it was extremely important for many of the current study participants, and in several different ways, which will be discussed in further detail below.

The specific types of hope I developed from the study participants during the interviews included the following: functional hope (wanting to retain functional ability, especially the ability to walk unaided), restorative hope (to be returned to their previous state of health), curative hope (hope for a cure) and defiant hope (challenging and resisting RRMS). To a smaller degree, realistic hope (acceptance at the current situation and a good understanding of the possibilities ahead) also had a place in almost every story, but was more inferred in their storytelling and overview of their condition rather than discussed openly as a form of hope. In addition, I believe that every participant harboured personal/secret hopes which live inside of them, mostly unsaid and perhaps never truly examined, shared and explored. I felt this because I witnessed the looks of longing, the pensiveness in conversation, the struggling to grasp something when discussing hope and put it into words. I am unsure of why this may be. Perhaps the participants were frightened to share their feelings of hope in case they are not shared by others and therefore may be extinguished, resulting in devastation. Or perhaps, speaking them out loud takes away some of the mystery and reveals too much of their soul. Or perhaps, these secret hopes are simply too complicated to summarise into words and feelings. In a study of hope in spinal cord injuries, the researcher felt that every participant in the study had hope, although for some it was "silent hope", remaining unexpressed when physical progress stagnated, but requiring courage and endurance (Lohne, 2001). Perhaps a similar concept could also apply to PwRRMS, hope remaining even in

times of distress or crisis, just remaining unexpressed at that particular time. But not far from the surface.

Hope has also been identified as both an active process and as a more passive one (Soundy et al., 2013). Active hope can be seen in patients who can identify and act on a goal, possessing connectedness and demonstrating optimism (I see this as being aligned with Snyder's version of high-hope) as opposed to those patients demonstrating more passive hope where they may have a vision of hope but cannot use that vision to move forward, often kept back by fears (I see this as being aligned with Snyder's (2002) version of low-hope) (Soundy et al., 2013). Most of the types of hope uncovered in the current research study are quite active in their character, perhaps participants did not express more passive hope in keeping with the nature of the concept. Being able to identify different types of hope in patients enables MS Nurses to be able to engage more deeply, to gain more from interactions with patients and perhaps most importantly, to be able to help patients in adjusting to RRMS and to ensure the best possible outcomes, assisting with realistic goal setting, pathways management and goal achievement.

Functional hope

Functional hope captures the hope of retaining functional capacity, the ability to perform activities of daily living such as walking, showering and getting dressed. Functional hope aligns somewhat with Soundy et al.'s (2013) description of adaptive hope, which centres on the hope to manage and retain functional ability in neurological conditions. However, functional hope in the current study appeared more urgent, more determined and more centred on *keeping* function rather than adapting (as shown in the quote from Paul below). Expressions of functional hope were very common in the interviews and pertained mainly to ambulation and the ability to walk. Functional hope was expressed by the study participants in one of either two ways; to stay out of a wheelchair/walking aids or to be actively walking and ambulant. Two sides of essentially the same hope, to retain walking function. Optimistic, goal directed cognitions are aimed at distancing a person from negative outcomes (Gillham et al., 1995), which is slightly different to hope theory where the person aims for future positive goals and the methods to achieve them (Snyder,

2002). In the current research study, the participants most often expressed this as an overt wish to stay away from anything to do with wheelchairs and ambulation aids such as walking sticks and canes. Thinking optimistically to distance from negative outcomes, this would be a desire to not be wheelchair bound or requiring a walking stick. Thinking in terms of hope theory, it would be a desire to stay fully ambulant, to be walking “as normal” and the methods to achieve this state, such as participating in yoga classes, taking DMTs as directed or seeing a physiotherapist for an exercise prescription.

As discussed in an earlier theme, (Re)defining Me now that I have RRMS, under the subtheme dare to compare, Paul expressed determination to stay out of a wheelchair in the future, having glimpsed a little of what that type of life could entail during his unhappy, early visits to MSA meetings not long after his diagnosis (he refused to attend these meeting again). What he witnessed there made him determined to avoid the “wheelchair scenario”, demonstrating optimistic goal directed cognition. This was also Paul’s reasoning in the theme The DMT Dance with his wanting to front end load and have a higher efficacy DMT despite the side effect risks. Paul did not want to end up in a wheelchair as a result of RRMS, his functional hope active and determined. Paul’s quote is breathtaking, almost childlike in its simplicity about camping being the other option to a wheelchair.

I don't want to be in a wheelchair, I want to be able to go camping. Paul line 727

For Rudi, Margot, Ruby and Piper, the physical act of walking holds personal importance for them, and their hope for the future involves being ambulant and functional, and the reason they pay such close attention to their own health, fitness and well-being.

I see life being good and I hope to continue to travel and do the things I want...I see my future as I am today...I dream of me walking in that. Rudi line 1707

So the future I see...I hope that I don't get to the stage where I need a wheelchair all the time...but hopefully...I think, use it or lose it...I make myself do things. Margot line 2459

I'm going to walk...to do things with my husband...let's go do this, let's go do that...my son really wants to go to Hawaii, so I hope my legs can work enough to take him. Ruby line 1560

If I wasn't being treated it might be a slippery slope downwards...I feel more confident knowing that a lot of these drugs are showing positive results...I do envisage myself hopefully never being with a walking aid, purely because of the medications...that's what I'm hoping for. Piper line 2021

Restorative hope

Similar to functional hope, restorative hope is mainly about retaining function, but differs from functional hope in that it is more of a hope to be returned to previous levels of function, before the onset of RRMS. This would have been considered impossible even a decade ago, but some of the newer DMTs have been reported to improve function and reduce disability, for the first time in MS care (Coles et al., 2012).

For study participant Ruby, recently completing a course of the DMT alemtuzumab encouraged her to be hopeful for a complete recovery and return to earlier function, of restorative hope. Rudi had experienced bouts of hopelessness after several severe, debilitating attacks, but also gained confidence from her neurologist that the newer DMTs may restore her to better health.

I don't feel so weak...I was walking yesterday, it's no marathon but for me it was pretty good...so fingers crossed I really hope so, I want the function back...I used to be able to walk with the kids everyday when we first moved here...so I want that sort of function back. Ruby line 629

Normal, I just want a very normal lifestyle...I just don't want to be in bed or on the sofa...I want to be moving...just a very simple life...and not all about me, it would be nice if it wasn't all about me. Ruby line 1575

(The neurologist said) with treatment we don't hope to keep you where you are at, we hope to keep you better...so I think...I had a bit of confidence in her...great. Rudi line 1635

Curative hope

Of course, hope for a cure in the future was also very common in this group, fuelled by recent advances in DMT development and in new therapies. For many participants, they felt lucky to be diagnosed in a time where a cure could be possible, and this was expressed as a form of hope. Will and Susan feel certain that a cure for MS is imminent. Evie was also hopeful of a cure, but not in her lifetime, perhaps also exercising a form of realistic hope.

In this small amount of time we're only getting better, we're getting more efficient at what we do...it's only a matter of time...a cure is going to happen so I know for me it's not going to be an issue, but now I need to make sure I keep on top of myself. Will line 374

I believe that some type of drug...will be a permanent solution. I believe there will be something. Will line 1507

I feel very positive about the future and with all the new medications, all the support out there...a cure...and with all the research and new medications, there's a lot there to help people to lead a normal life. Susan line 1047

All of this research happening, one day they'll find a cure and I might be dead by that point, but it's going to happen...you need to be optimistic about it, the future and what you can do...there's a lot of good people doing good work. Evie line 1458

Defiant hope

I really don't do things by halves...getting back to gym so soon after treatment was very important to me...I was being more defiant...it helps...you know what, MS? You

can knock me down, but I'm going to get up, and then you bounce back, kinda defiant. Evie line 1299

Defiance has also been referred to as a “fighting spirit” as the PwMS shows determination to battle MS (Reynolds & Prior, 2003), demonstrated succinctly by Evie in the quote above. One of the hardest aspects to accept for patients can be the drastic change to their identity brought about by MS, often hoping to return to their pre-diagnosis identity (Soundy et al., 2012). A recent study of 11 PwMS, five of whom had RRMS, used content analysis and thematic analysis to explore patients expressions of hope in a rehabilitation setting (Soundy et al., 2012). Some study participants set themselves a challenge to overcome, to defy MS and the expectations and passiveness that other patients or clinicians had towards MS, by taking action they were doing something to progress hope (Soundy et al., 2012). After several interviews in the current study, I identified this type of defiant attitude as a direct expression of hope, almost at its most bold and daring and key to the participants in their hope journey. Defiant hope provided a way to challenge the expected prognosis and progression of MS. Defiance didn't come easily for most study participants and involved more than positive thoughts and an optimistic outlook; defiance needed deliberate action, clear goals, and to be supported with plans, resources and active engagement. The majority of the participants in the current study openly challenged their RRMS, issuing a resistance that at times captured the very essence of defiance.

After twenty years of living with RRMS, Evie still offers resistance to RRMS and remains positive about the future, regularly challenging her physicality and expressing defiance as a means to show others that RRMS doesn't stop her doing anything.

I did go bungee jumping six months later (after MS diagnosis) just because I could...trying to prove a point and now I'm almost 40 and I still do those things just to prove a point...I went indoor rock climbing a few weeks ago...you're not going to get me, it's not going to happen...sky diving, same thing. Evie line 657

Piper tries to live each day issuing resistance to MS, becoming even more defiant when she is troubled by debilitating symptoms of MS such as fatigue and nerve pain.

OK...just get out there and do stuff while you can...and I do that everyday. I like going for my walks and runs...people say to me “why do you do that to yourself?” and I say “well, I do it because I can...because I know what it’s like to not be able to walk”...Even when I’m feeling lousy and I’m feeling fatigued with the MS in particular, I will do it, I will push myself and I will do it. Piper line 990

Kate was working full time, mothering, looking after sick parents and studying for a higher degree when she experienced many debilitating relapses. Although many would have reduced their workload at such a busy time, for Kate, studying was her lifeline, her turning point against the disease. Kate describes achieving her higher degree as her greatest life accomplishment and representing active defiant hope against RRMS.

MS would just pop up it’s ugly head but I didn’t make it important...I tried not to. I did not place too much emphasis, it was an inconvenience yeah, but it was not my biggest problem...I thought...you’re not going to beat me, I’m going to do what I want. Kate line 1777

Joy was confined to wearing sensible, flat shoes due to her significant gait issues and depended on a local shoe shop in her small rural town to order her supplies. Trying to recapture positive and happier times, Joy decided she wanted to try high heels. Of course, the shop assistant used to Joy’s usual symptoms didn’t think this was a good idea and questioned her choice, but Joy was determined. This simple act of defiance led to a simple, yet remarkable turnaround.

So I took a deep breath and I stood up in these high heels...so I stood up, adjusted my gait and then I walked towards the mirror...I walked with my head held high, with confidence...I was so empowered, I felt so strong...I felt like I got my whole life back...it was really special. Joy line 1291

The study participants seemed to garner more hope with their defiance, perhaps because this meant that they were actively taking a stand and actively taking control, rather than MS taking control. Defiance gave a certain sense of purpose, a reason to get up in the morning, a reason to exercise, a reason to take DMTs even when the

going gets tough. Defiance is a form of hope and an expression of being hopeful, of belief in oneself. MS Nurses can foster defiance in patients by helping them to understand their current capabilities (not just their disabilities), to resist comparisons with others and to concentrate on the resources and value that they already have and which can be developed even further.

Nurses have been identified as having a crucial role in facilitating hope in patients and their families (Tutton, Seers, & Langstaff, 2009). It has been suggested that nurses are an important source of hope for people that are vulnerable and ill (Herth, 1990; Herth, 1996; Cutcliffe & Gant, 2001) due to their constant and prolonged contact with those who are suffering, forming close connections and being in an ideal position to influence feelings of hope (Travelbee, 1971). Nursing strategies to inspire hope involve the presence of another human who demonstrates unconditional acceptance, tolerance and understanding (Cutcliffe & Herth, 2002). Other hope promoting strategies include fostering interpersonal connectedness with others, assisting with attainable aims and goals, encouraging spiritual practice in those who value spirituality, encouraging personal attributes such as a sense of humour and affirming the worth of a person (Herth, 1990), benefit finding, expanding coping skills and sustaining caring, therapeutic relationships (Miller, 1991), functions all at the heart of the MS Nurse's role. Communicating one's own sense of hope is also an important strategy for inspiring hope in others (Fitzgerald Miller, 2007), and for the modern day MS Nurse, this is a somewhat easier task than in years gone by, with so many new, proven, efficacious DMTs and many promising treatments on the horizon. As demonstrated by the forms of hope discussed above, for PwRRMS today, hope burns brightly as the possibilities for the future, for treatments and for the Holy Grail, a cure, are for the first time very real.

Purposeful positivity

I think there's a measure of optimism, I think it's not even control, I think you can decide what path you're going to take...if you're being negative all the time it's going to be bad for your MS, if it's negative, it's down, it's feeling awful, woe is me...it's getting out of that perpetual cycle of negativity, it's being optimistic about the future, about looking forward to something going well. Evie line 1435

Throughout the interviews I detected a sense of purpose for many participants when they were discussing hope and remaining positive through their journey, a process where they actively engaged with being positive, which I later termed “purposeful positivity” to capture this intention. It didn’t seem to just happen randomly, as highlighted by Evie in the quote above, purposeful positivity was a very active process which was more conducive to living well and happily with RRMS for the study participants. Examples of purposeful positivity included choosing and sustaining optimism, benefit finding, searching for meaning, harnessing a sense of humour, expressing spirituality, and giving back to the MS community.

Perhaps one of the most poignant examples of purposeful positivity came from Joy, whose obese husband suffered a sudden fatal heart attack, falling on top on her and crushing her beneath him. She managed to crawl out from underneath him and survive, the incident starting a new path for Joy where positivity became key to regaining control.

That instant (my husband died unexpectedly) was beyond devastating...but that surge of whatever it was when he fell on top of me...that choosing life...whatever it was that surged through me at that point did something in my chemistry...at his funeral I was battling into the church to walk...but I started to improve, in fact I made an absolute heart felt decision that I would get better no matter what...something switched on, I chose life...if my body won't do what I want it to do...there's got to be another road...I started fighting for it...I felt like I had the power to control my health...it may or may not have been true, but I made it true. Joy line 969

Optimism and a positive outlook

Being diagnosed with RRMS in the current climate of breakthroughs in scientific research and newer, more efficacious DMTs gives rise to the possibility of greater positivity and optimism. Additionally, the huge variability in possible RRMS symptoms and disease severity can also inspire confidence. A recent study exploring parents’ experiences of their child living with RRMS, interviewed 31 parents in semi-structured interviews and used grounded theory to analyse the results (Hinton & Kirk, 2017). One of the important findings identified in managing the uncertainty

of MS was “optimistic thinking”, hoping for a future where their child would be minimally affected and lead a “normal life”, the huge variability of RRMS by its very nature aiding optimism in this regard (Hinton & Kirk, 2017). Although this was the viewpoint of the parents and not the PwRRMS, the concept of the latitude for hope and positivity in an uncertain disease is an important one, and also has applicability to adults living with RRMS. As MS Nurses, the unknown disease variability forms the basis of many consultations with our patients and allows positivity and hope to always have a place in our care.

Often the diagnosis of RRMS can cause negative reactions in the PwRRMS, as explored by the earlier themes of this study in chapter 6. Over time however, many PwMS report positive changes in terms of values and outlooks, as well as an increased appreciation for life (Irvine et al., 2009). It has been reported that thoughts are effective tools in garnering the motivation necessary to commit to behavioural change and that positive thinking may benefit motivation in MS (Hall-McMaster, Treharne, & Smith, 2016). Positive thinking is an active behaviour and entails having a goal in mind, being self sufficient, letting go of the past and reinforcing positive actions by doing something good (Hall-McMaster et al., 2016). Once again, as with hope theory, it is postulated that positivity takes deliberate cognitive action and working out what is necessary to reach goals, of possessing determination (Hall-McMaster et al., 2016). Traumatic events challenge beliefs, with the result that humans make active efforts to restore, or to enhance their beliefs and exercising positivity is a way to cope with adversity (Taylor & Armor, 1996). Dennison’s model of adjustment to MS suggests that those who adjust more successfully to the diagnosis use the following resources: positive reappraisal, optimism, hope, benefit finding and spirituality (Dennison et al., 2009).

Strategies to sustain optimism include avoiding being around those with negative views who challenge (sometimes fragile) hope (Hinton & Kirk, 2017). Staying away from negativity in others could involve distancing from family members, friends, work colleagues and sometimes MS organisations in some cases. In the current study, participants Will, Paul and Jane elected not to become involved with the local MSA meeting groups to avoid being reminded of the negative aspects that MS could

bring and to maintain and instead to nurture optimism and positivity from their own family and friends.

Patient attitude has been identified as a major influence on overall disability burden in MS in a large, cross sectional Belgian study of 1372 participants living with RRMS (D'Hooghe et al., 2013). This study reported that those patients who scored higher on health promoting behaviour (such as physical activity, spiritual growth) were significantly less likely to reach a level of disability where they needed assistance to ambulate (a single walking stick) (D'Hooghe et al., 2013). As patient attitude is an area of possible control for the PwMS, educating patients about the importance of a positive attitude could significantly contribute to better and more positive outcomes (Lysandropoulos et al., 2015).

Both Piper and Griff exercise the power of positivity, of being in control of the disease and verbalising a better future. A sense of control appears to resonate heavily with a sense of hope and positivity. Piper has had extensive counselling so that she can feel in control of MS and enjoys the challenge of keeping the disease in check. This leads to hopeful feelings for her future health. Griff, ever the optimist, simply regards himself as lucky and is pragmatic about what may happen in the future.

Even if I'm having a bad day with MS I know that I'm in control of my thoughts and I can think whatever I want...I can change that thought process. Piper line 1772

I think I live almost day by day...I can't picture what it's going to be like...if I look to a future with MS I do believe that I'll be dead and buried before my MS puts me in a wheelchair...I just don't think it's going to happen. I'm lucky. Griff line 1367

Susan, unhappy with the way RRMS was controlling her emotions and keeping her from her dreams, embarked on a counselling course so she could learn to take back control of her life, and understand herself better in the process. Susan regards this course as a life-changing event for her, finally enabling her to enjoy life, help others in her role as a HCP, exude positivity and put years of despair firmly behind her. Susan uses the skills she learnt during the course now as a new mother with RRMS and fatigue, to see things differently and remain optimistic and positive.

Accept it, embrace it, because it doesn't mean the end...and then I looked at it...that it was a new beginning for me...I did look after myself more with what I ate and I exercised. Susan line 806

You always have to hold on to your dreams because that's what keeps you going...what you are striving for...you have that to help you get up each day and get on with life and make yourself a better person and stronger to help others around you. Susan line 1128

I feel positive about the future and people being diagnosed with MS now...this medication will be able to help them...there's a lot that's happened. Susan line 1202

MS Nurses can foster positive thinking in patients by encouraging a focus on positive aspects of their life and by using positive self talk (Roger et al., 2014). MS Nurses can also remind patients that cultivating optimism and hope will assist with self confidence and regaining control of their lives, and taking part in programs such as intensive wellness programs can also improve self efficacy and positivity (Ng et al., 2013). As a positive attitude helps with regaining control over MS and more positive outcomes overall (Lysandropoulous et al., 2015), providing education on the importance of positivity and methods of achieving a positive state of mind can potentially have a significant impact on the future for the PwRRMS.

Searching for meaning

Searching for meaning is another expression of positivity and has been described as a cognitive process to find order and purpose in illness (Sharpe & Curran, 2006). Creating meaning in life for PwMS can involve participating in meaningful activities, developing new interests, and engaging in life with more purpose. This concept was captured in a recent study where participants learning to live with MS were likened to “learning to fly with broken wings” (Flesner & Rudolfsson, 2016). Several of the participants in the current study expressed feelings of gladness that things changed in their life, sometimes for the better, as a result of MS. Rudi described the time where she couldn't work due to recurrent severe relapses leaving her with residual neurological dysfunction for several years. At the time she was

raising four young children and really needed the money to support the family. However, she chose to look at the situation differently and saw meaning in the illness as giving her time to spend with her family during some very important years.

When I lost my job, I thought I can be down and think I'm unemployable...I can't work...the path I chose to take was that work's always going to be there forever, the kids are going to grow up and I need to look at this as I'm lucky because I get to spend this time with my children...whilst it was tough financially, we adapted. Rudi line 944

Choosing to rise above the possibilities of the diagnosis and concentrate on a life well lived with MS is a conscious, positive choice. Kate looked inward to find her life meaning and Rudi changed her perspective on money to live life to the full and uncover new meaning. By seeing RRMS as something she lives with, but not the entire story, Evie makes a choice to find meaning in all she can do rather than what she cannot do.

It gave me strength to think, whatever this is, I want to get over it...I've got things to do...more important things...and that's the way I was driven. Kate line 388

Finances play a big role with anyone and I had lost my full time job (because of RRMS) but you know, stuff it, it's just money, so we went to Fiji last year...I'm just doing a lot more and loving it...you change perspective. Rudi line 910

MS is not the main life...it doesn't define who I am, yes I have it, but it isn't who I am...I do not let it define me, I have it, it bothers me, it drives me insane and it makes me angry, but it is not the core of who I am as a person. Evie line 1184

It's not all doom and gloom like people might think...if I ever go rock climbing again I want some photos because I want to upload to MS Society so people can see that you can do these things...you shouldn't focus on what you can't do, it's what you can do, it's what you want to do. Evie line 1232

Harnessing a Sense of Humour

Another strategy to maintain a positive sense of self whilst living with a neurological condition is to use humour (Roger et al., 2014). A qualitative study interviewed 27 women with MS and used interpretative phenomenological analysis to investigate the results, finding that positive thinking and finding “jewels” in their situation were important themes when living with MS (Reynolds & Prior, 2003). Participants were found to consciously value special and positive moments, actively looking for benefits, maintaining social relationships and enjoying fun and humour (Reynolds & Prior, 2003). Similarly, an earlier study reported exercising a sense of humour, along with maintaining a positive attitude, as important tools to living a life well with MS (Gulick, 2001). Several study participants demonstrated a healthy sense of humour during our interviews, at times telling me poignant or distressing stories but laced with laughter, giggles and the ability to have a laugh at their own expense. It has been reported that humour is a way to maintain a positive sense of oneself and play down the challenges in life, playing an important role in encouraging positivity in neurological diseases (Roger et al., 2014). Kate and Margot in particular, perhaps the two most physically disabled participants in the study, recalled sad stories at times, but quickly focused on humour to see the funny and bright side.

Kate was describing to me a time when she had to do a presentation but was crippled by severe spasticity which affected her gait. Recalling the situation, which could have also been portrayed with torment, Kate laughed and re-enacted the walking motion in front of me.

I can't bend my knees...and when I walk, I walk like, you know, the Tinman! (laughing) in the midst of all this I had to give this lovely presentation (giggles). Kate line 1343

Margot, who initially experienced so much angst thinking about the possibility of a wheelchair as her mobility gradually and intermittently deteriorated, saw the funny side of a wheelchair mishap on holidays with her husband overseas.

We unwrapped the wheelchair...it was all bubble wrapped that's got fragile all over it...everything was chucked on top...and one of the struts on the side was bent, so (husband) is manoeuvring it (laughs boisterously) and he ended up breaking it (more laughing)...and broke the strut...so off we go...(bouncing on) cobblestones all through (the town) (giggles). Margot line 1633

Margot also told a story of rising from her wheelchair in a shop to shock the shop assistant, walking slowly away from the wheelchair and proclaiming at the assistant's puzzled look "I know, it's a miracle!". For some, a touch of humour (at the appropriate time) can be a more comfortable way to address some of the more uncomfortable aspects of living with RRMS. MS Nurses can also support and encourage PwRRMS in the value of humour in their life journey.

I did wonder if Kate and Margot laughed at the time of the incidents, or if time allowed them the luxury of being able to look back on an initially emotionally painful event with a new sense of humour. But, getting to know Kate and Margot through the life history interviews, I suspect they both did feel the brighter side of the situation at the time.

Faith, religion and spirituality

Improving the health and well-being of the whole person, mentally, physically and spirituality has been at the forefront of nursing since inception (Nightingale & Skretkowicz, 1992; Reinert & Koenig, 2013), therefore considering the impact of spirituality in the life journey of RMMS is essential. For the purpose of this study, concepts of faith, religion and spirituality will be viewed as not just as traditional religious faith, but as belief or belonging to any sort of higher being or spirit and will collectively be referred to as "spirituality".

It has been suggested that spirituality is related to better adjustment to illness, providing a sense of coherence and meaning, purpose and the courage to endure suffering (George, Larsen, Koenig, & McCullough, 2000). However, there are very few studies exploring spirituality in MS and those that have been published have somewhat contradictory messages regarding the importance of spirituality in MS. An

early study in Australia surveyed a group of 101 participants with MS (phenotype not specified) and reported that those PwMS who derived high levels of meaning from personal belief systems also experienced high levels of quality of life and psychological well-being, as well as lower levels of depression and anxiety (Makros & McCabe, 2003). A small study of seven PwMS (type not specified) found that PwMS did have an increased appreciation for spirituality in their lives (Irvine et al., 2009), which has also been supported by others suggesting that spirituality may be a helpful resource to cope with chronic disease in general (Bussing et al., 2009; Bussing et al., 2013; Levine, Aviv, Yoo, Ewing, & Au, 2009).

However, contrasting with this work are early empirical findings in larger studies which have suggested that PwMS may be less engaged in spirituality when compared to patients living with other chronic diseases (Bussing et al., 2005). A more recent study of 213 participants, half of whom identified as RRMS, found relatively low levels of faith importance in the study sample, with only 10% of participants reporting reliance on faith to carry them whilst living with MS, most participants citing family or themselves as their source of support in the MS journey (Wirth & Bussing, 2016). It is worth noting however, that this particular study enrolled younger participants between the ages of 25 and 40 years, possibly influencing the results as it has been suggested that age is also positively related to higher measures of spirituality (Bussing et al., 2005).

In the current study, Joy expressed positivity from actively practicing spirituality, when she recalled stories about the disciples of Jesus healing a cripple, which is how she used to see herself. She used this story to inspire positivity in herself and a belief that miracles could happen.

I was reading my bible one day and I read this passage that talked about the disciples and there was a beggar there crippled from birth...they said "in the name of Jesus Christ rise up and walk" and then the cripple stood up...walking and leaping and praising God...and this really impacted me....suddenly I could relate to it...if that kind of miracle is possible, what does walking, leaping and praising God look like in my life? And I pushed my body to walk. Joy line 1120

In western religious thought, individuals strive to maintain an idea of self that is in harmony with the universe and God and suffering has a purpose and provides a way for humankind to enter a divine relationship with God (Goodrick-Clarke, 2008). It is important for the MS Nurse to have an awareness of the cultural/spiritual beliefs of the patient, as it is helpful to form the basis of individualised and patient-centred care, and can be incorporated into the nursing care plan.

When things aren't going so well in life, spirituality can provide an avenue of support that adds another element to purposeful positivity. For Evie, this was an important support in her hour of need, for Joy as a child it was the only real support she had, and for Davina, re-engaging with spirituality during a dark time gave her new insights, although she started off angry and disbelieving.

It doesn't scare me because I think there's more...there's more...I have always believed there's more...call it God, or whatever religious faith, I don't particularly hold any, I consider myself very spiritual...you have to turn to your faith when life isn't so great. Evie line 683

Faith was really the only thing I had growing up as support. I took myself to church from age six...faith is a huge part for me...in spite of everything around me...I couldn't explain that to people...it was my faith that kept me going especially when I lost my ability to comprehend (when Joy became dyslexic). Joy line 1819

The other thing I got back that's really helped me...I got my faith back...after I was diagnosed with MS I went back to church...but I went back really angry. Davina line 1152

The minister helped me I was this screaming possessed woman and he turned my life around, got me in contact with women in the church who had been in really bad situations overseas, older women...having my faith back actually made me a bit stronger, it has helped me tremendously...I feel a bit more supported. Davina line 1176

Expressions of spirituality were not confined to participants in the current study. At times, spirituality was an important coping mechanism for their loved ones as well. Susan's family engaged in regular prayer groups after her diagnosis, drawing strength from others in the group, whilst Susan elected not to become involved. Kate's mother was deeply religious and although Kate herself was absolutely terrified of her symptoms, her mother was convinced from her spiritual beliefs that RRMS was going to go away. Because of the natural relapsing and remitting evolution of the disease, this may have enhanced this aspect of hope for families as symptoms disappeared and their loved one regained usual function, possibly as a result of their faith.

Giving back and being involved

Another strategy to inspire hope and positivity demonstrated by the participants was a willingness to become involved in the fight against MS and to give back to the MS community in some way. Kate expressed one of the most incredible stories of selflessly giving back to the MS community. Kate had experienced a miserable time on an interferon DMT and eventually ceased it due to intolerable side effects, despite persevering for some time. Kate was keen to help medical science and "give back" and sought information on a new clinical drug trial. Kate made enquiries and was disappointed to find that the trial involved being randomised (randomly allocated) to one of two medications - a new oral medication that she was keen on trying and the older DMT she had suffered greatly with. Kate elected to participate in the trial and was randomised to the old interferon DMT. Not only did Kate administer the DMT again for another year, suffering significant side effects, Kate also completed all of the trial requirements, demonstrating both persistence and altruism.

Evie acts as a mentor for newly diagnosed PwRRMS and also as a speaker and advocate in the MS community, regularly participating in MS events and raising awareness of the disease and the impact of RRMS. Evie is adamant that she wants to show the world the positive side of RRMS and what can be achieved, to be more positive in the message.

I want to believe in other people, that's why (I advocate for MS), so I want to make a difference and I figured that I can talk to people, I can write really well...if I'm going to have it, I may as well do something with it...I want people to see people who aren't disabled by MS. Evie line 1205

Other participants such as Griff helped out by educating newly diagnosed PwRRMS or those that are new to infusion treatments by performing a meet and greet role at the local MS infusion centre, especially being available to help young men during this challenging time. It was an important way of displaying positivity to others by demonstrating living positively with the disease by example.

Raising money for MS research was an important display of positivity for Susan after her diagnosis, becoming involved in fundraising bike rides even though she had never ridden a bike before. Susan also made herself readily available to help others newly diagnosed if they needed someone experienced to talk to, enhancing positivity for others as well.

I thought well, OK, I can do something for myself...so I started entering the charities...the MS bike rides...and I raised money. Susan line 538

My friends would ask me...can you talk to so and so...people who have been newly diagnosed...and encourage them and give them ways that they can help themselves...so they feel more positive and not to think that you'll end up in a wheelchair. Susan line 1225

Of course, by way of volunteering in the current research study, being willing to tell their stories and give up time for others in the hope of contributing to MS research, demonstrates being involved and giving back to the MS community for every participant involved in the current research study.

Towards a definition of hope in RRMS

After researching the hope stories of the study participants, the evolution of hope theory, hope nursing literature, MS specific hope literature and considering the

thousands of MS patient consultations I have performed over the last 15 years, I have come to my own beginnings of a definition of hope in the context of RRMS for MS Nurses. I say beginnings, because the hope story has such a long way to go in RRMS, and is likely to change as our understanding of hope deepens and as new research adds certainty to current uncertainty in RRMS. In addition, further disease-specific hope research is greatly needed in all aspects of MS, in both RRMS and in progressive forms of the disease, before we can truly understand its significance.

My current definition: The experience of hope is a future inspired phenomenon, remarkable for its elements of promise, possibility and positivity. Hope is essential to human life, can be inspired, sustained and coached in others and is contagious in nature. Hope is tangible and a very important aspect of living well with RRMS. The MS Nurse can be, and often is, a beacon of positivity and potential for PwRRMS, providing inspiration and hope in words and in actions.

A final word on hope

In order to assess, recognise and to inspire hope in others, MS Nurses need to feel hopeful themselves. This has been aided tremendously in recent years as the first DMTs have been developed to halt progression of the disease and prevent future disability, with MS Nurses often administering the medications and monitoring progress and therefore at the forefront of positive change in RRMS. However, in order to inspire and sustain hope, it has been well reported that MS Nurses need to strategise self-care within themselves (Morgante, 2000). As workload increases dramatically, patient numbers grow and as DMT monitoring becomes more time consuming and critical due to potential life threatening side effects, self-care becomes even more important than ever before. Networking with peers, exercising regularly and eating nutritiously, using confidantes, nurturing supportive relationships, expanding knowledge bases, sharing expertise, taking holidays and stress reduction are all methods the MS Nurse can use to nurture self care (Morgante, 2000). Feeling hopeful themselves is also a way that MS Nurses inspire hope in others (Morgante, 1996). This should be a priority for MS Nurses, not just for themselves and their own health, but because it will shine through and inspire in all

interactions with PwRRMS, their loved ones and other HCPs working in the speciality.

Take one's adversity

Learn from their misfortune

Learn from their pain

Believe in something

Believe in yourself

Turn adversity into ambition

Now blossom into wealth

Emily Dickinson

This theme concludes Chapter 7, Finding the High Road, and the thematic and poetical findings of the current study. Following along the lines of hope and positivity which completed the formal study findings, the next chapter will discuss the study themes in relation to the life journey of RRMS. How the ebbs and flows of life and the life history methodology fits together with the study findings to further enhance the participant stories and bring the key concepts of the lived experience of RRMS alive.

CHAPTER 8: THE LIFE JOURNEY – EBBS AND FLOWS OF LIVING WITH RRMS

*I have many faces, I am never still
Today I am here, tomorrow I am gone
I haunt you for days and then I leave
You can never work out what to believe
Darting in and darting out
I cause havoc and play games with your mind
I cause you to second guess yourself, to self-doubt
And before you know it I'm in and I'm out
My face tomorrow looks completely new
I can still creep up, I can still surprise you
But then you change, you get better at this
You learn, you discover, you realise what I am
You start to beat me down and tell me I'm a sham
I've now met a considerable foe, you're ready for a fight
We'll face up against each other and you'll show me your might
TB*

The life journey of RRMS takes many twists and turns; it is never a linear journey, but rather one of continual flux, which is mainly due to the innate unpredictability and uncertainty that comes with the diagnosis of RRMS. I have been surprised many times in my clinical work by the stability of a patient's condition at a routine appointment, only to see things change dramatically and seriously, within a matter of days. Nothing is set in concrete in this disease. The great advantage of the life history approach is that it reflects the entire life journey; with and without RRMS. By using this process I was able to uncover many aspects of each participant's life, which had an impact on their later journey with RRMS. In particular, many participants described events in childhood, which gave rise to the development of resilience, such as childhood neglect, illness and migration from non-English speaking countries. This resilience was then to serve the study participants well in later life, drawing on coping skills to help them through the difficult and challenging times of RRMS. In their narratives, I was able to uncover details about the participants which profoundly

affected their RRMS story, even if they were unaware of it or of any connection between other life events and their personal development and understanding of RRMS. Even the process of telling the life history helped the participants to understand where they came from and where they were situated now. They recognised their achievements, revelled in their joys and respected their lows.

Although presented theme by theme in a logical succession, the eight themes presented in these study findings do not always follow in sequence and definitely do not always “end” with hope and positivity. Instead, the themes intermingle with each other to reflect the ebb and flow of life. They tell the story of possible stops along the life journey with RRMS and the constant moving backwards and forwards. For example, a newly diagnosed PwRRMS might go through various aspects of the first three themes in fairly quick succession, Piecing Together the Puzzle, (Re)defining Me Now That I have RRMS and Battling the Demons, then encounter theme seven, The DMT Dance with an attitude of theme eight’s Holding Hands with Hope. Then an unexpected pregnancy throws everything into chaos. The PwRRMS is right back to Piecing Together the Puzzle, (Re)defining Me, Battling Demons and having to face difficult decisions about whether to proceed with the pregnancy considering their exposure to medications known to cause foetal harm. Putting together a medical team to help support and solve this problem will form part of Taming the Beast and then (hopefully) using skills from Holding Hands with Hope to move forward.

Thereafter may be a year of stability and quiescence living with RRMS, with perhaps the occasional Battling the Demons making an appearance on days of significant fatigue or with the occurrence of a bladder infection. Then the uncertainty presents again with the development of a severe motor relapse just days before a big work event. A hospital admission and many tests follow, unleashing Piecing Together the Puzzle and Battling the Demons (worry, anxiety, despair) as their perceived world falls apart. The DMT Dance is set to start again as the specialist highly recommends changing to a new, higher efficacy DMT, with several potentially life threatening side effects. Whilst trying to use the skills learnt in Taming the Beast, the PwRRMS is unable to see past the side effect profile and Battling the Demons threatens to take over all they have learnt so far. Will I walk again? Will my Boss want to sack me? What about the mortgage? Maybe this is my life now? Will my husband want to

leave me now he can see what is possible with RRMS? I've always been unlucky, surely I will get that side effect that kills...and there starts the long road back to Taming the Beast, The DMT Dance and Holding Hands with Hope to reign in positivity and belief about the future. As symptoms subside, the new DMT starts to take effect, work allows time off to recover and life starts to settle again, Holding Hands with Hope moves back into the foreground of life. Until a year later when a work opportunity means a move to another town without an MS Specialist...and the possibility of either Battling the Demons, or Taming the Beast arises. It could go either way.

Using ethnography methodology, and the life history method in particular, to uncover the study themes works in skilfully with the life trajectory of RRMS. The most effective way to demonstrate the linking of the life trajectory, life history methodology and the themes uncovered by this research study, is to illustrate the life course of several study participants and the interlinking of the study theme findings with their individual stories. The true value of the life history methodology can then be clearly seen as the themes overlay their life lived with RRMS. The ebbs and flows are shown below in four examples of life stories and recurring themes of Susan (Table 6), Will (Table 7), Griff (Table 8) and Piper (Table 9). These participants have been selected to represent a cross section of male and female experiences, short and long term diagnoses, a range of other health issues and a range of disease severity living with RRMS. Similar tables for the remaining nine study participants have also been completed and can be located in Appendix 13.

Susan's life story instilled in me a sense of resilience acquired by many years of suffering, mostly in silence. Susan absorbed much of her parents' grief and blame when she was diagnosed with RRMS and remained strong as those around her crumbled. It wasn't until many years later that Susan realised she was dormant in her journey; she wasn't able to move forward. Working as a HCP, Susan was well aware of the journeys of others with chronic illness, further complicating her view of self and how she was progressing compared to others. Determined to change, Susan began a counselling course, which set her on a new path (finding her North Star) and life gradually began to change for the better. Today Susan is thrilled with her family and totally in love with life, despite continued hardships along the way.

Table 6: Susan's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • <i>Child of a migrant family</i> • <i>Severe illness of glandular fever as a child</i> • <i>Physically and emotionally demanding employment</i> • <i>Working in healthcare</i> • <i>Living and working overseas</i>
Onset of first symptoms	<p>Piecing Together the Puzzle</p> <p>High (In)visibility (strive to be visible)</p> <p>Surplus Suffering (brushed off)</p>
Symptoms worsen	<p>Piecing Together the Puzzle (what's happening?)</p> <p>Surplus Suffering (brushed off)</p> <p>Piecing Together the Puzzle (tests, tests, tests)</p> <p>Battling the Demons (fear, worry & anxiety)</p>
Hospitalised, it could be MS	<p>Surplus Suffering (inflicted by clinical care)</p> <p>Battling the Demons (fear, worry & anxiety)</p> <p>Holding Hands with Hope (purposeful positivity)</p>
Confirmed diagnosis of RRMS	<p>Piecing Together the Puzzle (the day my life changed forever)</p> <p>Re(defining) Me now that I have RRMS (getting acquainted)</p> <p>Battling the Demons (fear of burden)</p> <p>Holding Hands with Hope (faith)</p>
Learning to live with RRMS	<p>Re(defining) Me now that I have RRMS (getting acquainted, dare to compare)</p> <p>Battling the Demons (fear, worry & anxiety, despair)</p> <p>High (In)visibility (strive to be visible)</p> <p>The DMT Dance (hardyards: decisions based on hope)</p>

	Battling the Demons (fear of the wheelchair)
Sharing journey with family and friends	Re(defining) Me now that I have RRMS (getting acquainted, reverse stigma, normalcy) Taming the Beast (support from family, friends and community)
Relapse	Piecing Together the Puzzle (what's happening?) Battling the Demons (fear, worry & anxiety) High (In)visibility (strive to be visible) The DMT Dance (hardyards: decisions based on fear <i>and</i> hope)
Completes life counselling course to better understand self and illness	Taming the Beast (support from family, friends and community)
Relapse	Re(defining) Me now that I have RRMS (getting acquainted, dare to compare) Piecing Together the Puzzle (what's happening?) The DMT Dance (decisions based on fear <i>and</i> hope) Re(defining) Me now that I have RRMS (working out work, normalcy)
Living with RRMS alone	Battling the Demons (fear, worry & anxiety) Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, search for meaning)
New beginnings	Re(defining) Me now that I have RRMS (normalcy) Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, finding my A-Team) Holding Hands with Hope (purposeful positivity, defiant hope)
Searching for a life partner	Battling the Demons (fear of being a burden) Holding Hands with Hope (purposeful positivity, defiant hope)

Relapse	Battling the Demons (all fears, worry & anxiety) The DMT Dance (hardyards: decisions based on fear <i>and</i> hope)
Meeting husband and beginning relationship	Taming the Beast (support from family, friends and community) Holding Hands with Hope (purposeful positivity)
Infertility issues	The DMT Dance (hardyards: decisions based on fear) Taming the Beast (resilience) Re(defining) Me now that I have RRMS (balancing losses & gains, parenting with RRMS)
Pregnancy achieved	Holding Hands with Hope (purposeful positivity, optimism) Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, finding my A-Team) Battling the Demons (fear of being a burden)
Life parenting with RRMS	Taming the Beast (support from family, friends and community) Holding Hands with Hope (purposeful positivity, optimism) Battling the Demons (fear of being a burden) Re(defining) Me now that I have RRMS (balancing losses & gains, parenting with RRMS)
Change of DMT	The DMT Dance (decisions based on fear & hope) Holding Hands with Hope (purposeful positivity, optimism) Re(defining) Me now that I have RRMS (getting acquainted)
Serious illness for husband	Battling the Demons (fear, worry & anxiety) Holding Hands with Hope (purposeful positivity, optimism, defiant hope)

Taming the Beast (support from family, friends and community, resilience)

Life settles with RRMS- Holding Hands with Hope (giving back and getting involved)
current status quo

Taming the Beast (support from family, friends and community, maintaining health & wellness)

Will's life story also reflected several years of hardship as he battled depression after his diagnosis and fought his way back to a happier life, determined to live life to the full. One of his most difficult challenges came about when the DMT that was successful in controlling his relapses, natalizumab, needed to cease due to an unexpected high-level JCV result, which put him at higher risk for the serious and potentially fatal side effect, PML. Will had experienced many years of disease stability up until this time and this came as a shock. However, as his life journey reflected, this time when challenge presented itself, his life circumstances were different to earlier in his journey, and he now had the close support and love of his wife helping him in Taming the Beast.

Table 7: Will's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • <i>Fractured family life, childhood neglect</i> • <i>Death of mother when he was 13 years old</i> • <i>Experience of MS from a close friend who suffered progressive MS and was severely disabled and blind</i>
Onset of first symptoms at 17 (with no follow-up)	<p>Piecing Together the Puzzle (what's happening?)</p> <p>Battling the Demons (fear)</p> <p>High (In)visibility (welcome cloak, hide)</p>
Living well, no symptoms	<p>Battling the Demons (fear, worry & anxiety)</p> <p>Taming the Beast (maintaining health & wellness)</p> <p>Piecing Together the Puzzle (tests, tests, tests)</p>
Travelling overseas, working	Taming the Beast (maintaining health & wellness)

hard

Onset blindness and unexplained neurological symptoms, hospitalised with no diagnosis for weeks

High (In)visibility (welcome cloak, hide)

Battling the Demons (fear, worry & anxiety)

Piecing Together the Puzzle (what's happening?, tests,tests,tests)

Surplus Suffering (misdiagnosis)

High (In)visibility (welcome cloak, hide)

Diagnosis of RRMS

Piecing Together the Puzzle (the day my life changed forever)

Re(defining) Me now that I have RRMS (getting acquainted, working out work, non-disclosure)

Battling the Demons (fear of burden, worry & anxiety, saboteurs, uncertainty)

Holding Hands with Hope (purposeful positivity, optimism)

Learning to live with RRMS

Re(defining) Me now that I have RRMS (getting acquainted, dare to compare)

Battling the Demons (fear, worry & anxiety, depression & despair, uncertainty)

High (In)visibility (welcome cloak, hide)

The DMT Dance (decisions based on hope)

Holding Hands with Hope (defiant hope)

Taming the Beast (Finding my North Star, choosing my A-Team)

Battling depression

Piecing Together the Puzzle (what's happening?)

Taming the Beast (support from family, friends and community)

The DMT Dance (hardyards: decisions based on fear)

Battling the Demons (depression & despair, I'm

	never free, social isolation)
	High (In)visibility (welcome cloak, hide)
	The DMT Dance (hardyards: decisions based on fear <i>and</i> hope)
	Taming the Beast (Finding my North Star, choosing my A-Team)
Recovering from depression and living well with RRMS	<p>Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, searching for meaning, harnessing a sense of humour)</p> <p>The DMT Dance (hardyards: decisions based on hope, switching to a better life)</p> <p>Re(defining) Me now that I have RRMS (working out work, balancing losses & gains)</p> <p>Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)</p> <p>High (In)visibility (welcome cloak, hide)</p>
Well and relapse free on natalizumab	<p>The DMT Dance (hardyards: decisions based on hope, switching to a better life)</p> <p>Taming the Beast (support from family, friends and community, finding my North Star, resilience)</p> <p>Holding Hands with Hope (purposeful positivity, optimism)</p> <p>Re(defining) Me now that I have RRMS (balancing losses & gains, dare to compare, normalcy, working out work)</p>
Meeting life partner and starting a family	<p>Taming the Beast (support from family, friends and community, finding my North Star)</p> <p>Re(defining) Me now that I have RRMS (normalcy, parenting with RRMS)</p> <p>Holding Hands with Hope (purposeful positivity, optimism, searching for meaning)</p>

Missed JCV blood test and then a positive high titre result- immediately cease natalizumab	The DMT Dance (decisions based on fear)
	Battling the Demons (fear, worry & anxiety)
	Taming the Beast (support from family, friends and community, resilience)
	Re(defining) Me now that I have RRMS (balancing losses & gains)
Decision to start alemtuzumab	Taming the Beast (support from family, friends and community)
	The DMT Dance (the hardyards: decisions based on hope)
	Holding Hands with Hope (purposeful positivity, optimism, restorative hope)
Living with RRMS, finding life balance	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
	Holding Hands with Hope (purposeful positivity, optimism, curative hope)
	Re(defining) Me now that I have RRMS (normalcy, working out work, balancing losses and gains, parenting with RRMS, disclosure)
	High (In)visibility (welcome cloak, hide)

Griff feels that he has lived for many decades with RRMS, despite not being diagnosed until his late forties. He recalls symptoms he covered up in his twenties and thirties that indicate he may have been living with RRMS for much longer than 15 years. This situation gives Griff confidence to view the future as bright, knowing he is (relatively) mildly physically disabled by RRMS after so many years of living with the disease. However, there is a flip side to this scenario, one where this confidence was severely impacted. This was discussed in Chapter 6, when Griff

attended an MSA meeting and was confronted by the mother of a severely disabled young lady with MS. To this day Griff often feels he isn't as worthy as others to have the diagnosis of RRMS. This is because he feels he doesn't have the added suffering and disability that more severe MS entails.

Table 8: Griff's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • <i>Severe illness as a child and young adult- multiple respiratory conditions, hospitalisations</i> • <i>Working in government agency</i> • <i>Death of parents</i> • <i>Several long term relationships</i> • <i>Marriage separation</i>
Onset of first symptoms in early twenties	<p>Piecing Together the Puzzle (what's happening?)</p> <p>High (In)visibility (welcome cloak)</p> <p>Battling the Demons (fear, worry)</p>
Intermittent symptoms continue for next 20 years on and off	<p>Piecing Together the Puzzle (what's happening?)</p> <p>Battling the Demons (fear, worry)</p>
Diagnosed with Guillian Barre 12 years prior to RRMS diagnosis	<p>Piecing Together the Puzzle (what's happening, tests, tests, tests)</p> <p>Battling the Demons (fear, worry)</p> <p>Surplus Suffering (misdiagnosis)</p>
Personal relationship issues with partner, separation	<p>Battling the Demons (fear, worry)</p> <p>Holding Hands with Hope (purposeful positivity)</p>
Relationship strengthens through separation, back	<p>Taming the Beast (support from family, friends and community)</p>

together, children	
Severe relapse at work	<p>Holding Hands with Hope (purposeful positivity)</p> <p>Piecing Together the Puzzle (what's happening, tests, tests, tests)</p> <p>Battling the Demons (fear, worry)</p>
Confirmed diagnosis of RRMS	<p>Piecing Together the Puzzle (the day my life changed forever)</p> <p>Re(defining) Me now that I have RRMS (getting acquainted, disclosure, working out work)</p> <p>Battling the Demons (fear of burden)</p> <p>Holding Hands with Hope (purposeful positivity, optimism)</p>
Learning to live with RRMS	<p>Re(defining) Me now that I have RRMS (getting acquainted, dare to compare)</p> <p>Battling the Demons (all fears, worry & anxiety, saboteurs, social isolation)</p> <p>High (In)visibility (strive to be visible)</p> <p>The DMT Dance (hardyards: decisions based on hope)</p> <p>Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)</p>
Comparing self with friend with progressive MS	<p>Re(defining) Me now that I have RRMS (getting acquainted, dare to compare)</p> <p>Battling the Demons (fear, worry & anxiety)</p> <p>Taming the Beast (support from family, friends and community, getting a handle on RRMS)</p>
Unemployment and role as "house husband"	<p>High (In)visibility (strive to be visible)</p> <p>Battling the Demons (fear, worry & anxiety, saboteurs, uncertainty, social isolation)</p> <p>Re(defining) Me now that I have RRMS (working</p>

			<p>out work, dare to compare, parenting with RRMS, losses & gains)</p> <p>Holding Hands with Hope (purposeful positivity, optimism, searching for meaning)</p>
Confrontation at MSL meeting with mother of a severely disabled girl			<p>Re(defining) Me now that I have RRMS (getting acquainted, dare to compare, parenting with RRMS, normalcy)</p> <p>Battling the Demons (fear, saboteurs, uncertainty, social isolation)</p> <p>Surplus Suffering (inflicted by community)</p> <p>High (In)visibility (strive to be visible)</p>
Sexual health dysfunction			<p>Piecing Together the Puzzle (what's happening?, tests, tests, tests)</p> <p>Re(defining) Me now that I have RRMS (losses & gains, normalcy)</p> <p>Battling the Demons (fear, worry & anxiety)</p>
Struggling with glatiramer acetate	with DMT		<p>The DMT Dance (hardyards: decisions based on hope)</p> <p>Battling the Demons (fear, worry & anxiety)</p> <p>Re(defining) Me now that I have RRMS (losses & gains)</p> <p>Taming the Beast (getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)</p>
Treatment change to natalizumab		to	<p>Holding Hands with Hope (purposeful positivity, defiant hope, restorative hope, functional hope)</p> <p>The DMT Dance (switching to a better life)</p> <p>Battling the Demons (worry)</p> <p>Taming the Beast (support from family, friends and community)</p>
Struggling with severe fatigue /feeling a poor role model to his children			<p>Battling the Demons (fear of burden, worry, despair, saboteurs, social isolation)</p>

	Re(defining) Me now that I have RRMS (losses & gains, parenting with RRMS, normalcy, dare to compare)
	Holding Hands with Hope (purposeful positivity)
	Taming the Beast (resilience, North Star, maintaining health & wellness)
	High (In)visibility (strive to be visible)
Thriving on natalizumab with social interactions at the hospital, mentoring others with RRMS	Taming the Beast (support from family, friends and community)
	Holding Hands with Hope (purposeful positivity, optimism, giving back and being involved)
	Re(defining) Me now that I have RRMS (balancing losses & gains, negotiating normalcy)
	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
Missed blood test for JCV, then high titre JCV blood test positive - ceased natalizumab immediately	Battling the Demons (fear of burden, worry, despair, saboteurs, uncertainty, social isolation)
	The DMT Dance (hardyards: decisions based on fear)
	Re(defining) Me now that I have RRMS (dare to compare, normalcy, losses & gains)
	Taming the Beast (support from family, friends and community, maintaining health & wellness, resilience)
Commencing new treatment fingolimod and refusing alemtuzumab	Holding Hands with Hope (optimism, restorative hope)
	Taming the Beast (maintaining health & wellness, North Star)

	The DMT Dance (hardyards: decisions based on fear, switching to a better life)
	Battling the Demons (uncertainty, social isolation)
Moving forward, living well with RRMS	Taming the Beast (maintaining health & wellness, North Star, support from family, friends and community, resilience)
	Holding Hands with Hope (optimism, restorative hope, searching for meaning, giving back & getting involved)
	Re(defining) Me now that I have RRMS (normalcy, losses & gains)

The final life story presented in this section is Piper’s story, reflecting a shorter life span living with RRMS than the previous three participants presented, but still an abundance of applied themes and subthemes to her story. Piper’s life journey has been marred by many years of Surplus Suffering due to constant brush-offs of her symptoms by HCPs in her small rural community. However, her fierce determination to not be defined by the disease and to live her best life possible is completely overwhelming in intensity. Piper starts every day believing she is capable of Taming the Beast and is constantly on the lookout to do so. Although disappointed by her many years of struggle, she is in no way bitter about it, she still views many other PwRRMS as going through worse scenarios and is grateful that she was eventually diagnosed correctly.

Table 9: Piper’s life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • <i>Child of a migrant family</i> • <i>Debilitating headaches and nerve pain as an early teen through to adulthood</i> • <i>Small rural community upbringing</i>
Onset of first symptoms	<p>Piecing Together the Puzzle (what’s happening?)</p> <p>High (In)visibility (strive to be visible)</p>

	Surplus Suffering (brushed off)- <i>repeated</i>
Symptoms worsen- come and go over many years	Piecing Together the Puzzle (what's happening?)- <i>repeated</i>
	Surplus Suffering (brushed off)- <i>repeated</i>
	Piecing Together the Puzzle (tests, tests, tests)- <i>repeated</i>
	Battling the Demons (fear, worry & anxiety, depression & despair)
	High (In)visibility (strive to be visible)
Depression	Battling the Demons (depression)
	Taming the Beast (support from family, friends and community)
	Surplus Suffering (brushed off)- <i>repeated</i>
Recovery from depression	Holding Hands with Hope (purposeful positivity)
	Taming the Beast (support from family, friends and community)
Infertility	Piecing Together the Puzzle (tests, tests, tests)
	Taming the Beast (resilience)
	Battling the Demons (fear, worry & anxiety)
Significant relapse with new symptoms	Piecing Together the Puzzle (what's happening, tests, tests, tests)
	Taming the Beast (choosing my A-Team)
	Battling the Demons (fear, worry & anxiety)
	High (In)visibility (strive to be visible)
Confirmed diagnosis of RRMS	Piecing Together the Puzzle (the day my life changed forever)
	Re(defining) Me now that I have RRMS (getting acquainted, normalcy)
	Battling the Demons (fear of burden, worry & anxiety, fear of the wheelchair)
	Holding Hands with Hope (restorative hope, purposeful positivity- searching for meaning)
	The DMT Dance (hardyards: decisions based on

Learning to live with RRMS	<p>hope)</p> <p>Re(defining) Me now that I have RRMS (dare to compare, parenting with RRMS, normalcy)</p> <p>Battling the Demons (fear, worry & anxiety, despair, uncertainty)</p> <p>High (In)visibility (strive to be visible)</p> <p>The DMT Dance (hardyards: decisions based on hope)</p> <p>Battling the Demons (fear of the wheelchair)</p> <p>Taming the Beast (finding my North Star, maintaining health & wellness, getting a handle, resilience)</p>
Sharing journey with family and friends	<p>Re(defining) Me now that I have RRMS (getting acquainted, normalcy, dare to compare)</p> <p>Taming the Beast (support from family, friends and community, getting a handle)</p> <p>Battling the Demons (fear)</p>
Side effects from DMT interferon	<p>Piecing Together the Puzzle (what's happening?)</p> <p>Holding Hands with Hope (defiant hope, functional hope, search for meaning)</p> <p>High (In)visibility (strive to be visible)</p> <p>The DMT Dance (hardyards: decisions based on fear <i>and</i> hope)</p>
Commence new DMT dimethyl fumarate	<p>The DMT Dance (switching to a better life)</p> <p>Re(defining) Me now that I have RRMS (getting acquainted)</p> <p>Battling the Demons (all fears, worry & anxiety, saboteurs)</p>
First travel overseas	<p>Holding Hands with Hope (purposeful positivity, defiant hope, search for meaning)</p> <p>Taming the Beast (support from family, friends and</p>

	community, finding my North Star)
	High (In)visibility (a welcome cloak)
New relapse	Piecing Together the Puzzle (what's happening?) Battling the Demons (fear, worry & anxiety, saboteurs) Re(defining) Me now that I have RRMS (normalcy) Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
Living with RRMS	High (In)visibility (strive to be visible) Holding Hands with Hope (purposeful positivity, defiant hope, search for meaning, sense of humour) Taming the Beast (support from family, friends and community, maintaining health & wellness) Re(defining) Me now that I have RRMS (dare to compare, normalcy, parenting with RRMS, losses & gains)
Sister has a neurological episode	Battling the Demons (fear, worry & anxiety, saboteurs) Taming the Beast (support from family, friends and community) Holding Hands with Hope (purposeful positivity)
Relapse at Christmas	Re(defining) Me now that I have RRMS (balancing losses & gains, parenting with RRMS) The DMT Dance (hardyards: decisions based on fear) Taming the Beast (getting a handle, support from family, friends & community, resilience) Battling the Demons (fear of being a burden) Holding Hands with Hope (purposeful positivity, functional hope, restorative hope)
Moving forward with RRMS	Taming the Beast (support from family, friends and

community, maintaining health & wellness, resilience)

Holding Hands with Hope (purposeful positivity, optimism, giving back and getting involved)

Re(defining) Me now that I have RRMS (getting acquainted, parenting with RRMS, normalcy)

As noted life history author Plummer (2001, p.7) reflects “life is in fluctuating praxis, always in flow and ever messy.” As I began the task of linking each individual’s life events with the themes and subthemes, the process, although “messy”, felt incredibly straightforward despite being very time consuming. This process flowed organically and seemed to fit together very neatly, participant after participant as I worked manually through each transcript. I was surprised at first at the ease in which the themes and life events all fit together so well. I then realised that this organic flow was demonstrating to me that the themes fit back with the data well, and that this was a reflection of good coding and theme development. As Braun and Clarke (2013) suggest, to be able to invoke the original data just by reading the code or theme is the result of capturing the both latent and salient features well, and is a fundamental aim of the coding process. The further inclusion of specific subthemes within each theme category in the life trajectory tables gave the added ability to “drill down” even further into each theme, to identify a feature of the theme that was more descriptive of the life event, but still fell under the same central organising concept of the overarching theme.

Life history gives voice to the ordinary members of a culture as they cope on a daily basis with the joys and challenges of life (de Chesnay & Fisher, 2014), and was embraced and welcomed by every participant in the current study. The use of focused ethnographic life history methodology worked cleverly with the ebbs and flows of living with a chronic illness such as RRMS to reveal themes and subthemes exploring the lived experience of RRMS. As RRMS is most commonly diagnosed in young adults and is usually not life threatening (Compston & Coles, 2008), it represents a long period of time to live with a chronic illness. Hopes, dreams, school, study, sport, work, relationships, marriages, pregnancies, children, friends, relationship breakdowns, grieving, set-backs, loss, pride, happiness, contentment;

these are some of life's typical challenges and joys, occurring with or without the presence of RRMS. Using the life history approach generated rich and detailed data about the experiences of living with RRMS and unearthed some extraordinary insights, which have been outlined throughout the study findings chapters and will be given deep clinical relevance in the following, concluding chapter.

CHAPTER 9 - CONCLUSIONS AND RECOMMENDATIONS FOR PRACTICE

The final chapter of this thesis will re-examine the aims and findings of the research study and discuss how the research question is answered by attributing meaning and understanding to the lived experience of RRMS. This chapter will also link the study findings to recommendations for MS clinical practice. These clinical recommendations will concentrate particularly on MS *nursing care*, however, they will also be applicable in varying ways for all HCPs involved in the management of MS.

Introduction

This research study posed the question “What is the experience of living with RRMS?”. The aim of this research study was to explore the experiences of people living with RRMS, in order to gain insights and understanding of the lived experience. It is anticipated greater understanding will positively impact on the care provided by MS Nurses in particular, but also for all MS HCPs in general. The purpose of these insights and understandings is to be able to provide improved clinical care, to offer patient-centred support in patient-focused areas, and to ultimately improve the quality of life and nursing care for PwRRMS. This life history study revealed the meaning of the lived experience of 13 people as they met the daily challenges and joys of life, living with RRMS. This understanding of their lived experience was accomplished initially by co-creating a life history, through the telling and ordering of the life history by the participant to me as the researcher, and further co-created by my questions and reactions as this interview took place. Mishler (1995, p.90) suggests this model of narrative analysis is “reconstructing the told from the telling” and highlights the active role of the researcher in this process. Importantly, the co-construction of the data also supported the epistemological basis of the study, a constructivist approach, where the participant and research co-create knowledge together.

The second part of the research process centred on revealing meaning in my interpretation and ordering of the life history into a life story, and the subsequent development of themes and subthemes to reflect this meaning. A third step in the process will occur, and is indeed occurring now, as readers of this thesis and future journal articles, and the listeners of future presentations and workshops, will develop further meaning from the stories and themes as they are presented.

Alongside these meanings, the study participants also reported a deeper understanding of themselves throughout the process. The act of reflecting on their lives allowed both introspection and benefit finding. Throughout all phases of the research, I too, deepened my understanding of not just PwRRMS, but also of myself as an MS Nurse, a mother, a wife, a friend, a patient and a carer.

Throughout the research process, new meaning constantly evolved as the participants merged their experiences of RRMS between the past and the present, often moving backwards and forwards through the life history. Although at times recalling their life history could be uncomfortable or distressing, all study participants concluded their life history interview interpreting their experiences with RRMS in a mostly positive light. This constantly amazed me; mainly because many of the participants had suffered significant hardship during their life with RRMS, however they constantly moved adversity aside to bring in positivity and end on an optimistic note. There was a real sense of moving RRMS into the background of life and keeping positivity, hope, family, friends, health and wellness in the foreground. This was mostly achieved by employing the elements of one of the major study themes, Taming the Beast. The elements identified in the study findings included finding my North Star, getting a handle on RRMS symptoms and relapses, maintaining physical and mental health and wellness, choosing my medical A-Team, harnessing support from family, friends, organisations and workplaces and riding high on resilience. For the study participants, these components all added up to one overwhelming factor- ***regaining as much control as possible over a disease with no cure, no predictability and no certainty***. It was all about finding ways to once again be in charge of their life after their diagnosis of RRMS.

However, as Chapter 8 explored, this is not always a “done deal” or something that automatically happens once a checklist is completed or a DMT is commenced. Any number of negative experiences could threaten to take away the gains made by the PwRRMS, at any stage and at any time in the life journey. These were the forces explored in *Battling the Demons*; dealing with fear of disability and fear of losing mobility and becoming dependant on a wheelchair, fear of DMTs and potentially life threatening side effects, and living with the constant fear of relapse. Living with this fear presented, in some participants, as sheer terror, especially when thinking about the possibility of using a wheelchair in the future. However, although initially fearful of the consequences of RRMS, others who previously thought they would be unable to cope with physical disability adapted over time and came to respect and appreciate the advantages that a walking stick or wheelchair gave them, especially during a severe relapse. But the road to this point could be frequently fraught with high emotion.

Participants in the study also highlighted a “push/pull” relationship with their RRMS, part of them did not want to see what RRMS could develop into (as SPMS) in years to come and deliberately avoided gatherings such as MSA meetings and education seminars where it was expected to meet others living with MS. However, they would find themselves engaging in internet searches and reading to find out more information about what progression might look like. The main difference was they could do this in the privacy and safety of their own home. A slightly different variation on this push/pull relationship was the scenario of a PwRRMS attending an MSA meeting (often with people living with progressive MS) in order to prove to themselves that their RRMS was “better”, or that their MS was going to be different to that lived by others with the disease. These examples of the push/pull relationship reveal the PwRRMS once again *trying to regain some control over the disease*, of being “in charge” and wanting to look at the future, but in small doses that they could attempt to control. Being aware of the intricacies of this “push-pull” relationship could help MS Nurses and other HCPs in assisting adjustment to the diagnosis of RRMS and in times of relapse, disease progression, symptom change or other life events impacting on RRMS.

I believe that one of the most shocking revelations of the current study findings was the abundance of Surplus Suffering for many PwRRMS. This suffering over and above that caused by living with RRMS, was frequently caused by HCPs, and mostly (and hopefully) unknowingly. Unequal power relationships between doctors and patients led to many of the scenarios described by study participants, scenarios which could have been easily diffused if the doctor had taken the time to explain things more carefully and to realise the impact of a diagnosis of RRMS on a person. It has been suggested from previous research that the day of diagnosis for a PwMS is a day they remember clearly with very strong memories (Solari et al., 2007), for many study participants these memories and feelings came flooding back in great detail during our interview. Surplus Suffering was often caused by HCPs brushing off PwRRMS. This sense of being brushed off stemmed from not understanding the symptoms, not believing the symptoms existed, relying too heavily on previous patient assessments or simply not being aware of RRMS and the need to quickly refer on for treatment early in the disease process because this leads to the best clinical outcomes (Giovannoni et al., 2016).

Understanding what has led to Surplus Suffering is key to unravelling the causes. Other specialities have reported difficulties and stress in nurses looking after diseases which are incurable or unpredictable, such as in cancer (Corner, 2002; Lange, Thom, & Kline, 2008) and myeloma (Cormican & Dowling, 2016), an area which is under-researched in MS care. The area of Surplus Suffering in MS deserves further exploration to try and understand why it is occurring in the first place; understanding the underlying causes of Surplus Suffering is the only way it can be prevented in the future, rather than simply managed by nurses and other HCPs.

The invisibility of many common symptoms of RRMS had some interesting flow-on effects for those living with the disease. For some, invisibility was seen as a welcome component of the diagnosis, the fact that others could not always see the symptoms and know the diagnosis gave a positive slant to the disease. These participants felt this invisibility allowed them to avoid the stigma of a chronic and poorly understood illness. For others, they desperately wanted their condition to be seen, they wanted to “out” the invisible symptoms and earn understanding from others as to how difficult and challenging it is to live with debilitating symptoms which were difficult to

explain to others. These symptoms in particular were fatigue, cognition issues and the “hushed one”, sexual dysfunction. Interestingly, these invisible symptoms are also amongst the most difficult to effectively treat, further compounding their invisibility. For MS Nurses and other HCPs, being aware of the challenges of verbalising and discussing these symptoms in an important step forward to guiding patients to negotiate MS jargon and language in a way that helps them explain the complexities and difficulties of these invisible and difficult to describe symptoms.

Although the role of Piecing Together the Puzzle began the sequence of themes in the findings, this concept actually lasts a lifetime of living with RRMS. Due to the unpredictability of the next relapse (in terms of the exact area of demyelination in the CNS), RRMS can be a constantly surprising disease to live with. Often each new relapse brings a host of new symptoms. Building experience to learn exactly what a new relapse is often proves difficult, as one relapse may involve visual symptoms and the next motor weakness and the next a bout of severe fatigue or cognitive difficulty. It is all unpredictable. Thus, life is a constant act of defining and (re)defining self as RRMS changes and morphs. Comparing oneself against others can also be difficult as every case of RRMS is different, however this also gives the PwRRMS an advantage, a chance to define, or (re)define themselves.

On the other hand, completing the study themes with Holding Hands with Hope, exploring the different types of hope and purposeful positivity, doesn't mean that the life journey ends neatly there either. Life with RRMS is constantly in flux and although the role of hope will always weave into the RRMS life in some way, it will be more present at certain times and it will be harder to find at others. As a disease with no current cure, hope represents an integral part of the “toolkit of living well with RRMS” of both the MS Nurse and the PwRRMS.

Summary of the key findings and recommendations for clinical practice

This study set out to explore and capture a rich, thick and comprehensive examination of diverse experiences of living with RRMS. Using focused ethnography and a life history approach, the study gained insight into many key areas of living with this unpredictable autoimmune, neurological disease over the life

trajectory. This knowledge, partly supporting previous research further and partly innovative, develops the body of literature that is available to enhance nursing practice in MS care.

Several previous studies (Beshears, 2010; Clair, 2003; Courts et al., 2006; Miller, 1997) were identified in Chapter 3 as being the most similar in terms of study aims to the current study, exploring the lived experience of MS. However, only Miller (1997) and Beshears (2010) specifically stated that their research involved only PwRRMS, not PwMS in general. Examples of themes, subthemes and sub-subthemes from the current study supporting the previous literature identified in chapter 3 include: harnessing social support, concepts of hope and hopelessness, getting acquainted with RRMS, conflict with HCPs, facing fears, coping with uncertainty and disclosure (Miller, 1997; Beshears, 2010); concepts of MS as an adversary and of a saviour (Clair, 2003); concepts of brush-off, symptom devastation, regaining control and self advocacy (Courts et al.; 2004) and feelings of living with uncertainty and RRMS always being in the backdrop of life (Beshears, 2010).

There are subtle elements of previous qualitative studies in all of the current study themes, some stronger than others. For example, themes such as MS as an adversary (inspiring to overcome obstacles) (Clair, 2003) are not semantically linked to the current study, but may integrate more latently with the themes of purposeful positivity and searching for meaning. Other themes such as getting acquainted with MS in the current study explore the difficulties in navigating communication and information resources, representative of changing times and new outlooks, as we learn more about the disease process, symptom management and treatments. Information access has become easier for patients in recent times with the internet, but more challenging in terms of understanding the content and which information is accurate and secure. Although a different process nowadays, these current themes integrate back to Miller's (1997) earlier themes of getting to know MS and the importance of correct information, locating appropriate resources and observing others with MS.

There are many novel findings from the current study findings. The most significant of these include Surplus Suffering (novel to reporting in RRMS), the push/pull relationship with comparing to others with RRMS, finding my North Star, choosing my medical A-Team, feeling a pretender to the throne (involving elements of reverse stigma), the welcome cloak of invisibility, giving back and getting involved and The DMT Dance - the hardyards: decisions based on fear and decisions based on hope. The new study findings provide the opportunity for review of current MS nursing practices and also the opportunity to make changes based on the new knowledge. These new findings will be woven throughout the clinical recommendations to follow.

In addition to the thematic findings outlined in Chapters 6, 7 and 8, there are numerous clinical practice recommendations that have been developed from the study findings. I have kept these clinical practice recommendations linked to the theme they pertain to, for consistency in the story and for clarity of the context of the recommendation. Although applicable and practical for all HCPs involved in MS or chronic illness care, these recommendations particularly honour the unique role of nursing and support patient focused nursing care of the PwRRMS.

Piecing Together the Puzzle

- During the investigative phase for a diagnosis of RRMS, there may be important points at which HCP intervention can assist each patient considerably. Consideration should be made to providing information for the patient detailing the multiple diagnostic tests, the reasons why they are necessary and a discussion about the difficulties and intricacies in an MS diagnosis. Consider support from MSA during the pre-diagnostic period if MS is strongly suspected and it is appropriate and sought by the patient.
- MS Nurses should take particular note of the past experiences and HCP encounters that PwRRMS bring to their initial appointments and be mindful that the path to the MS Clinic/Neurologist may not have been an easy one. There may have been much suffering in the years prior, undiagnosed or diagnosed as RRMS; being ignored by HCPs, having symptoms dismissed or

trivialised and some made to feel like they “are going mad”. The MS Nurse can discuss with PwRRMS how they came to be diagnosed and goals for the path forward to build their confidence and trust. Asking about prior experiences in healthcare and what their expectations are of RRMS care can enable effective communication and goal setting for the future, and a mutually acceptable, and achievable, nursing care plan.

- The day of diagnosis is vividly remembered by many PwRRMS. Often HCPs can be distracted, tired and busy managing multiple patients and situations at the one time in a clinical setting. It is vital to be aware of just how influential the day of diagnosis is for the PwRRMS and the considerable impact kindness and compassion at this time can have on the life journey ahead. The involvement of an MS Nurse at the time of diagnosis delivery would be an optimal situation.
- MS Nurses are in an ideal position to implement the need for flexibility, repetition, time and understanding when delivering a diagnosis of RRMS. The approach should be tailored to individual patients in a format that is straightforward for them to understand. The involvement of families and significant others can also assist engagement with information and improve communication within the family and significant other networks.

(Re)Defining Me Now That I have RRMS

- Individual education and information needs at the time of diagnosis for PwRRMS differ greatly. MS Nurses should personalise disease education and information at a time when the PwRRMS is ready to accept the information, taking into account their preferred method of learning and also including family members or friends (where this is desired by the PwRRMS).
- Early referrals should be made for psychological assistance when the PwRRMS seems to be struggling with adjusting to the diagnosis and maintaining a positive sense of self. This should also be revisited regularly at routine clinic visits, even when things appear to be going well from a clinical point of view.

- MS Nurses can share with the PwRRMS the perspective that “time can be their friend”, and that many people dealing with similar issues after an RRMS diagnosis, *do adjust successfully in time*. Discuss openly with PwRRMS the particular challenges of dealing with the unpredictability and uncertainty of the disease and how challenging this can be. Discuss the value of maintaining a positive attitude and investing in skills which promote personal coping. These include resources such as managing stress, faith and spirituality, and cultivating optimism.
- MS Nurses are ideally positioned to enquire as to which MS symptoms are affecting a PwRRMS’s life to the greatest extent, and thereby potentially threatening identity, at any given time. These symptoms may be different to the symptoms HCPs pay the most attention to, but may be impacting the patient’s QOL significantly. Care should be taken to provide advice for these symptoms in order to safeguard mental health and wellbeing.
- MS Nurses can skilfully provide information on the benefits and the disadvantages regarding disease disclosure in the workplace. Employment, and maintaining employment, provides a sense of personal fulfilment, socialisation and empowerment to many PwRRMS. Such discussions should be highly individualised and take into account personal needs as well as the workplace environment. Referral to an Occupational Therapist skilled in workplace adjustments may be helpful. Adjustments can enable work to continue to be an important part of life and socialisation for the PwRRMS.
- MS Nurses can enhance awareness of the significant impact of RRMS on parenting; the joys and the challenges, and offer support and guidance to the PwRRMS. This concept should be revisited regularly over the course of the disease, and particularly with events such as relapse or disease progression, which could present new challenges to parenting with RRMS at different stages of the family life trajectory.
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Battling the Demons

- MS Nurses are ideally positioned to ask about childhood illnesses and life challenges at the beginning of the RRMS journey. Look for clues about prior displays of *resilience*, which may be helpful the PwRRMS in their current battle. This will also provide information for the MS Nurse to assess coping styles and the need for psychological referrals. It is also beneficial to build confidence for the PwRRMS on their journey, reminding them of their strengths and what they are capable of overcoming.
- Signs of depression and anxiety need to be assessed for and addressed early, and often. As depression and anxiety both strongly correlate with a lower quality of life, it is important for MS Nurses to recognise anxiety and make appropriate referrals early on. Similarly, accessing social support can reduce anxiety and the need for this should be regularly assessed. Anxious patients may also have distorted perceptions of the availability of support, so gentle guidance from the MS Nurse may also be required. Social support systems also assist with managing depression.
- It is important for MS Nurses to understand that the uncertainty of RRMS can be a source of concern, regardless of the individual's degree of symptoms or stage of RRMS. During clinical appointments, emotional well-being can often be overlooked by more pressing physical symptoms, discussions on DMTs, MRI results and medication side effects. MS Nurses and HCPs need to ensure emotional well-being is assessed thoroughly at every routine clinic visit. Emotional illness can be just as fatal as physical/DMT issues, just sometimes much quieter.
- It is vital for MS Nurses to be aware of “fear points” on the RRMS life journey where even the most seemingly well-adjusted PwRRMS may experience upheaval and require assistance to navigate the life journey. These fear points include times of relapse, reports of MRI progression, new symptom onset, pregnancy, change to personal circumstances, loss or change in employment, DMT medication change or DMT risk factor change.

- MS Nurses are ideally positioned to assess for the possibility of PTSD in all PwRRMS, and be familiar with possible signs of PTSD such as nightmares, flashbacks, emotional detachment and avoidance of social situations. If signs of PTSD are identified, urgent referral to a psychologist/psychiatrist is indicated.

Surplus Suffering

- The MS Nurse is perfectly positioned to lead the MS health care team by example, practicing holistic care, empathetic nursing, “turning toward” and demonstrating compassion. MS Nurses can also support and educate the loved ones, work colleagues and friends of PwRRMS regarding appropriate resources to help them partner with the PwRRMS on their life journey.
- Patients undergoing testing or assessment for RRMS should be treated with dignity, respect and recognised as a holistic human being in a unique and challenging context, rather than a diagnosis or potential diagnosis. An extra minute or two, an opportunity for questions, a gesture, eye contact and nods of understanding can significantly influence a health care encounter and can go a long way to providing a positive experience, despite what the eventual diagnosis and prognosis might be.
- A new patient under care, no matter what stage of the RRMS journey they are at or how many years they have been diagnosed with RRMS, may benefit from a frank discussion on their previous healthcare and any issues that may have come up in the past. This can provide opportunities for discussion about past encounters with HCPs but also provides an opportunity to discuss current expectations. Goals for future RRMS care to improve care effectiveness and HCP relationships can also be discussed.
- Every patient is an expert in his/her own body and feelings. Acknowledging this and using the patient’s knowledge is an important part of individualised and holistic care. Connecting with, engaging with, and preserving the dignity

of patients as human beings are fundamental not just to MS nursing care, but and to all HCPs caring for PwMS.

- A critical function of the MS Nurse is to lend strength, until the PwRRMS recovers their own. Not taking over, not racing ahead, not leaving behind. Lending strength can be conceptualised as nurses providing information/education, guidance, emotional support and advice. This is also a key function of all MS HCPs in the healthcare team and MS support organisations in the community.

High (In)Visibility

- MS Nurses provide education and guidance for PwRRMS suffering invisible symptoms about specific symptom management. Open discussion from an early stage of the MS life journey on the high probability of invisible symptoms (at least at some stage of the disease) can facilitate honest and frank conversations in the future and possibly earlier detection and treatment if and when they do arise. This will also assist PwRRMS to understand the reasons and challenges behind invisible symptoms and how symptoms can be treated and managed, thereby aiding confidence and self-efficacy.
- Discussion of invisible symptoms should be a regular part of MS consultations from the outset of the MS life journey so that the PwRRMS will feel more comfortable discussing the more socially taboo subjects, such as sexual health issues, cognition and bowel and bladder issues, if and when they do arise. Early detection and treatment is key.
- MS Nurses can provide guidance on managing invisible symptoms with family, friends and work colleagues, and advise the PwRRMS how to explain invisible symptoms to others and how to ask for support. Educational materials can also be supplied to assist in discussions and adaptations that may be needed. If the PwRRMS feels secure in understanding their own invisible symptoms, they will be more confident explaining to others.

Taming the Beast

- To feel comfortable with an MS Nurse or other HCP, to be provided with individualised information/education, to have confidence in their RRMS management and to understand treatment plans and goals are all important factors to consider for PwRRMS. MS Nurses in particular can encourage PwRRMS to develop a supportive MS care team around them which meets their individual needs – choosing my A-Team. MS Nurses should be particularly mindful of PwRRMS living in isolated situations or rural communities, facilitating effective communication with local health care teams and to have plans in place in the event of relapse or other crisis.
- Asking for help from others can be difficult for many PwRRMS. MS Nurses are in an excellent position to provide guidance and advice for PwRRMS on how to ask families, friends and organisations for assistance and to pinpoint times when they may need special help, such as during a relapse, for the duration of post partum care and during times of co-morbid illness.
- MS Nurses can help build and enhance resilience in PwRRMS by providing reflections and narratives on how other PwRRMS have managed similar problems and moved forward. By being aware of strategies to enhance resilience and encouraging these strategies in PwRRMS, MS Nurses and HCPs can assist in confidence building and later overcoming difficulties during the life trajectory with RRMS. The issue of resilience should be assessed and discussed regularly and skills continually enhanced.
- MS Nurses can assist families and friends of the PwRRMS to understand the challenging nature of the disease, the invisible symptoms and the difficulties that the PwRRMS may experience. MS Nurses in particular can provide guidance and support as the loved ones of PwRRMS also come to terms with what RRMS means and the many ways that they can help on the life journey.

The DMT Dance

- MS Nurses need to develop effective tools to improve communication and support for PwRRMS in learning more about the disease and the specific role of DMTs within their disease management. Being educated and engaged will encourage active participation in DMT decision-making and help PwRRMS to become more effective self-advocates.
- There is no cure or one size fits all approach for treatment in RRMS. Sometimes DMTs need to be trialled to assess their effectiveness and compatibility on a PwRRMS. As perceived lack of efficacy can be an important barrier against medication adherence, MS Nurses are ideally suited to ensure PwRRMS have realistic expectations from their prescribed DMT and also provide written information, which can be referred to at anytime.
- Adherence to treatment regimes is essential to ensure PwRRMS receive the maximum benefit from their treatment and also to ensure that the treatment is cost-effective. Adherence to the DMT plan should be assessed at every MS Nurse encounter, whether in the clinic or by text, internet based consultation, phone or email.
- PwRRMS should be informed of DMT options, the potential benefits and risks of each treatment and the importance of adherence, using an approach which suits their style of learning and their level of health literacy. Allowing an active role for PwRRMS in treatment decisions may also give a sense of empowerment and provide motivation to continue DMT when things don't go according to plan.
- MS Nurses can provide guidance and support for PwRRMS to build their own support network to assist with adherence. This can take the form of education regarding the possible avenues of company support with the chosen DMT, the importance of the support of family and friends, or by providing information on how to access clinic, local medical and community support.

Holding Hands with Hope

- Hope is never static; it is always dynamic and changing form, requiring constant supervision by the MS Nurse during the entire life journey with RRMS.
- Being at the forefront of care in RRMS, the MS Nurse is in a unique position of trust to be able to observe and assess all aspects of emotional and spiritual health. The MS Nurse can inspire, demonstrate, nurture, coach, educate about and sustain of forms of hope for the PwRRMS.
- Tools for the MS Nurse to inspire and sustain hope include regular hope assessments, education, storytelling, advocacy, counselling and referrals where necessary. Educating the PwRRMS about the importance of maintaining optimism, a positive outlook, searching for constructive meaning, maintaining a sense of humour, considering faith and spirituality, where appropriate, and possible avenues to “give back” and be involved in the MS community. These are examples of *purposeful positivity*, an important component of the MS Nurse role.
- MS Nurses build particularly strong therapeutic relationships with their patients, often built on respect, caring, empathy, invested time and their strong knowledge base. Being a symbol of hope is also an important part of this relationship, leading by example and inspiring hope by living with hope and positivity themselves. This requires self awareness, insight and self-care by the MS Nurse. Living hope teaches hope.

Limitations of the study

There are some limitations to this research study. As a qualitative study this data draws on a relatively small number of participants, however the information rich informants gave the study powerful information. Additionally, the study was confined to participants living in the state of NSW, Australia and the themes may not be transferable to other geographic regions and countries.

My role as an MS Nurse in clinical practice invariably influenced the data interpretations in the study. I did my best to disclose and to be acutely aware of these possible influences, not just during the interviews but also at all stages of the data analysis process. However, despite these safeguards, it is likely that my MS Nurse role has influenced the research findings in some way and may in fact have brought greater depth to the study.

Directions for future research

This life history study has explored the lived experience of RRMS in the state of NSW, Australia. Further research is required to explore the experiences of PwRRMS in other contexts, in other regions, in other countries. Many previous studies have purposively or inadvertently enrolled mainly women in their research, and the lived experience of men with RRMS is also grossly under-researched and requires further attention. Additionally, similar research to the current study needs to be performed in currently overlooked areas of living with RRMS - in both children/adolescents and in the aged population living with RRMS, interestingly both ends of the life trajectory. There also exists little research on the lived experiences of carers of PwRRMS and also on the lived experience of MS Nurses other MS HCPs.

Surplus Suffering in RRMS care emerged as a key, novel finding for this particular population and would be the ideal concept to form the basis of further research work in RRMS. Not just in recognising and managing Surplus Suffering, but in truly understanding the underlying causes of the phenomena. Additionally, the concepts of parenting with RRMS, comparisons with others with MS, invisibility as a welcome cloak, harnessing resilience, the experiences of reverse stigma, worry and fear in RRMS all warrant further exploration to better understand their basis and their direction. Moreover, all aspects of hope and purposeful positivity could be examined in further detail for further support and evidence on how the MS Nurse can best assist and promote this important function.

This thesis explores and discusses how PwRRMS are active in Taming the Beast, but just as importantly, the study highlights the importance of Holding Hands with Hope.

In a time of great scientific and biomedical progress into RRMS, this situation requires careful observation and monitoring so that knowledge of the patient experience does not get left behind the rapidly changing and expanding medical knowledge.

The life history method, the study findings and me

As a researcher, choosing the life history method proved to be an absolute privilege for me, gaining so much more from the data than I had ever dared imagine. The depth of emotions and information the participants shared with me still profoundly affects me. I feel eternally grateful to the study participants for sharing their deepest despair and their most rising joy, and amongst it all telling me about all of the other facets of life that we so rarely have time to ask about in the roles of MS Nurse and patient. It was these facets of life that ultimately helped me build up a picture of hope, resilience and overcoming adversity that I had never really thought too much about. My previous understanding was generated by the perspective of a perpetually exhausted, task-orientated, problem solving MS Nurse. Perhaps I was a little frightened to ask more questions because it might just open a “Pandora’s box” that we didn’t have time to explore in a time-limited and already rushed clinical appointment.

The life history methodology gave the study much more emotion and insight than would have been achieved by simply asking pre-determined interview questions in a structured format, or by presenting the participants with a survey or questionnaire of things that I felt were important. Instead, life histories flowed naturally for the study participants, forming stories and presenting a wide range of themes. These were stories that sometimes broke my heart, and sometimes healed it, but always affected my heart and understanding in some way.

Within a life trajectory it is possible to identify critical life events working through central life themes such as love, work and play (Plummer, 2001). For PwRRMS, these components make up their daily life living with the disease and how they get through them, survive and thrive is what we, as MS Nurses and MS HCPs need to understand more about in order to provide optimal care and education. It is not just

about the exact moment of the person living with RRMS sitting in a consultation. Patients cope and live with a lifetime of experiences which could ultimately be affecting the present. Whilst it is impossible to assemble a life history for every patient, it is possible to ask the **right** questions to bring together important details which may affect current and future consultations, and have a significant impact on their life journey with RRMS.

This thesis explored the experiences of 13 people living with RRMS, and has outlined important areas of reflection for MS Nurses and provided recommendations for clinical MS nursing care. The reason for this is to generate insights of the lived experience of PwRRMS so that nurses have a deeper understanding of the RRMS experience in order to plan nursing care accordingly. A critical role of the MS Nurse is to lend strength whilst we repair and support Piecing Together the Puzzle, we guide (Re)defining self, we assess, act and refer on when Battling the Demons, we repair and prevent Surplus Suffering, we advocate for High (In)Visibility, we teach skills in Taming the Beast, we educate and monitor The DMT Dance, we acknowledge and inspire Holding Hands with Hope. In short, we, as MS Nurses, act in the capacity of strength for our patients through the life journey of RRMS. From Eric Cassell (2004, p.43):

“Recovery from suffering often involves borrowing the strength of others as though persons who have lost parts of themselves can be sustained by the personhood of others until their own recovers”.

As MS Nurses, we lend strength so very well. My hope is that through the new knowledge gained into the life journey of RRMS in the current study, and by generating future research, we can enhance and build upon this even further.

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APPENDICES

Appendix 1. HREC approval documents

Appendix 2. Flyer: for recruiting study participants

Appendix 3. Reflection questions prior to interviews

Appendix 4. Safety checklist before interviews

Appendix 5. Policy to notify of interview attendance/completion

Appendix 6. Example of field notes

Appendix 7. Example of the development of semantic and latent codes

Appendix 8. Example of thematic map development

Appendix 9. Patient information and consent forms (PICF)

Appendix 10. Flyer: procedure to follow-up participants if needing psychological care

Appendix 11. Questions to ask myself before/after interviews

Appendix 12: Diary excerpt from reflexive diary on how I was feeling

Appendix 13. Interlinking of the life journey reflecting the study themes and subthemes of participants, Margot (13a), Kate (13b), Rudi (13c), Joy (13d), Jane (13e), Paul (13f), Ruby (13g), Davina (13h), Evie (13i).

Appendix 1 HREC correspondence



19 Mouat Street (PO Box 1225) Fremantle WA 6959
+61 8 9433 0555 | enquiries@nd.edu.au

18 February 2016

Associate Professor Tracey Moroney & Ms Therese Burke
School of Nursing
The University of Notre Dame, Australia
PO Box 944
Broadway NSW 2007

Dear Tracey and Therese,

Reference Number: 016002S

Project title: "What is the experience of living with Relapsing Remitting Multiple Sclerosis?"

Thank you for submitting the above project for Full Ethical Review. Your application has been reviewed by The University of Notre Dame Human Research Ethics Committee in accordance with the *National Statement on Ethical Conduct in Human Research (2007)*. I advise that ethical clearance has been granted conditional on the following issues being addressed:

- Researchers to store a copy of the data collected in the School of Nursing as per university policy *Code of Conduct for Research*.
- Researchers should include the Notre Dame logo in the advertisement.

Please send your response addressing each of the issues as listed above, including supporting information where applicable, to me at Natalie.Giles@nd.edu.au by **Tuesday 1 March 2016**. Failure to respond and/or communicate by this time could result in a suspension of the ethical review of the project.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Natalie Giles'.

Dr Natalie Giles
Research Ethics Officer
Research Office

cc: Anna Williams, Acting SRC Chair, School of Nursing Sydney.

Broome Campus 88 Guy Street (PO Box 2287) Broome WA 6725
Sydney Campus 140 Broadway (PO Box 944) NSW 2007

Fremantle

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Therese Burke
69 Grove St Lilyfield 2040 NSW

22nd February 2016

Dr Natalie Giles
Research Ethics Officer
Research Office
The University of Notre Dame Australia
Fremantle Campus

Dear Natalie,

Reference Number: 016002S

Project Title: "What is the experience of living with RRMS?"

The table below outlines the conditions/issues raised by the HREC and the researcher's response summary, including the location of the required amendment in the full application.

Condition / Issue Raised	Researcher Response
Storage plans for data collected during the research	A copy of the data collected will be stored in the School of Nursing, Darlinghurst Campus, to comply with university policy: Code of conduct for research. This is now amended in the original submission section 6.2b and 6.2c and a copy of the electronic form with this addition clearly marked is attached.
Addition of UNDA logo to subject recruitment advertisement/flyer	The UNDA logo has been added and the subject recruitment advertisement/flyer is now known as version 2, dated 22 nd February 2016. The new advertisement is attached.

I hope this addresses the concerns raised by the HREC. I look forward to hearing from you.

Yours sincerely,

Therese Burke (Student)

23 February 2016

Associate Professor Tracey Moroney & Ms Therese Burke
School of Nursing
The University of Notre Dame, Australia
PO Box 944
Broadway NSW 2007

Dear Tracey and Therese,

Reference Number: 016002S

Project title: "What is the experience of living with Relapsing Remitting Multiple Sclerosis?"

Your response to the conditions imposed by the university's Human Research Ethics Committee, has been reviewed and assessed as meeting all the requirements as outlined in the *National Statement on Ethical Conduct in Human Research* (2014). I am pleased to advise that ethical clearance has been granted for this proposed study.

All research projects are approved subject to standard conditions of approval. Please read the attached document for details of these conditions.

On behalf of the Human Research Ethics Committee, I wish you well with your study.

Yours sincerely,



Dr Natalie Giles
Research Ethics Officer
Research Office

cc: Anna Williams, Acting SRC Chair, School of Nursing Sydney.



**ARE YOU LIVING WITH RELAPSING REMITTING MULTIPLE
SCLEROSIS?**

A research study is being undertaken to explore the life experiences of people living with Relapsing Remitting Multiple Sclerosis (RRMS). To be eligible for inclusion in this study, you need to meet the following criteria:

- to have been diagnosed with RRMS
- aged 18 years or over
- be able to read and understand English
- be able to walk unassisted
- To be available for an individual interview with the researcher at a mutually agreed location in Sydney

If you are interested in finding out more information, please contact the Principal Researcher, Therese Burke, by mobile telephone on 0412 365 667 or by email on therese.burke2@my.nd.edu.au

There is no obligation to participate in the research by making an enquiry.

This research study has been approved by the Human Research Ethics Committee of the University of Notre Dame, Australia.

Appendix 3: Reflection questions

Reflection questions prior to interview

These are some reflection questions you might like to think about before the interview, to help organise your thoughts and give you an opportunity to give consideration to important things or personal events of significance that may have happened in your life.

What have been the major events in your life so far?

What have been the major turning points in your life?

In what ways has the diagnosis of relapsing remitting multiple sclerosis (RRMS) changed or altered your life plan/s?

When were you first diagnosed with RRMS and what was happening in your life at that time?

What symptoms did you have leading up to the diagnosis of RRMS?

How did you feel waiting for the diagnosis?

How did you feel when the diagnosis was confirmed?

What effect have the relapses had on your life?

Has RRMS affected your relationships, and if so, who with, and in what ways?

Has RRMS affected your work life or employment, and if so, in what ways?

How have the new medications to treat RRMS impacted on your life?

What impact has RRMS had on your life generally?

What other health issues have you experienced and what impact have they had on your life?

Appendix 4: Safety checklist

Safety checklist prior to participant interviews

HDR project TB/ "What is the experience of living with RRMS?"

Where possible, perform the interview during the day.

Information on name, address and contact number of the participant should be provided to the nominated Supervisor on the day of the interview (TM or JP depending on their lecturing schedule).

Have Supervisor numbers pre-programmed into mobile phone, as well as emergency number (000) and ensure the phone is charged and in working order for every interview.

Phone questions PRIOR to interview to assess safety risks:

Are the premises a unit, house or place of business?

Are the premises easily accessible from the street?

Are there any stairs to gain entry?

Are there fences around the premises?

Is it likely that there will be anyone else home at the time of the interview? If so, who?

Are there any pets on the premises? If yes, what sort and are they aggressive?

Are there any other safety issues that I need to be aware of?

On arrival:

Contact nominated Supervisor (TM/JP) with time of entry and expected time of departure.

Assess the premises for the presence of safety risks, weapons, the influence of drugs or alcohol.

Leave the premises immediately if any safety risk is identified or observed.

Keep mobile phone and keys with me at all times.

After the interview:

Contact nominated Supervisor (TM/JP) to advise of interview completion and leaving the premises.

Appendix 5: Interview policy

SUBJECT INTERVIEW POLICY

HDR study: "What is the experience of living with RRMS?"

Subject interviews will take place at a mutually agreed location between subject and Interviewer (Therese Burke). Ideal locations for the interview include:

- UNDA interview rooms at Broadway
- UNDA interview rooms at Darlinghurst
- Library interview rooms (public libraries in Sydney)
- Subject homes if preferred by subject
- Interview room at Westmead Education Centre (under Westmead Hospital research and education network) – this is not a clinical area

Therese will contact Tracey Moroney and Joanna Patching (Supervisors) to let them know she has an interview planned and where and when the interview will take place.

Therese will check in by phone and/or email on arrival to the interview and also at interview completion so that all parties are aware of proceedings and safety is monitored.

Appendix 6: Field notes

TB HDR STUDY: FIELDNOTES FOR EACH SUBJECT INTERVIEWED

Interview name:

Date of Interview:

Time of interview:

Time on and off:

Breaks:

General demeanour (mood/dress etc):

Periods of Distress:

Periods of Joy:

Difficulties encountered during life :

Things which went well during life:

Themes/areas that came up during the interview:

Overall feelings after interview:

Things I could work on/do differently next time:

Appendix 7: Code development

Examples of the development of semantic and latent codes from raw study data

Study participant and line: Rudi, line 276

Quote: “It was degrading that time because I had to be wheeled to the toilet and so that sort of stuff was hard to cope with...and so I do tend to crash and burn emotionally as most people probably tend to do because things are just taken from you”

Semantic data codes: feelings of degradation, hard to cope, crash and burn emotionally, RRMS takes from you

Latent data codes: Losses from RRMS, despair, negotiating normalcy and disability, fear of progression/disability, seeds of resilience

Study participant and line: Susan line 788

Quote:” I remember how I was trying to be strong...that I think it didn’t help me because it delayed my grieving...it delayed me dealing with it because I was trying to be strong for Mum and Dad...just you know, accept it, embrace it, because it doesn’t mean the end...and I then looked at it, you know, it was a new beginning for me and how I had to look at it.

Semantic data: trying to be strong for others, delayed grieving, accepting the diagnosis, new beginnings

Latent data: how others see me, maintaining independence, impact of RRMS on parenting, accepting gains, worry about being a burden to family, purposeful positivity, optimism, searching for meaning

Appendix 8 : Thematic map

Thematic map development

Theme example 1: Searching for answers (original title when still a candidate theme, later became Piecing Together the Puzzle)

What's going on → Lead up symptoms what could it be?

↕

I need an answer

↕

Seeing doctors → brushed off, go away, nothing's wrong with you

↕

More doctors → brushed off

↕

Tests

↕

More tests → No answers → I need an answer

→Answers

↕

Whose fault?

↘

I have a diagnosis

↕

What now?

↘

Is MS causing what I feel?

↘

Triggers, reasons

Who do I tell? And how?

Theme example 2: Imposter to the throne (original title when still a candidate theme, later became High Invisibility)

Quest to be normal
This is good
No-one can see, no-one suspects
I don't want to look disabled to others



Benefits- what's good about invisible symptoms?

Disclosure, keep secrets
Normal- I look normal
I can fit in better
I'm in charge



Imposter to the throne
Invisible symptoms
Things you can't see



The push/pull of symptoms- the good and the bad



What's bad about invisible symptoms?

Frustration
Lack of understanding
Relationship tolls
Family burdens
Hard to explain
Brush-offs
Centre of attention
"imposter"

PARTICIPANT INFORMATION SHEET

What is the Experience of Living with Relapsing Remitting Multiple Sclerosis?

Dear

You are invited to participate in the research project described below.

What is the project about?

This research project will explore your experiences of living with Relapsing Remitting Multiple Sclerosis (RRMS) in today's world. There have been many recent advances in RRMS treatment and science over the last decade, but very little information for Multiple Sclerosis (MS) Nurses and other health care professionals (HCPs) working in the field of MS, about what the experience of living with MS is like for the patient. This research study aims to understand your experiences and the impact that RRMS has on your life, with the ultimate goal of providing more individualised, holistic, patient focused care to people diagnosed with RRMS.

By sharing your experiences of living with RRMS, you may be helping people working in MS care to have a richer understanding of what it feels like to be living with this condition.

Who is undertaking the project?

This project is being conducted by Therese Burke and will form the basis for a higher degree by research at The University of Notre Dame Australia, under the supervision of Associate Professor Tracey Moroney and Associate Professor Joanna Patching in the School of Nursing, Sydney, NSW.

What will I be asked to do?

If you consent to take part in this research study, it is important that you understand the purpose of the study and the tasks you will be asked to complete. Please make sure that you ask any questions you may have, and that all your questions have been answered to your satisfaction before you agree to participate.

You will be asked to participate in a one-on-one interview with the researcher, and possibly further follow-up interviews or telephone interviews, if they are needed **and** if you are happy to participate further. One interview may provide enough information. The interview/s will be audio taped to assist the researcher with capturing all of the important information you provide and will not be used for any other purpose. It is anticipated that the interview/s will take approximately 1-2 hours and will take place at a mutually convenient location.

The question you will be asked to respond to will revolve around the experiences you have had in your life in relation to living with RRMS – “What is the Experience of Living with

Relapsing Remitting Multiple Sclerosis?" You will be provided with some reflection questions prior to the interview to think about and you may or may not choose to use them to help you get your thoughts in order prior to the interview.

There will be no reimbursement to you for taking part in the research study.

Are there any risks associated with participating in this project?

It is possible that you may experience some level of anxiety or distress during the session as a result of talking about your experiences of living with RRMS. You will be monitored closely during the interview and you are free to withdraw at any time during the session, or to stop the session to have a break at any time you need to. If these feelings persist after the completion of the session, arrangements will be made for you to access support from an experienced counselor at no expense to you.

What are the benefits of the research project?

There may be no immediate benefits to you by taking part in this research project. General benefits to the wider MS community are not yet known, but may possibly include an improved understanding of the experiences of people living with RRMS to others in the MS community.

What if I change my mind?

Participation in this study is completely voluntary. Even if you agree to participate, you can withdraw from the study at any time without discrimination or prejudice. If you withdraw, all information you have provided will be erased and removed from the study findings where possible. You may stop or suspend the interview at any time and for any reason. Withdrawal from the study will not affect your ongoing treatment with your MS medical team or any potential future care from the researchers.

Will anyone else know the results of the project?

Information gathered about you will be held in strict confidence. This confidence will only be broken if required by law. Only the researchers will have access to your data, which will be coded after the interview to remove your real name in order to protect your identity. All data related to you will be known by a pseudonym (a pretend name) and special features about your case that may identify you (such as suburb, specific occupation and the like) will be generalised so that you cannot be individually identified. The audiotapes and the written data (transcripts) will be stored securely and electronic data will be stored on a password-protected computer with all identifying information removed ("de-identified").

Once the study is completed, the data collected from you will remain de-identified and stored securely with the researcher for at least a period of fifteen years, as directed by current NSW laws. The results of the study will be published as a thesis, and for the purposes of education, may be presented in the form of journal articles and presentations at medical and nursing educational meetings in Australia and overseas. Your privacy will be protected by continuing use of the pseudonym and protection of your case features throughout these various publications and presentations.

Will I be able to find out the results of the project?

Once we have analysed the information from this study, the researcher, Therese Burke, will contact you by mail or email with a summary of the study findings. You can expect to receive this feedback in about 1-2 years. If you do not wish to receive information about the study findings, please let the researcher know.

Who do I contact if I have questions about the project?

If you have any questions about this project please feel free to contact either the researcher, Therese Burke on phone number 0412 365 667 or email: therese.burke2@my.nd.edu.au or the study Supervisors, Associate Professor Tracey Moroney, on email tracey.moroney@nd.edu.au or Associate Professor Joanna Patching on email joanna.patching@nd.edu.au. The researcher and Supervisors are happy to discuss with you any concerns you may have about this study.

What if I have a concern or complaint?

The study has been approved by the Human Research Ethics Committee at The University of Notre Dame Australia (approval number 016002S). If you have a concern or complaint regarding the ethical conduct of this research project and would like to speak to an independent person, please contact Notre Dame's Ethics Officer at (+61 8) 9433 0943 or research@nd.edu.au. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

How do I sign up to participate?

If you are happy to participate, please sign both copies of the consent form, keep one for yourself and mail the other to the researcher in the envelope provided. The researcher will then contact you to organise further details.

Thank you for your time. This sheet is for you to keep.

Yours sincerely,

Therese Burke RN CNC MSCN

Associate Professor Tracey Moroney

Associate Professor Joanna Patching



CONSENT FORM

What is the Experience of Living with Relapsing Remitting Multiple Sclerosis?

- I agree to take part in this research project.
- I have read the Information Sheet provided and been given a full explanation of the purpose of this study, the procedures involved and of what is expected of me.
- I understand that I will be asked to attend an interview/s with the researcher, Therese Burke, and I will be asked questions about my experience living with RRMS. The interview will be audio-taped only for the purpose of the researcher transcribing the interview to analyse my responses to better understand my experiences.
- The researcher has answered all my questions and has explained possible problems that may arise as a result of my participation in this study.
- I understand that I may withdraw from participating in the project at any time without prejudice.
- I understand that all information provided by me is treated as confidential and will not be released by the researcher to a third party unless required to do so by law.
- I agree that any research data gathered for the study may be published provided my name or other identifying information is not disclosed.
- I understand that research data gathered may be used for future research but

Name of participant			
Signature of participant		Date	

my name and other identifying information will be removed.

- I confirm that I have provided the Information Sheet concerning this research project to the above participant, explained what participating involves and have answered all questions asked of me.

Signature of Researcher		Date	
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POST INTERVIEW CARE

If you feel any distress after we finish the interview and you would like to talk to someone else about it, please let me know on the contact details listed below. I can put you in touch with a counsellor who is experienced in MS care or refer you to a psychologist for further management. Alternatively you can see your GP to discuss further and they can assess to see if you would benefit from a mental health care plan.

Therese Burke

Mobile: 0412 365 667

Email: therese.burke@sydney.edu.au

If you feel suicidal or extreme distress, please present to your closest emergency department for access to a mental health emergency team.

Questions to ask myself and comments to remind myself of, prior to each interview

Before interviews:

1. How am I presenting myself physically to the study participants?
2. I need to be aware of my tendency to problem solve, and instead, just listen and let the study participant direct the interview. Probe when necessary to obtain more information or to delve deeper about living with RRMS.
3. I am not the clinical MS Nurse in this situation. I am a researcher listening to a PwRRMS describe their experiences and then asking questions to better understand the lived experience of RRMS. That's it. No clinical care.
4. These participants are not my friends and not my children. I am empathic, but I don't have to take their struggles on as my own. I need to "feel" the data but not have it overtake my analysis emotionally. I need to firmly ground in the data. I have an important job to do for the participant here.
5. Don't assume anything, always ask for clarification and further explanation (if and when appropriate).

After interviews:

1. How did the interview proceed? Was there a natural flow? Did I overtake the conversation too much?
2. Was I able to step away from my clinical role and fulfill the position of researcher/listener?
3. What can I do better in next time?

Appendix 12 : Diary excerpt

Diary excerpt from reflexive journal: Participant interview/feelings related

Date: 27th May 2016, home NSW

Context: I had just completed the interview and writing the field notes for participant number 3, Kate.

Quote from diary: I had lots of feelings after this interview, which I just discussed with JP (Supervisor). I felt changed forever. I am not sure if this was in recognition of Kate's work as a scientist and my "fan-like" view of her achievements or as a fellow mother with her absolute dedication to her career whilst still having a strong bond with her child. I felt I learnt life lessons from her in resilience, reaching for your dreams and pushing on.

I felt sorry that she was clearly pushed out of her job when she had significant things to contribute. Did they base this decision on her physical disabilities and assume her mind was following? Did she display some cognitive signs not apparent to her, but to others? (I am recalling the literature and how PwRRMS may not read facial cues etc) Were there other, unrelated reasons?

Diary excerpt from reflexive journal: Methodology/method related

Date: 23rd June 2017, Balmoral NSW

Context: Pondering nursing core values

Quote from diary: "What is the essence of nursing? What makes us nurses? What makes us a "good" nurse and is a "good" nurse defined differently by other nurses than a patient would define a "good nurse"?"

What makes patient insights and understandings more valuable?

Why should people care what a nurse thinks?

Do patients care what we, as nurses, think?

I downloaded 8-10 articles to review, looking at nursing, core values, social justice and the like to help me come up with a statement that I could use in my Methodology chapter- under nurses and ethnography/qualitative research.

"This study is inspired by patient focused, holistic care and is rooted in the nursing values/core beliefs of honesty, empathy and understanding".

Appendix 13: Life journey and themes

13a. Margot's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<i>Child of a migrant family fleeing revolution</i> <i>Multicultural issues</i> <i>University graduate</i> <i>Two children</i>
Onset of first symptoms prior to diagnosis- injury from sudden fall	Piecing Together the Puzzle (what's happening?)
	High (In)visibility (strive to be visible)
	Surplus Suffering (brushed off)
Symptoms remain and reinvestigated by GP	Piecing Together the Puzzle (what's happening?, tests, tests, tests)
	Battling the Demons (fear, worry & anxiety)
	Taming the Beast (support from family, friends and community)
	High (In)visibility (strive to be visible)
	Taming the Beast (support from family, friends and community)
Confirmed diagnosis of RRMS	Piecing Together the Puzzle (the day my life changed forever, vivid recall, relief, disclosing, with-holding disclosure)
	Holding Hands with Hope (purposeful positivity, optimism)
	Taming the Beast (support from family, friends and community, resilience)
	Battling the Demons (fear, worry & anxiety)
	Re(defining) Me now that I have RRMS (getting acquainted, normalcy, working out work, losses & gains, parenting with RRMS)
Commenced Betaferon®	The DMT Dance (hardyards: decisions based on hope)
	Taming the Beast (support from family, friends and community)
	Re(defining) Me now that I have RRMS (getting acquainted)
Stopped Betaferon® commenced Tysabri®	The DMT Dance (hardyards: decisions based on hope)
	Taming the Beast (support from family, friends and community)

	Re(defining) Me now that I have RRMS (getting acquainted, dare to compare)
	Holding Hands with Hope (restorative hope, purposeful positivity, searching for meaning)
Learning to live with RRMS	Re(defining) Me now that I have RRMS (dare to compare, parenting with RRMS, negotiating normalcy)
	Battling the Demons (all fears, worry & anxiety, uncertainty)
	Piecing Together the Puzzle (with-holding disclosure)
	Battling the Demons (fear of the wheelchair)
Travelling around the world	Taming the Beast (finding my North Star, maintaining health & wellness, getting a handle, resilience)
	Re(defining) Me now that I have RRMS (normalcy)
	Battling the Demons (fear of the wheelchair)
Keeping RRMS secret from parents	Piecing Together the Puzzle (with-holding disclosure)
	Battling the Demons (fear of the wheelchair)
	Holding Hands with Hope (defiant hope, functional hope, search for meaning)
	High (In)visibility (welcome cloak)
Disclosing to parents	Piecing Together the Puzzle (disclosure)
	Holding Hands with Hope (defiant hope, functional hope, search for meaning)
	Re(defining) Me now that I have RRMS (normalcy)
	Battling the Demons (fear, worry, saboteurs, uncertainty)
Struggling with disability and loss of mobility, carpark stories	Re(defining) Me now that I have RRMS (normalcy, dare to compare, losses & gains)
	Battling the Demons (fear of the wheelchair, worry, saboteurs, uncertainty, I'm never free, social isolation)
	High (In)visibility (strive to be visible, reverse stigma)
	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness)
Retiring from work	Re(defining) Me now that I have RRMS (normalcy, working out work, losses & gains)
	Holding Hands with Hope (purposeful positivity, functional hope, search for meaning, sense of humour)
Life gets busy living with RRMS	Re(defining) Me now that I have RRMS (normalcy, losses & gains, parenting with RRMS)
	Holding Hands with Hope (purposeful positivity, defiant hope, search for meaning, sense of humour)

Surrendering to wheelchair when travelling or fatigued	Re(defining) Me now that I have RRMS (dare to compare, normalcy, losses & gains)
	Taming the Beast (support from family, friends and community, maintaining health & wellness, resilience)
	Holding Hands with Hope (purposeful positivity, functional hope, search for meaning, sense of humour)
Moving forward with RRMS	Taming the Beast (support from family, friends and community, maintaining health & wellness, resilience)
	Re(defining) Me now that I have RRMS (getting acquainted, normalcy)
	Holding Hands with Hope (, purposeful positivity, optimism, sense of humour, giving back and getting involved)

13b. Kate's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<i>Child of a migrant family Studying forensic work Working with sick children Married with a baby, working full time and studying</i>
Onset of first symptoms – sudden blindness	Piecing Together the Puzzle (what's happening? Tests tests tests)
	High (In)visibility (strive to be visible)
Told it could be a brain tumour	Battling the Demons (fear, worry & anxiety, uncertainty)
	Taming the Beast (support from family, friends and community)
Not a brain tumour, but no other diagnosis - symptoms worsen- repeated episodes of blindness come and go over several years	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
	Piecing Together the Puzzle (what's happening?)-repeated
	Surplus Suffering (brushed off)- repeated
	Piecing Together the Puzzle (tests, tests, tests)- repeated
	High (In)visibility (strive to be visible)
Consults a neurologist- it <i>may</i> be MS	Piecing Together the Puzzle (the day my life changed forever)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
	Taming the Beast (support from family, friends and community)

	Surplus Suffering inflicted by clinical care and by brush-off
Prescribed antidepressants “to get over it”	Battling the Demons (worry & anxiety, depression & despair, fear of disability and the wheelchair)
	Surplus Suffering inflicted by clinical care and by brush-off
New specialist- works out possible connection between scar infection and symptoms- stop antidepressants, start treatment, still no confirmed diagnosis	Piecing Together the Puzzle (what’s happening? Tests tests tests)
	High (In)visibility (strive to be visible)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
	Taming the Beast (getting a handle, choosing my A-Team, resilience)
	Holding Hands with Hope (restorative hope, purposeful positivity, optimism, faith from mother)
Infection scar extracted, thereafter a long period of remission	Taming the Beast (finding my North Star, maintaining health & wellness, getting a handle, resilience)
	Holding Hands with Hope (defiant hope, functional hope, search for meaning)
Continuing to study, work, parent	Battling the Demons (all fears, worry, uncertainty)
	Taming the Beast (finding my North Star, maintaining health & wellness, getting a handle, resilience)
Symptoms return, start methotrexate (unconventional treatment to suppress immune system) and many courses of steroids	The DMT Dance (hardyards: decisions based on hope)
	Holding Hands with Hope (restorative hope, purposeful positivity, optimism)
	Battling the Demons (all fears, worry & anxiety, uncertainty)
First MRI to show active lesions, now confirmed diagnosis of RRMS, nondisclosure to son	Piecing Together the Puzzle (the day my life changed forever, with-holding disclosure)
	Re(defining) Me now that I have RRMS (getting acquainted, negotiating normalcy, parenting with RRMS)
	Battling the Demons (fear of burden, worry & anxiety, fear of the wheelchair)
	Holding Hands with Hope (restorative hope, purposeful

	positivity- searching for meaning)
	The DMT Dance (hardyards: decisions based on hope)
Learning to live with RRMS	Re(defining) Me now that I have RRMS (dare to compare, parenting with RRMS, negotiating normalcy)
	Battling the Demons (all fears, worry & anxiety, despair, uncertainty)
	High (In)visibility (strive to be visible)
	The DMT Dance (hardyards: decisions based on hope)
	Battling the Demons (fear of the wheelchair)
	Taming the Beast (support from family, friends and community, finding my North Star, maintaining health & wellness, getting a handle, resilience)
Chance opportunity to meet initial neurologist and cause of Surplus Suffering	High (In)visibility (strive to be visible)
	Holding Hands with Hope (defiant hope, search for meaning)
	Re(defining) Me now that I have RRMS (getting acquainted)
	Taming the Beast (finding my North Star)
	Battling the Demons (fear, despair, saboteurs)
Commence new DMT Betaferon® when it comes onto the Australian market	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
	Re(defining) Me now that I have RRMS (getting acquainted)
	Holding Hands with Hope (purposeful positivity, restorative hope, functional hope, defiant hope, search for meaning)
	Taming the Beast (getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
Struggling with side effects Betaferon®	Piecing Together the Puzzle (what's happening?)
	Holding Hands with Hope (defiant hope, functional hope, search for meaning)
	High (In)visibility (strive to be visible)
Decision to stop all DMT	Taming the Beast (getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
	Battling the Demons (despair, uncertainty, social isolation, I'm never free)
	Holding Hands with Hope (defiant hope, search for meaning)

Referral to new neurologist, commence Copaxone®	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
	Holding Hands with Hope (purposeful positivity, restorative hope, functional hope, defiant hope, search for meaning)
	Battling the Demons (uncertainty, I'm never free)
Still relapsing regularly on treatment	Battling the Demons (all fears, worry & anxiety, despair, I'm never free, uncertainty)
	Taming the Beast (getting a handle on RRMS, maintaining health & wellness)
Change to Rebif® when it comes onto the Australian market	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
	Holding Hands with Hope (purposeful positivity, restorative hope, functional hope, defiant hope, search for meaning)
Rebif® side effects unbearable but continues treatment and tries to hide symptoms	Battling the Demons (uncertainty, I'm never free)
	High (In)visibility (welcome cloak)
	Holding Hands with Hope (purposeful positivity, optimism)
	Re(defining) Me now that I have RRMS (balancing losses & gains, parenting with RRMS)
	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness)
Decision to stop Rebif®	Battling the Demons (all fears, worry & anxiety, saboteurs)
	Re(defining) Me now that I have RRMS (normalcy, parenting with RRMS, losses & gains)
Tysabri® opportunity	Holding Hands with Hope (purposeful positivity, optimism, restorative hope, functional hope)
	Re(defining) Me now that I have RRMS (normalcy, parenting with RRMS, losses & gains)
	Taming the Beast (getting a handle on RRMS, finding my North Star)
	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
Anaphylaxis to Tysabri®	Battling the Demons (all fears, worry & anxiety, despair, I'm never free)
	Re(defining) Me now that I have RRMS (normalcy, losses & gains)
Volunteers for research trial- back to	Holding Hands with Hope (purposeful positivity, defiant

interferon treatment Betaferon®	hope, search for meaning, giving back & getting involved)
	Taming the Beast (support from family, friends and community, finding my North Star, choosing my A-Team)
Remission from relapses for four years	Holding Hands with Hope (purposeful positivity, defiant hope)
	Re(defining) Me now that I have RRMS (normalcy, parenting with RRMS, losses & gains)
Fall and injury: mobility affected	Battling the Demons (all fears, worry & anxiety, despair, I'm never free)
	Re(defining) Me now that I have RRMS (normalcy, losses & gains)
	Taming the Beast (support from family, friends and community, finding my North Star)
Faces losing career & employment: symptoms from fall and MS make work difficult and then employer makes the decision and stops funding	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness)
	Re(defining) Me now that I have RRMS (dare to compare, normalcy, losses & gains)
	Battling the Demons (all fears, worry, despair, I'm never free, uncertainty, social isolation)
Living in forced retirement and coping with RRMS, now on Gilenya® as DMT	Holding Hands with Hope (purposeful positivity, defiant hope, search for meaning, sense of humour)
	Re(defining) Me now that I have RRMS (dare to compare, normalcy, parenting with RRMS, losses & gains)
	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
Advocates for others with MS	Holding Hands with Hope (purposeful positivity, defiant hope, search for meaning, sense of humour, giving back & getting involved)
	Taming the Beast (finding my North Star)
	Re(defining) Me now that I have RRMS (dare to compare, normalcy, losses & gains)

13c. Rudi's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • <i>Tumultuous childhood</i> • <i>Mother lives with bipolar disorder</i> • <i>Rebellious teens</i> • <i>Small rural community upbringing</i> • <i>Stillbirth of her third son at full-term</i>
Onset of first symptoms	Piecing Together the Puzzle (what's happening?)
	High (In)visibility (strive to be visible)
	Surplus Suffering (brushed off)
Symptoms worsen	Piecing Together the Puzzle (what's happening?)
	Surplus Suffering (brushed off, misdiagnosis)
	Piecing Together the Puzzle (tests, tests, tests)
	Battling the Demons (fear, worry & anxiety)
	Holding Hands with Hope (purposeful positivity)
Hospitalised into intensive care	Battling the Demons (all fears, worry & anxiety, despair, uncertainty)
	Piecing Together the Puzzle (what's happening? tests, tests, tests)
Confirmed diagnosis of RRMS after waiting for several weeks	Piecing Together the Puzzle (the day my life changed forever)
	Re(defining) Me now that I have RRMS (getting acquainted)
	Battling the Demons (fear of burden, worry & anxiety)
Learning to live with RRMS	Re(defining) Me now that I have RRMS (getting acquainted, dare to compare, normalcy)
	Battling the Demons (all fears, worry & anxiety, despair)
	High (In)visibility (strive to be visible)
	The DMT Dance (hardyards: decisions based on hope)
	Battling the Demons (fear of the wheelchair)
	Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, search for meaning)
	Taming the Beast (support from family, friends and community, resilience, choosing my A-Team, finding my North Star)
Severe relapse	Piecing Together the Puzzle (what's happening?)
	Battling the Demons (fear, worry & anxiety, saboteurs: social isolation, uncertainty)
	High (In)visibility (strive to be visible)
	The DMT Dance (hardyards: decisions based on fear <i>and</i>

	hope)
Recovery from relapse	Taming the Beast (support from family, friends and community, resilience)
	Re(defining) Me now that I have RRMS (getting acquainted, dare to compare)
Relapse	Piecing Together the Puzzle (what's happening?)
	Battling the Demons (all fears, worry & anxiety, uncertainty, parenting with RRMS)
	The DMT Dance (decisions based on fear <i>and</i> hope)
	Re(defining) Me now that I have RRMS (working out work)
Anxiety in children, especially daughter	Battling the Demons (all fears, worry & anxiety, uncertainty, parenting with RRMS)
	Taming the Beast (support from family, friends and community, resilience, choosing my A-Team)
	Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, search for meaning)
MS condition worsens and advised to stop working to recover	Re(defining) Me now that I have RRMS (working out work, normalcy, balancing losses & gains)
	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, finding my A-Team)
	Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, restorative hope)
	Battling the Demons (fear of being a burden, fear of the wheelchair)
	The DMT Dance (hardyards: decisions based on fear <i>and</i> hope)
Start Gilenya®	The DMT Dance: switching to a better life)
	Taming the Beast (resilience)
Stop Gilenya® due to skin cancers developing	The DMT Dance (hardyards: decisions based on fear)
	Holding Hands with Hope (purposeful positivity)
	The DMT Dance (decisions based on fear)
	Taming the Beast (resilience, maintaining health & wellness)
	Re(defining) Me now that I have RRMS (balancing losses & gains)
	Battling the Demons (fear, worry, I'm never free)
Starts travelling, trips away, playing sport	Taming the Beast (resilience, maintaining health & wellness, finding my North Star)

	Holding Hands with Hope (purposeful positivity, optimism)
Life parenting with RRMS	Taming the Beast (support from family, friends and community)
	Holding Hands with Hope (purposeful positivity, optimism, harnessing sense of humour)
	Battling the Demons (fear of being a burden, worry)
	Re(defining) Me now that I have RRMS (balancing losses & gains, parenting with RRMS, working out work)
Change of DMT to Tecfidera®	The DMT Dance (hardyards: decisions based on fear & hope)
	Holding Hands with Hope (purposeful positivity, optimism)
	Re(defining) Me now that I have RRMS (getting acquainted)
Further severe relapse	Piecing Together the Puzzle (what's happening? tests, tests, tests)
	Battling the Demons (fear of being a burden, worry, I'm never free, uncertainty)
	Taming the Beast (support from family, friends and community, maintaining health & wellness)
	The DMT Dance (hardyards: decisions based on fear & hope)
Trying to regain a sense of self	Holding Hands with Hope (purposeful positivity, optimism, giving back & getting involved, functional hope, restorative hope, defiant hope)
	Taming the Beast (support from family, friends and community, maintaining health & wellness, resilience)

13d. Joy's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • Neglect as a child • Constant illness and pain as a child and teen • Married and baby at 18 years of age • Divorced twice, two children • Multiple life challenges • Raised in a small rural town
Onset of first neurological symptoms – dyslexia at age 16	Piecing Together the Puzzle (what's happening?)
	High (In)visibility (strive to be visible)
Ignored, brushed off by family and school	Battling the Demons (fear, worry, despair uncertainty)
	Piecing Together the Puzzle (what's happening?)-repeated

	Surplus Suffering (brushed off)- <i>repeated</i>
	High (In)visibility (strive to be visible)
	Holding Hands with Hope (restorative hope, purposeful positivity, optimism, faith)
Drop out from school, pregnant the next year, married at age 18	Surplus Suffering (brushed off)
	Battling the Demons (fear, worry, despair uncertainty)
	High Invisibility (strive to be visible)
Sudden episode of intermittent blindness	Battling the Demons (fear, worry, despair uncertainty)
	High (In)visibility (strive to be visible)
	Surplus Suffering (brushed off)
	Piecing Together the Puzzle (what's happening?)- <i>repeated</i>
Difficult birth, further symptoms not investigated	Surplus Suffering (brushed off)
	High (In)visibility (strive to be visible)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
	Taming the Beast (resilience)
(Non related to RRMS) post partum complications	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
Sudden onset deafness	Surplus Suffering (brushed off)
	High (In)visibility (strive to be visible)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
	Piecing Together the Puzzle (what's happening?)- <i>repeated</i>
Sudden onset leg weakness	Surplus Suffering (brushed off)
	High (In)visibility (strive to be visible)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
Marriage breakdown	Battling the Demons (worry, despair, uncertainty, social isolation)
New relationship begins, intermittent neurological symptoms persist	Holding Hands with Hope (restorative hope, purposeful positivity, optimism, faith from mother)
	High (In)visibility (strive to be visible)
	Surplus Suffering (brushed off)
	Taming the Beast (support from family, friends and community, resilience)

Second child arrives, breakdown of relationship ensues	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
	Holding Hands with Hope (restorative hope, purposeful positivity, optimism, faith)
Remission from neurological symptoms, only fatigue remained	Taming the Beast (getting a handle, resilience)
	Holding Hands with Hope (purposeful positivity, optimism, faith)
	Battling the Demons (uncertainty)
Symptoms, nerve pain returns with a vengeance	Piecing Together the Puzzle (what's happening?)-repeated
	High (In)visibility (strive to be visible)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
Begins relationship with and marries a HCP who organises referral to a neurologist	Piecing Together the Puzzle (what's happening; tests, tests, tests)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
Diagnosed formally with RRMS	Piecing Together the Puzzle (the day my life changes forever; relief at the diagnosis, vivid recall)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
	Re(defining) Me now that I have RRMS (getting acquainted, normalcy, parenting with RRMS, losses & gains, working out work)
Begins treatment for nerve pain and also DMT glatiramer acetate	Holding Hands with Hope (restorative hope, purposeful positivity, optimism, faith)
	Taming the Beast (support from family, friends and community, finding my North Star, maintaining health & wellness, getting a handle, resilience)
	High (In)visibility (strive to be visible)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty, I'm never free)
	The DMT Dance (hardyards: decisions based on hope)
Husband becomes abusive, won't allow sick-leave with relapse, forces medication overdosage and toxicity	Battling the Demons (fear, worry, despair, uncertainty, I'm never free, social isolation)
	Surplus Suffering (inflicted by family)

	Re(defining) Me now that I have RRMS (normalcy, losses & gains, working out work)
Husband dies, collapsing on top of her and trapping Joy, she survives...Joy decides to take control	Holding Hands with Hope (restorative hope, functional hope, defiant hope, purposeful positivity, optimism, faith, search for meaning)
	Battling the Demons (all fears, worry & anxiety, uncertainty)
	Re(defining) Me now that I have RRMS (dare to compare, parenting with RRMS, negotiating normalcy)
	Taming the Beast (support from family, friends and community, finding my North Star, maintaining health & wellness, getting a handle, resilience)
Sees a new neurologist	Holding Hands with Hope (restorative hope, purposeful positivity, optimism)
	Re(defining) Me now that I have RRMS (dare to compare)
	Taming the Beast (getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
Diagnosed with co-morbidity complex partial epilepsy, neurologist unsure of cross-over between the two neurological diseases, begins treatment but remains off DMT since Copaxone by choice	Piecing Together the Puzzle (the day my life changes forever; relief at the diagnosis, vivid recall)
	Battling the Demons (fear of burden, worry & anxiety, fear of the wheelchair)
	Re(defining) Me now that I have RRMS (dare to compare, parenting with RRMS, negotiating normalcy)
	Holding Hands with Hope (restorative hope, functional hope, defiant hope, purposeful positivity, optimism, search for meaning)
Offered Tysabri® DMT by neurologist but politely refuses	The DMT Dance (hardyards: decisions based on hope; switching to a better life)
	Battling the Demons (fear of burden, worry)
	Holding Hands with Hope (restorative hope, purposeful positivity, searching for meaning, faith)
Begins to improve, remission from relapses, travels overseas for the first time	Re(defining) Me now that I have RRMS (dare to compare, normalcy)
	Taming the Beast (support from family, friends and

	community, finding my North Star, maintaining health & wellness, getting a handle, resilience)
	Battling the Demons (uncertainty)
Gains employment in a community/counselling environment, and thrives	Taming the Beast (support from family, friends and community, finding my North Star, resilience, choosing my A-Team)
	Holding Hands with Hope (defiant hope, search for meaning)
	Re(defining) Me now that I have RRMS (normalcy, working out work, losses & gains)
	High (In)visibility (welcome cloak)
Neurologist retires, new young neurologist takes an interest in the case and revisiting investigations	Re(defining) Me now that I have RRMS (dare to compare, normalcy, losses & gains)
	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
	Holding Hands with Hope (purposeful positivity, defiant hope, search for meaning, sense of humour, giving back & getting involved)
Advocates for others with MS, thriving being a grandmother, working and living well with RRMS	Holding Hands with Hope (purposeful positivity, defiant hope, search for meaning, sense of humour, giving back & getting involved)
	Taming the Beast (finding my North Star)
	Re(defining) Me now that I have RRMS (normalcy, losses & gains)

13e. Jane's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • <i>University degree</i> • <i>Very active and fit</i> • <i>Unmarried</i> • <i>World traveller, remote locations, adventurer</i> • <i>Works in education</i> • <i>No prior medical conditions</i>
Onset of first symptoms – visual disturbance and headache	Piecing Together the Puzzle (what's happening? Tests, tests, tests)
	Battling the Demons (fear)
Told possible brain tumour	Piecing Together the Puzzle (what's happening? Tests, tests, tests)

	tests)
	Surplus Suffering (misdiagnosis)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
	Taming the Beast (maintaining health & wellness)
No diagnosis, continues on with intermittent symptoms	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
New symptoms- referral to neurologist	Piecing together the Puzzle (what's happening? Tests, tests, tests)
	Taming the Beast (support from family, friends and community, choosing my A-Team)
	High (In)visibility (strive to make visible)
Diagnosis of RRMS	Piecing Together the Puzzle (the day my life changed forever, relief at diagnosis, disclosure, with-hold disclosure)
	Battling the Demons (fear of wheelchair, fear of disability, worry & anxiety)
	Re(defining) Me now that I have RRMS (getting acquainted, working out work, normalcy)
Decision not to have DMT at first	Re(defining) Me now that I have RRMS (getting acquainted, working out work, dare to compare, normalcy,)
	Battling the Demons (all fears, worry & anxiety)
	High (In)visibility (welcome cloak, hide)
Living well with RRMS, raising money for MS research	Battling the Demons (uncertainty)
	Re(defining) Me now that I have RRMS (getting acquainted, working out work, normalcy)
	High (In)visibility (welcome cloak, hide)
	Holding Hands with Hope (defiant hope, giving back & getting involved)
Inconsideration by MS event organisers	Surplus Suffering (inflicted by community)
	High (In)visibility (strive to make visible)
	Piecing together the Puzzle (what's happening?)
Going to MSL groups to meet others living with MS	Re(defining) Me now that I have RRMS (getting acquainted, dare to compare, normalcy)
	Holding Hands with Hope (defiant hope, giving back & getting involved)
	Taming the Beast (finding my North Star, choosing my A-Team)

	Battling the Demons (fear of disability, of the wheelchair, worry, despair, uncertainty)
	High (In)visibility (strive to make visible)
Further relapses, decision to start Rebif®	The DMT Dance (hardyards: decisions based on hope)
	Holding Hands with Hope (restorative hope, restorative hope)
	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
	High (In)visibility (welcome cloak, hide)
Continuing to work, not disclosing diagnosis	Piecing Together the Puzzle (with-hold disclosure)
	Battling the Demons (worry, uncertainty)
	Taming the Beast (getting a handle on RRMS, finding my North Star, maintaining health & wellness)
	High (In)visibility (welcome cloak, hide)
Issues taking DMT Rebif®	Re(defining) Me now that I have RRMS (working out work, losses & gains)
	Battling the Demons (worry & anxiety, despair, uncertainty, social isolation)
	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
Change to Gilenya®	Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, optimism)
	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
	High (In)visibility (welcome cloak, hide)
	Re(defining) Me now that I have RRMS, losses & gains, normalcy)
Masters degree at university	Holding Hands with Hope (purposeful positivity, defiant hope, optimism)
	Re(defining) Me now that I have RRMS, losses & gains, normalcy)
	Taming the Beast (getting a handle on RRMS, finding my North Star, resilience)
Fear of losing contract at work is RRMS disclosed	Battling the Demons (worry & anxiety, I'm never free, uncertainty)
	Re(defining) Me now that I have RRMS (balancing losses & gains, dare to compare, normalcy)

Belief in future living with RRMS	Holding Hands with Hope (purposeful positivity, curative hope, searching for meaning)
	High (In)visibility (welcome cloak, hide)
	Re(defining) Me now that I have RRMS (normalcy, working out work, losses and gains)
	Taming the Beast (resilience, getting a handle, finding my North Star, choosing my A-Team, support from family, friends and community, health & wellness)

13f. Paul’s life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • University degree • Very active and fit • Unmarried • World traveller, remote locations, adventurer • Works in education
Onset of first symptoms five years before diagnosis – optic neuritis	Piecing Together the Puzzle (what’s happening? Tests, tests, tests)
	Battling the Demons (fear)
	High (In)visibility (welcome cloak, hide)
	Surplus Suffering (misdiagnosis, brushed off)
Living well, no symptoms	Taming the Beast (maintaining health & wellness)
Two years later neck sensations– in hindsight, L’hermittes	Piecing Together the Puzzle (what’s happening? Tests, tests, tests)
	High (In)visibility (strive to make visible, welcome cloak, hide)
	Surplus Suffering (misdiagnosis, brushed off)
Onset cognitive “cloud”	High (In)visibility (strive to make visible)
	Battling the Demons (all fears, worry & anxiety)
	Taming the Beast (support from family, friends and community, choosing my A-Team)
GP refers to a neurologist	Piecing Together the Puzzle (what’s happening?, Tests,tests,tests)
	Battling the Demons (all fears, worry & anxiety)
	High (In)visibility (strive to make visible)
Diagnosis of RRMS and referred to another neurologist with more MS experience, awaiting appointment	Piecing Together the Puzzle (the day my life changed forever, with-hold disclosure)

	High Invisibility (welcome cloak, hide)
	Re(defining) Me now that I have RRMS (getting acquainted, working out work, dare to compare, normalcy, parenting with RRMS)
	Battling the Demons (fear of burden, worry & anxiety, despair, saboteurs, uncertainty)
Panic attack shortly after diagnosis, new symptoms	Piecing Together the Puzzle (what's happening?)
	Battling the Demons (worry & anxiety, despair, uncertainty)
	Re(defining) Me now that I have RRMS (knowledge, dare to compare)
Coincidental meeting with third neurologist- unsure of role- enters clinical trial without explanation, starts fingolimod	Surplus Suffering (inflicted by research care, brushed off)
	Re(defining) Me now that I have RRMS (getting acquainted)
	Piecing Together the Puzzle (what's happening?)
Learning to live with RRMS	Battling the Demons (all fears, worry & anxiety, depression & despair, uncertainty)
	High (In)visibility (welcome cloak, hide)
	The DMT Dance (hardyards: decisions based on hope)
	Holding Hands with Hope (defiant hope, giving back & getting involved)
	Taming the Beast (finding my North Star, choosing my A-Team)
	Piecing Together the Puzzle (with-hold disclosure)
Meets new neurologist, life turns, confidence rises	Holding Hands with Hope (defiant hope, restorative hope)
	The DMT Dance (hardyards: decisions based on hope)
	Taming the Beast (Finding my North Star, my A-Team)
	High (In)visibility (welcome cloak, hide)
Well and relapse free on fingolimod	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, choosing my A-Team)
	Piecing Together the Puzzle (with-hold disclosure)
	Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, curative hope searching for meaning)
	Re(defining) Me now that I have RRMS (working out work, parenting with RRMS balancing losses & gains)

MSA meetings and meeting others with MS- confronting, chooses never to do this again	Battling the Demons (fear of disability, of the wheelchair, worry & anxiety, despair, uncertainty, social isolation)
	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star)
	High (In)visibility (welcome cloak, hide)
	Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, curative hope)
	Re(defining) Me now that I have RRMS (balancing losses & gains, dare to compare, normalcy)
Constant research and reading – I want a more efficacious treatment	Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, curative hope, optimism, searching for meaning)
	Re(defining) Me now that I have RRMS, losses & gains, dare to compare, normalcy, parenting with RRMS)
	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
	Battling the Demons (fear, worry & anxiety)
	Taming the Beast (resilience, choosing my A-Team)
New MRI lesion- radiological relapse	Battling the Demons (fear of the wheelchair & disability, worry & anxiety, I'm never free, uncertainty)
	Re(defining) Me now that I have RRMS (balancing losses & gains, dare to compare, normalcy)
	Piecing Together the Puzzle (what's happening?)
	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
	High (In)visibility (welcome cloak, hide)
	Holding Hands with Hope (purposeful positivity, defiant hope, searching for meaning)
Fighting on, awaiting appointment with a new neurologist to hopefully escalate treatment (his current neurologist prefers not to)	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
	Re(defining) Me now that I have RRMS (negotiating normalcy, disability and independence, working out work, balancing losses and gains, parenting with RRMS)
	Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, curative hope, optimism, searching for meaning)

	Taming the Beast (resilience, getting a handle, finding my North Star, choosing my A-Team)
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13g. Ruby's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
Earlier life story: major life events and clues to resilience	<ul style="list-style-type: none"> • Child of a migrant family • University degree • Long distance relationship • Working in education • Married with two children, working full time
Onset of first symptoms	Piecing Together the Puzzle (what's happening? Tests tests tests)
	Surplus Suffering (brushed off)
	Battling the Demons (fear, worry & anxiety, uncertainty)
Consults a neurologist- it <i>may</i> be MS but not conclusive, told not to worry and to go away and have a family	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
	Piecing Together the Puzzle (what's happening?)
	Surplus Suffering (brushed off)
Has two children, continues to work	Holding Hands with Hope (restorative hope, purposeful positivity, optimism, defiant hope)
	Re(defining) Me now that I have (<i>may have</i>) RRMS (dare to compare, parenting with RRMS, normalcy)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
Severe relapse – reported to neurologist by phone and posted a prescription for steroids, no consultation	Surplus Suffering (brushed off)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
I can't pick up my baby	Re(defining) Me now that I have RRMS (dare to compare, parenting with RRMS, normalcy)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
Referral to new neurologist and MS Clinic	Piecing Together the Puzzle (tests, tests, tests, the day my life changed forever)
	Battling the Demons (fear, worry & anxiety, despair,

	uncertainty I'm never free)
	Taming the Beast (finding my North Star, maintaining health & wellness, getting a handle, resilience)
	Re(defining) Me now that I have RRMS (dare to compare, parenting with RRMS, normalcy, working out work, getting acquainted)
	The DMT Dance (hardyards: decisions based on hope)
	Holding Hands with Hope (restorative hope, purposeful positivity, optimism)
Commenced Tysabri®	The DMT Dance (hardyards: decisions based on hope)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty)
	Holding Hands with Hope (restorative hope, purposeful positivity, optimism)
	Taming the Beast (getting a handle, choosing my A-Team, resilience)
	Re(defining) Me now that I have RRMS (dare to compare, normalcy, getting acquainted)
Continues to worsen on Tysabri® and now losing ambulatory function	Battling the Demons (fear, worry & anxiety, despair, uncertainty, social isolation, I'm never free)
	Re(defining) Me now that I have RRMS (dare to compare, parenting with RRMS, normalcy, working out work, getting acquainted)
	Piecing Together the Puzzle (what's happening?)
Continuing to work, parent	Taming the Beast (finding my North Star, maintaining health & wellness, getting a handle, resilience)
	The DMT Dance (hardyards: decisions based on hope)
	Battling the Demons (fears, worry, uncertainty)
Decision to stop Tysabri® and change to Lemtrada® - guilt from not starting Lemtrada® earlier	The DMT Dance (hardyards: decisions based on fear, switching to a better life)
	Battling the Demons (fear, worry & anxiety, despair, uncertainty, I'm never free)
	Re(defining) Me now that I have RRMS (dare to compare, parenting with RRMS, normalcy, getting acquainted)
	Taming the Beast (finding my North Star, getting a handle, resilience)
	Holding Hands with Hope (restorative hope, functional hope, purposeful positivity, optimism)

	Piecing Together the Puzzle (what's happening?)
Fall at work in front of others	Re(defining) Me now that I have RRMS (dare to compare, working out work, normalcy)
	Piecing Together the Puzzle (what's happening?)
	Battling the Demons (fear, uncertainty, I'm never free)
Life in limbo awaiting to see if Lemtrada® has been effective	Piecing Together the Puzzle (what's happening?)
	Re(defining) Me now that I have RRMS (dare to compare, parenting with RRMS, normalcy, working out work)
	Battling the Demons (all fears, worry & anxiety, despair, uncertainty, I'm never free)
	Holding Hands with Hope (defiant hope, restorative hope, functional hope, defiant hope, search for meaning)
	Taming the Beast (support from family, friends and community, finding my North Star, maintaining health & wellness, getting a handle, choosing my A-Team, resilience)
	The DMT Dance (hardyards: decisions based on hope)
Decision to work part-time next year and concentrate of regaining strength and adoring her children	Holding Hands with Hope (defiant hope, restorative hope, functional hope, defiant hope, search for meaning)
	Taming the Beast (support from family, friends and community, finding my North Star, maintaining health & wellness, getting a handle, resilience)

13h. Davina's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • Felt vulnerable with father growing up (bullied), felt isolated • Unwell often as a child • Physically and emotionally demanding employment • Working in healthcare • Marries early at 20 years of age
Onset of first symptoms – visual disturbances – brushed off by GP	Piecing Together the Puzzle (what's happening?)
	High (In)visibility (strive to be visible)
	Surplus Suffering (brushed off)
	Battling the Demons (fear, worry & anxiety)
Symptoms worsen – sees a different	Piecing Together the Puzzle (what's happening?, tests, tests,

GP	tests)
	Surplus Suffering (brushed off)
	Holding Hands with Hope (purposeful positivity)
	Battling the Demons (all fears (uncle with MS), worry & anxiety)
Further relapse- sudden and severe - hospitalised, it could be MS	Surplus Suffering (inflicted by clinical care)
	Battling the Demons (all fears, worry & anxiety, depression & despair, uncertainty, social isolation)
	Holding Hands with Hope (purposeful positivity)
Confirmed diagnosis of RRMS – traumatic diagnosis delivery	Piecing Together the Puzzle (the day my life changed forever)
	Re(defining) Me now that I have RRMS (getting acquainted, normalcy, working our work, dare to compare)
	Battling the Demons (fear of burden, wheelchair, disability)
	Surplus Suffering (inflicted by clinical care)
Learning to live with RRMS	Re(defining) Me now that I have RRMS (getting acquainted, dare to compare, parenting with RRMS)
	Battling the Demons (all fears, worry & anxiety, despair)
	High (In)visibility (strive to be visible)
Changes neurologist	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, finding my A-Team)
	Re(defining) Me now that I have RRMS (getting acquainted, dare to compare, normalcy)
Regaining control, starting family	Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, search for meaning)
	Re(defining) Me now that I have RRMS (working out work)
	Taming the Beast (support from family (mother only) friends and community)
	Battling the Demons (all fears, worry & anxiety)
	High (In)visibility (strive to be visible)
Further relapses and temporary loss of function managing a young family of four children including newborn twins	Taming the Beast (support from family (mother only) friends and community, resilience, finding my North Star, choosing my A-Team)
	Battling the Demons (all fears, worry & anxiety, uncertainty, I'm never free, social isolation)
	Piecing Together the Puzzle (what's happening?)

	High (In)visibility (strive to be visible)
Starts interferon Avonex® when released onto Australian market, continues many years	The DMT Dance (hardyards: decisions based on hope)
	Re(defining) Me now that I have RRMS (balancing losses & gains, parenting with RRMS)
	Battling the Demons (all fears, worry & anxiety)
	Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, restorative hope, optimism)
Continues on managing family and worklife through several relapses	Taming the Beast (support from family, friends and community, getting a handle on RRMS, finding my North Star, maintaining health & wellness, finding my A-Team)
	Holding Hands with Hope (purposeful positivity, defiant hope, functional hope, restorative hope, optimism)
	Battling the Demons (all fears, worry & anxiety)
	High (In)visibility (strive to be visible)
Death of much loved and supportive mother	Battling the Demons (all fears, worry, depression & despair, uncertainty)
	Re(defining) Me now that I have RRMS (balancing losses & gains, normalcy, parenting with RRMS)
	Holding Hands with Hope (purposeful positivity)
	Taming the Beast (resilience)
Seeks help from a psychologist, diagnosed with depression, refuses medication but accepts counselling	Battling the Demons (all fears, worry, depression & despair, uncertainty, I'm never free)
	Holding Hands with Hope (purposeful positivity, optimism)
	Taming the Beast (support from family, friends and community, finding my North Star, maintaining health & wellness, choosing my A-Team)
Leaves marriage	Battling the Demons (all fears, worry, depression & despair, uncertainty)
	Taming the Beast (support from family, friends and community, finding my North Star, maintaining health & wellness, choosing my A-Team)
	Holding Hands with Hope (purposeful positivity, optimism, faith, sense of humour)
Meets new life partner, feels loved, supported Children grown up and moved on	Taming the Beast (support from family, friends and community, finding my North Star, maintaining health & wellness, choosing my A-Team)

	Holding Hands with Hope (purposeful positivity, optimism, defiant hope)
	Battling the Demons (fear of being a burden)
Lack of support from family with new life	Re(defining) Me now that I have RRMS (balancing losses & gains, parenting with RRMS)
	Battling the Demons (all fears, worry, depression & despair, uncertainty)
	Holding Hands with Hope (purposeful positivity, optimism, defiant hope)
Change of DMT to Gilenya®	The DMT Dance (decisions based on fear & hope)
	Holding Hands with Hope (purposeful positivity, optimism, restorative hope)
	Re(defining) Me now that I have RRMS (getting acquainted)
	Battling the Demons (all fears, worry & anxiety)
	Holding Hands with Hope (purposeful positivity, optimism, defiant hope)
	Taming the Beast (support from family, friends and community, resilience)
Life settles with RRMS- current status quo	Holding Hands with Hope (optimism, giving back and getting involved, faith)
	Taming the Beast (support from family, friends and community, maintaining health & wellness, finding my North Star)

13i. Evie's life journey reflecting the study themes and subthemes

Life events	Links to study findings: themes and subthemes
<i>Earlier life story: major life events and clues to resilience</i>	<ul style="list-style-type: none"> • Significant childhood illness • Felt bullied at primary school, "left out" • Alcoholic, abusive father, loving and supportive mother • Later parental divorce • Estranged from only sibling • Same sex relationships • (Secretive) government career
Onset of first symptoms at 18 years of age	Piecing Together the Puzzle (what's happening?)
	High (In)visibility (strive to be visible)
	Surplus Suffering (brushed off)

Symptoms worsen – still no diagnosis	Piecing Together the Puzzle (what’s happening?, tests, tests, tests)
	Battling the Demons (fear, worry)
	High (In)visibility (strive to be visible)
	Taming the Beast (resilience)
Finally after two years, MRI confirms RRMS	Piecing Together the Puzzle (the day my life changed forever)
	Holding Hands with Hope (purposeful positivity, optimism)
	Re(defining) Me now that I have RRMS (getting acquainted, negotiating normalcy)
	Taming the Beast (choosing my A-Team)
Accepted diagnosis, moving on, but those around fall apart	Piecing Together the Puzzle (what’s happening?)
	Re(defining) Me now that I have RRMS (getting acquainted, negotiating normalcy)
	Taming the Beast (finding my North Star, maintaining health & wellness, getting a handle, resilience)
I don’t jump in, I choose to be positive	Holding Hands with Hope (purposeful positivity, optimism, defiant hope, sense of humour, spirituality, searching for meaning)
	Re(defining) Me now that I have RRMS (getting acquainted, negotiating normalcy, working out work, losses & gains)
	High (In)visibility (welcome cloak)
Commences interferon Rebif®	The DMT Dance (hardyards: decisions based on hope)
	Battling the Demons (fear, worry)
	Re(defining) Me now that I have RRMS (getting acquainted, losses & gains)
	Holding Hands with Hope (restorative hope, functional hope, purposeful positivity, optimism)
Intolerable side effects from Rebif®, missed doses and then cease medication altogether	Battling the Demons (worry, uncertainty)
	Re(defining) Me now that I have RRMS (normalcy)
	High (In)visibility (strive to be visible)
Relapses increase	The DMT Dance (hardyards: decisions based on hope)
	Re(defining) Me now that I have RRMS (dare to compare, normalcy, getting acquainted)
	Battling the Demons (all fears, worry, I’m never free, uncertainty)

Constant life stressors persist	Battling the Demons (all fears, worry, despair, uncertainty)
	High (In)visibility (strive to be visible)
	Taming the Beast (finding my North Star, maintaining health & wellness, getting a handle, resilience)
	Re(defining) Me now that I have RRMS (getting acquainted, normalcy)
	Holding Hands with Hope (defiant hope, search for meaning, spirituality)
Commences Betaferon®	Battling the Demons (all fears, worry, uncertainty)
	Holding Hands with Hope (defiant hope, functional hope)
	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
Enjoying career but previous disclosure at work induces collision between work and personal space	Re(defining) Me now that I have RRMS (getting acquainted, normalcy, working put work, dare to compare, losses & gains)
	High (In)visibility (welcome cloak)
Further relapses, change of treatment to Tysabri®, remains relapse free and well for several years	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
	Holding Hands with Hope (defiant hope, functional hope, restorative hope)
	Taming the Beast (support from family, friends and community, finding my North Star, choosing my A-Team)
	Re(defining) Me now that I have RRMS (getting acquainted)
JCV blood tests positive high titre- ceases Tysabri® immediately	The DMT Dance (hardyards: decisions based on fear)
	Battling the Demons (fear, worry, I'm never free, uncertainty)
	Taming the Beast (getting a handle on RRMS, finding my North Star, maintaining health & wellness)
Commences Tecfidera®	The DMT Dance (hardyards: decisions based on hope, switching to a better (safer) life))
	Re(defining) Me now that I have RRMS (normalcy)
	Battling the Demons (all fears, worry & anxiety, uncertainty)
Side effects from Tecfidera® – cease	The DMT Dance (hardyards: decisions based on hope, switching to a better (safer) life))
	Taming the Beast (getting a handle on RRMS, finding my North Star, maintaining health & wellness)
Decision to commence Lemtrada®	Holding Hands with Hope (purposeful positivity, defiant hope, search for meaning, spirituality)

	The DMT Dance (hardyards: decisions based on hope, switching to a better life)
	Taming the Beast (support from family, friends and community, maintaining health & wellness, resilience)
	Re(defining) Me now that I have RRMS (losses & gains)
	Battling the Demons (all fears, worry, uncertainty)
Relationship breakdown with partner – RRMS blamed by partner	Battling the Demons (all fears, uncertainty)
	Piecing Together the Puzzle (what's happening?)
	Re(defining) Me now that I have RRMS (losses & gains, normalcy)
	High (In)visibility (strive to be visible)
	The DMT Dance (hardyards: decisions based on hope)
	Taming the Beast (support from family, friends & community, resilience)
	Holding Hands with Hope (purposeful positivity, functional hope, restorative hope)
Moving forward with RRMS and advocacy work	Taming the Beast (support from family, friends and community, maintaining health & wellness, resilience, finding my North Star, choosing my A-Team)
	Holding Hands with Hope (purposeful positivity, optimism, giving back and getting involved, spirituality)
	Re(defining) Me now that I have RRMS (getting acquainted, normalcy, losses & gains, working out work)