

# “Taming the Beast”: Exploring the Lived Experience of Relapsing Remitting Multiple Sclerosis Using a Life History Approach

Therese Burke, RN, MSCN, PhD

*School of Nursing, The University of Notre Dame, Sydney, Australia*

Steve Vucic, MBBS, FRACP, PhD

*Faculty of Medicine, The University of Sydney, Sydney, Australia*

Joanna Patching, RN, BA (Psych), MLitt (Psych), PhD

*School of Nursing, The University of Notre Dame, Sydney, Australia*

**Background and Purpose:** The aim of this study was to gain insights and understanding into the lived experience of relapsing remitting multiple sclerosis (RRMS) in order to better inform patient-centered nursing and healthcare. **Methods:** This qualitative study used life history methodology, a form of focused ethnography, to explore the life history of 13 study participants living with RRMS. Semi-structured interviews were transcribed and analysed using thematic analysis. **Findings:** A total of eight key themes emerged, explaining the journey of living with RRMS. Commencing with “Piecing Together the Puzzle” of symptoms at the beginning of the RRMS journey, followed by “(Re)defining ME now that I have RRMS,” “Battling the Demons,” the experiences of “Surplus Suffering,” negotiating “High Invisibility,” gaining control by “Taming the Beast,” learning “The DMT Dance,” and ultimately “Holding Hands with Hope,” expressing hope and practising purposeful positivity. **Implications for Practice:** The eight key themes of living with RRMS were reflective of the ebbs and flows of life. By gaining these insights into the world of people living with RRMS, it is anticipated that clinical nursing care and quality of life for people living with this chronic neurological disease may be improved.

**Keywords:** relapsing remitting multiple sclerosis; lived experience; life history

**M**ultiple sclerosis (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 is relapsing remitting MS (RRMS) affecting 85% of people living with the disease, but there are other subtypes of the disease where progression of disease occurs after a number of years of living with RRMS, or no relapses occur at all (Compston & Coles, 2008). Typically in RRMS, people recover from a relapse and return to their usual function over a period of weeks, but recovery can be uncertain, variable, and incomplete (Sorensen, 2014). RRMS was chosen as the focus subtype of MS for this study for two reasons. As well as being the most common form of MS, RRMS also strikes in the prime of life as a young adult and as a chronic, incurable illness, lasts a lifetime. This makes it ideal to study along the life trajectory. Additionally, there is no cure for RRMS, however the prevention of relapses by using "disease-modifying therapy" (DMT) may reduce future neurological disability (Kalincik, 2015). There are very few treatments available for the progressive forms of the disease (Giovannoni et al., 2016). RRMS is characterized by a complicated array of symptoms, which may affect sensory function, motor function, vision, gait, cognition, mood, bladder, bowel, and sexual function among many others (Ben-Zacharia, 2011). RRMS can occur at any age, but most commonly between 18 and 40 years (Compston & Coles, 2008), with a female preponderance of 3:1 (Koch-Henriksen & Sørensen, 2010). Nurses and other healthcare professionals (HCPs) may come into contact with people living with RRMS (PwRRMS) in many settings; at the time of MS investigation, diagnosis, or relapse, during maternity care, for the period of another illness or in community health.

## AIMS OF THE STUDY

The purpose of this research study was to gain insights and understanding into the lived experience of RRMS, aiming to produce a rich account of the lived experience of RRMS. By gaining such insights, nurses caring for PwRRMS will have a deeper understanding of the patient experience to help guide them in more holistic and patient-centered care. The aim of the study was to understand the lived experience of this chronic illness from the patient perspective and to hear the patient voice, which is so rarely heard.

## LITERATURE REVIEW

Although there exists an abundance of literature examining different aspects of MS and MS symptoms, there is a paucity of literature which explores the whole life experience of living with RRMS. Several seminal studies explored the lived experience of MS, but did not disclose the type of MS included in the study (Clair, 2003; Courts, Buchanan, & Werstlein, 2004; Hainsworth, 1994) or else used

groups of mixed MS types (Barker-Collo, Cartwright, & Read, 2006; Malcomson, Lowe-Strong, & Dunwoody, 2008), making it challenging to assess transferability of findings to specific circumstances.

Miller (1997) was one of the first to explore the lived experience of RRMS, interviewing 10 participants attending MS clinics in the United States, using interpretative phenomenological analysis 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. This seminal study is the most similar to the current study, however it is important to note that Miller's study took place before DMTs were available to treat relapses, unlike the current study. More recently, a qualitative study explored the experience of six young female adults living with RRMS and found that RRMS involves uncertainty, is frustrating to live with, is scary, and is always in the backdrop of life (Beshears, 2010). No studies using life history exploring the whole life experience of RRMS were identified in the literature search.

## METHODOLOGY

The qualitative research paradigm was chosen to gain a greater understanding of the lived experience of RRMS, with the goal of describing and interpreting phenomena as perceived by the study participants (Holloway & Wheeler, 2013). The ontological and epistemological views of the study were based in constructivism, the researcher and the study participant co-creating knowledge together. Ethnography methodology was chosen to involve key informants representing the culture under study, discussing their lives so that others can better understand the culture (De Chesnay, 2014). This study used a particular form of focused ethnography, called life history, to explore a retrospective account of each participant's life. Participants were encouraged to tell their life histories in any way they wished, with an emphasis on their journey with RRMS.

## METHODS

### SAMPLE

Study participants were purposively recruited using a flyer provided to a local state based MS patient organization in New South Wales, Australia (MS Australia). The inclusion criteria required participants to be over the age of 18 years, diagnosed by a physician with RRMS, to be ambulant and to speak and understand English. A total of 14 expressions of interest were received, with 13 people enrolled into the study; one person declined to take part without giving a reason. The sample consisted of 10 female and three male participants, a mean age of 41 years and a mean time of 12 years since diagnosis. Participants were from diverse communities and social backgrounds. Study demographics are shown in Table 1.

**TABLE 1. Study Demographics for Enrolled Study Participants**

Study Number	Pseudonym	Gender	Age at Interview	Marital Status	Years Since RRMS Diagnosis
01	Piper	F	38	m	2
02	Margot	F	57	m	16
03	Kate	F	46	m	24
04	Rudi	F	40	m	4
05	Joy	F	57	d	12
06	Jane	F	42	s	10
07	Paul	M	38	m	2
08	Ruby	F	36	m	4
09	Will	M	32	m	4
10	Griff	M	62	m	10
11	Susan	F	40	m	14
12	Davina	F	54	m	32
13	Evie	F	39	s	20

*Note.* d = divorced; F = female; M = male, age is in years; m = married; RRMS = relapsing remitting multiple sclerosis; s = single.

### ETHICAL CONSIDERATIONS

Ethical approval for the study was granted by the University of Notre Dame, Australia, HREC under a full ethical review process (HREC approval number: 016002S). Informed consent was obtained prior to study-related activities. Pseudonyms were used to protect participant confidentiality. Counselling options, although not needed, were put in place in case the life history interviews induced distress in participants.

### DATA COLLECTION

Reflection questions were provided to participants before semi-structured, one-on-one, audio-recorded interviews took place, in a venue chosen by each participant. Participants were asked to tell their life history with particular attention to the question "What is the experience of living with RRMS?" and could commence their story at any stage. Recorded interviews were transcribed verbatim by the Principal Investigator (PI), Therese Burke (TB). Field notes recorded observations from the interviews.

### DATA ANALYSIS

Thematic analysis, as described extensively by Braun and Clarke (2006, 2013) was used to identify patterns within the dataset. This systematic and robust method of data analysis allowed inductive, semantic, and latent interpretations of the study data. Fundamentally the method involved familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes,

and producing a report. The method was followed directly as recommended by Braun and Clarke (2006, 2013).

## OPERATIONAL FRAMEWORK

The operational framework for the study is shown in Figure 1. The framework demonstrates the important links between the qualitative paradigm, ontology, epistemology, methodology, and methods involved in the research process, and was based on recommendations by Carter and Little (2007). Study rigor was enhanced by the use of a reflexive diary, systematic data analysis, peer debriefing of themes, thick and rich descriptions of the phenomena and the addition of direct quotes from study participants to support the study findings. Data collection ceased after 13 participant interviews, as there was an extensive amount of data (over 2,000 codes generated) and was deemed by the researchers to possess significant “information power” to answer the research question, as recommended by Malterud, Siersma, and Guassora (2016).

## STUDY FINDINGS AND DISCUSSION

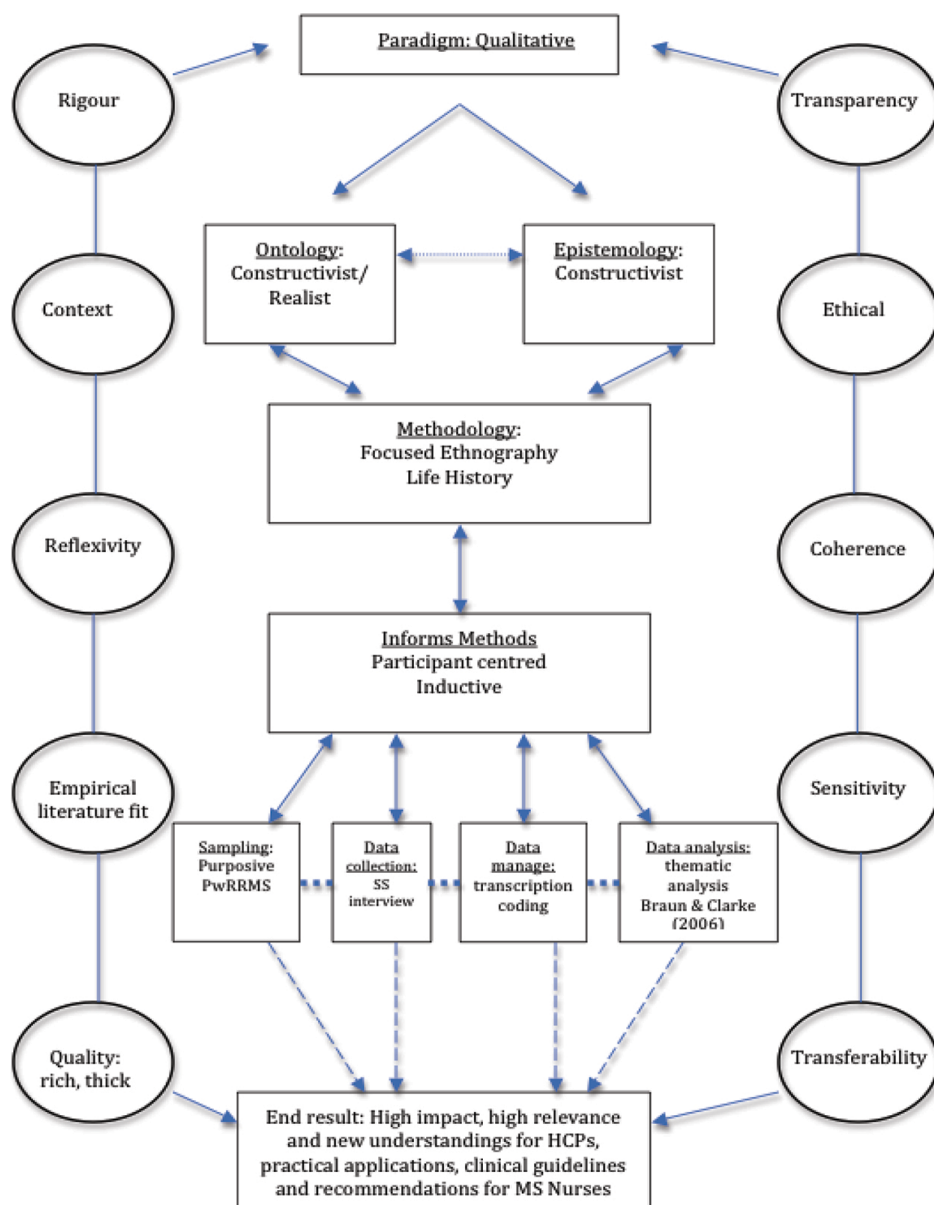
### PART I: “WALKING THE LOW ROAD”

“Walking the Low Road” tells the story of the first symptoms of RRMS and the months and years afterward adjusting to the diagnosis. There were five key themes and many subthemes identified, however, only the key themes will be reported here as the full findings are beyond the scope of this article. Each theme possesses its own central organizing concept as outlined in Table 2, a key component of anchoring the themes in the data as recommended by Braun and Clarke (2006, 2013).

**Theme 1: “Piecing Together the Puzzle.”** The diagnosis of MS is challenging and there may be poor awareness of MS by family doctors (Hinton & Kirk, 2015). In the current study, almost all participants faced challenges communicating with various HCPs, along their journey to the diagnosis of RRMS. Participants were often trying to make sense of intermittent and vague symptoms, with previous research reporting that people with MS (PwMS) may have trouble differentiating MS symptoms from routine ailments, making it difficult to know when to go to the doctor (Moriya & Suzuki, 2011). “Pieces of the puzzle” were the clues that something was amiss. Some participants experienced long periods of remission after the first symptoms disappeared, with no obvious connection between the various symptoms.

I had L’hermitte’s (an electric shock like symptom) . . . it only lasted a couple of days . . . but it was a really funny feeling . . . a couple of years later I had optic neuritis and it (my vision) just went completely white . . . he (doctor) said it was probably a virus. (Paul)

Almost half of the participants in the current study described feeling “brushed off” in their encounters with HCPs in the lead-up to a diagnosis of RRMS, meaning



**Figure 1.** 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.

that they disclosed their symptoms, but weren't taken seriously or investigated further. Piper describes suffering for many years struggling with her unexplained and undiagnosed symptoms.

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 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. (Piper)

**TABLE 2. Summary of Key Themes and Central Organizing Concepts From the Study Data in Walking the Low Road**

Theme	Central Organizing Concept
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.
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.
3. Battling the Demons	The battle with negative or difficult emotions that can get in the way of life enjoyment, threaten vulnerability, and steal away joy.
4. Surplus Suffering	Suffering over and above that imposed by the diagnosis and disease state of RRMS, and often inflicted by others.
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.

*Note.* RRMS = relapsing remitting multiple sclerosis.

For several participants in the current study, recalling the day they formally received their diagnosis of RRMS was fraught with emotional distress. It has been reported that the day of MS diagnosis can be recalled by PwMS with a great deal of emotion and detail (Solari et al., 2014). The manner in which the diagnosis itself was delivered caused utter devastation for Kate, clearly recalling the encounter over 20 years later.

The first thing he (neurologist) 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 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?” . . . I was a mess. (Kate)

Some participants felt a sense of relief after receiving their diagnosis of RRMS. “Downward comparisons” are common in the lead-up to a diagnosis of MS and happen when patients compare themselves favorably with the lives of others whom they believe to be worse off than themselves (Taylor, 1983).

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 . . . it was a relief . . . thank goodness it wasn’t MND. (Margot)

**Theme 2: “(Re)defining Me Now that I Have RRMS.”** In the time immediately following a RRMS diagnosis, study participants were determined to find out as much as possible about RRMS however, many questions remained unanswered. For those newly diagnosed with RRMS, trying to negotiate millions of MS related websites and work out what was helpful was extremely difficult. For some study participants such as Paul, there was a struggle in deciding whether to engage with, or to avoid the world of MS. This has been reported in previous work by Dennison, Moss-Morris, Silber, Galea, and Chalder (2010), as whether to engage or avoid “the cripple club.”

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 . . . I wanted to go and see . . . this sounds really terrible, but it was a comfort thing . . . well, I'm alright. (Paul)

It has been reported that mothers also experience loss related to their ability to fully engage in their children's lives due to MS (Tetley, Willson, Lloyd, Messmer Uccelli, & Mackian, 2017). In the current study this was expressed by Griff, who struggled with his sons observing him exhausted with fatigue.

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)

**Theme 3: “Battling the Demons.”** For the purpose of this study, “demons” were conceptualized as negative emotions, sometimes very strong emotions, threatening the livelihood of PwRRMS. Often PwRRMS never felt free, even when clinically things were in quiescence, there's potentially always something lurking beneath the surface. The mere thought of MS can strike fear in people, even without any knowledge of the disease (Lysandropoulos, Havrdova, & ParadigMS Group, 2015 ). When confronted with a diagnosis of RRMS, many study participants imagined life in a wheelchair.

The worst case scenario is I will be in a wheelchair . . . and that will be a very, very black day for me . . . 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)

In the current study some participants worried about themselves, but just as often they worried about their loved ones and how RRMS was affecting others. For Rudi, her children witnessing her last severe relapse has been a constant cause of worry.

[When my last relapse happened] the children were hysterical . . . the kids, so they were in tears . . . 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. (Rudi)



For people living with MS the lifetime prevalence rate of a depressive disorder has been reported as greater than 50% (Hoang, Laursen, Stenager, & Stenager, 2016). After her first MS society meeting, Jane met several young people living with significant disability and came away feeling worse.

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)

Social isolation has been reported to be a risk factor for suicide (Pompili, 2012). Living with RRMS, the daily grind of social isolation could be a constant saboteur to mental health and Griff felt this on a daily basis.

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. (Griff)

**Theme 4: "Surplus Suffering."** "Surplus Suffering" as a concept in healthcare was first described by James and Clarke (2001) and has been conceptualized in further work as suffering over and above an initial event or illness (Clarke, 2012; Clarke, 2013; Clarke & Fletcher, 2005; Clarke & van Amerom, 2007). In the current study of people living with RRMS, Surplus Suffering was present in several forms and often perpetuated by HCPs or loved ones. For Joy, Surplus Suffering lay in the emotional pain of being ignored by medical staff, of having her neurological symptoms belittled and not investigated further.

The doctors really weren't interested, they just didn't believe me . . . they thought I was a fruit loop . . . they just thought I was crazy and they weren't remotely interested. (Joy)

Davina was admitted as an inpatient to treat an MS relapse and recalls how she felt rejected and isolated at a time of intense vulnerability.

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)

For Joy, her husband also added to her Surplus Suffering, forcing her to continue work as she battled a severe relapse, not allowing her to take unpaid sick leave 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. (Joy)

**Theme 5: "High (In)Visibility."** Balancing whether to tell or not to tell others about invisible symptoms was individual for each participant. They wished to have invisible symptoms understood, but disclosing invisible symptoms might also mean disclosing the diagnosis of RRMS. Living with chronic illness where symptoms can be invisible can raise questions of illness validity (Moore, 2013). Susan

wanted to educate her family and friends about RRMS so they could understand her difficulties.

I took a couple of girlfriends and Mum (to an MS seminar) . . . 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)

At a seminar for newly diagnosed MS patients, Griff was surprised when the mother of a severely disabled and wheelchair bound young lady came over to him and verbally "attacked" him, accusing him of not having MS. This public humiliation threatened his newfound confidence, and the emotional scars are still borne by Griff today. He felt that he was 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 . . . and in one of those wheelchairs you never really get out of . . . her Mum's with her and absolutely distraught . . . and she came over . . . 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)

## PART 2: "FINDING THE HIGH ROAD"

"Finding the High Road" for PwRRMS is taking a turn in the road for a higher path, a journey of self-discovery, of packing a personal "toolkit" to live the best life possible with RRMS, active and engaged. The three key themes making up Finding the High Road and their central organizing concepts are outlined in Table 3.

**Theme 6: "Taming the Beast."** The theme of "Taming the Beast" represents a turning point for PwRRMS, a time of positive change, sourcing the best support, sharing tips, gaining confidence, and recognizing the incredible things they have achieved since Piecing Together the Puzzle. Taming the Beast brings life firmly into the foreground, working to be a person living with RRMS, not an RRMS person.

"Finding my North Star" has a positive feel, in recognition of the qualities invoked in the participants, finding a place where both the person and RRMS can cohabit the same body. 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 view it as a gift. (Rudi)

Learning to manage health and wellbeing is 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. Many participants embraced being with others with

**TABLE 3. Summary of Themes and Central Organizing Concepts From the Study Data in Finding the High Road**

Theme	Central Organizing Concept
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
7. The DMT Dance	Negotiating and coping with the medication therapies to treat RRMS
8. Holding Hands with Hope	Hope and positivity about reaching happier times and the beginnings of acceptance of RRMS into life and how looking to the future with hope brings its own peace and rewards

*Note.* DMT = disease-modifying therapy; PwRRMS = people with relapsing remitting multiple sclerosis; RRMS = relapsing remitting multiple sclerosis.

RRMS, talking with them, sharing tips looking forward to their treatment infusions together.

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)

"Choosing my Medical A-Team" is all about the PwRRMS gaining some control in Taming the Beast by selecting members of the healthcare team to be on their side, to take charge of their own care, to make decisions about who they trust to manage RRMS.

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)

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, Verrall, Alschuler, Smith, & Ehde, 2017). The stories of past resilience in the lives of the study participants differed, but the common thread they all had was overcoming difficulty and moving forward in life. Rudi realized that her special life challenges had given resilience to shape her life today.

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)

**Theme 7: "The DMT Dance."** 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). Seemingly 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). 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). Joy elected to forego DMTs as they could not cure the disease.

I don't see any point on going on a drug that could potentially kill me . . . that's not going to cure me and when it doesn't really alleviate the symptoms. (Joy)

For other study participants, their choice of DMT, and 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. Paul argued that with an unpredictable disease such as RRMS it was better to "front load" (to take more risk at the beginning for a better outcome) and take the most effective DMT, in spite of side effects, if it possibly halted the disease.

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 don't want to be at a stage where it is something they think about. (Paul)

Almost all of the study participants had stories to tell about past unhappiness on earlier DMTs, particularly as many participants had previously been self administering injections before the newer oral and infusible medications were introduced. 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)

## **THEME 8: "HOLDING HANDS WITH HOPE."**

The theme of "Holding Hands With Hope" encompasses ideas of hope, positivity, defiance, and spirituality, giving back to others and sharing stories. Specific types of hope identified from the study participants during the interviews included functional hope (wanting to retain the ability to walk unaided), restorative hope (to be returned to the previous state of health), curative hope (hope for a cure), and defiant hope (challenging and resisting RRMS). Will and Evie discussed curative and defiant 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)

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)

A sense of purpose was evident for many participants actively engaged with being positive, which was identified as "purposeful positivity." Examples included choosing and sustaining optimism, benefit finding, searching for meaning, harnessing a sense of humor, expressing spirituality. Another strategy to inspire hope and positivity demonstrated by the participants was a willingness to give back to the MS community in some way. Evie acts as a mentor for newly diagnosed PwRRMS, adamant that she wants to show the world the positive side of RRMS and what can be achieved.

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 . . . 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)

## THE LIFE JOURNEY OF RRMS

The use of focused ethnographic life history methodology worked in skilfully with the ebbs and flows of living to reveal themes exploring the lived experience of RRMS. 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 of RRMS. By using this process, many aspects of each participant's life were uncovered which had a positive impact on their later journey with RRMS. In particular, many participants described events in childhood, which gave rise to the development of resilience. Examples included 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. 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. They tell the story of possible obstacles along the life journey with RRMS and the constant growth to find ways to Tame the Beast of RRMS.

## LIMITATIONS OF THE STUDY

As a qualitative study this data draws on a relatively small number of participants. Additionally, the study was confined to participants living in the state of New South Wales, Australia and as such, the themes may not be transferable to other geographic regions and countries. The role of the PI (TB) as an MS Nurse in clinical practice invariably influenced data interpretations during the study. A constant assessment of reflexivity throughout the study aimed to recognize these influences, however, despite these safeguards, it is likely they influenced the research findings in some way.

## CONCLUSION

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. While it is not feasible to assemble an extensive life history of every patient under clinical care, 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 the life journey with RRMS. This study explored the experiences of 13 people living with RRMS, and has outlined important areas of reflection for MS clinical nursing care, whether that be in a dedicated MS setting or in a generalist hospital or community situation where PwRRMS attend. These insights may also help inform chronic illness knowledge more generally. The day of diagnosis is vividly remembered by many PwRRMS, it is vital to be aware of just how influential the day of diagnosis can be and the considerable impact kindness and compassion from nurses can have on the life journey ahead. Nurses can also offer important advice on parenting and other future challenges and provide guidance in times of crisis. Nurses are also perfectly positioned to be aware of “fear points” on the chronic illness journey and to provide skills to navigate difficult times.

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 individualized 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 chronic illness. Nurses can provide guidance on managing invisible symptoms of chronic illness with family, friends, and work colleagues, and advise the PwRRMS how to explain invisible symptoms to others and how to ask for support. Tools for nurses to inspire and sustain hope in RRMS 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 humor, 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 element for patients to regain control of their disease.

## INTERNATIONAL IMPLICATIONS FOR PRACTICE

Patients come to clinical care from many different backgrounds and experiences. A brief discussion at the beginning of the nurse–patient relationship can assist with understanding and managing expectations and set up an honest and effective communication style for the future.

Hope and Positivity are important aspects of the chronic illness experience, not just for patients and family, but also for nurses.

Experiences of previous Surplus Suffering may impact on future care. Nurses have the ability and skills to assess for previous Surplus Suffering and to help patients to manage and heal Surplus Suffering.

In chronic illness, there are many ways for nurses to help patients to Tame the Beast. Helping patients to find resilience, to choose their medical team, to maintain physical and mental health and wellness, and to find their inner strength until they develop their own are crucial and important nursing roles.

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Correspondence regarding this article should be directed to Therese Burke, RN, MSCN, PhD, School of Nursing, University of Notre Dame, Darlington campus, 160 Oxford Street, Darlington NSW, Australia. E-mail: therese.burke2@my.nd.edu.au