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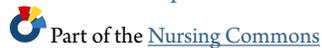
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"Taming the beast": Exploring the lived experience of relapsing remitting multiple sclerosis using a life history approach

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## **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.