

**Conductors of Care: Exploring skillsets, support and
education of Multiple Sclerosis Nurses and defining the role
in Australasia**

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Chapter 1: Introduction

Background

There has been a profound increase in MS related knowledge in recent years, leading to many advances in medicine, science, genetics, treatment and MS care in general. Alongside these advances has been the growth of the role of MS Nurse and an increase in nursing responsibilities associated with these developments. Contemporary knowledge about support and educational needs for MS Nurses in recent times has been lacking and must be explored and planned for the future in order to provide the support and education needed for professional and personal growth and safe, effective, informed and evidence-based nursing care. Additionally, a contemporary knowledge of skillsets and a definition of the MS Nurse role has been evasive, not just regionally in Australasia, but internationally as well. The role definition is needed for clarity about the nature of the work and professional responsibilities and to provide structure to career milestones and professional development.

Aims of the study

The purpose of this research was to gain the insights and understanding necessary to define the role of the MS Nurse in Australasia in 2020. Additional to this goal was to understand current sources of support and support needs, current areas of educational strength and learning needs and the current skillset of the MS Nurse. To fulfil this purpose, the study produced a rich and thick account of the lived experience of the MS Nurse. By gaining such a deep understanding of the MS Nurse role, other members of the health care team and the MS community (patients, clients, families, carers, organisations) can also appreciate how the role of the MS Nurse complements modern MS care and the niche aspects MS Nurses bring to their role. The ultimate aim of the study was for the findings to have the capability to provide direction for MS Nurses in their careers, bring clarity and focus to the MS Nurse role, improve support and education programs for MS Nurses and to promote a healthy and well supported MS Nurse community in Australasia with common, well differentiated goals.

The research questions

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

“What is the lived experience of MS Nurses in Australasia?”

Answering the research question comprehensively required asking additional questions directed in the following areas of special interest:

- What are the current sources of support for MS Nurses?
- What areas of support are needed by MS Nurses to function well in the role?
- How do MS Nurses currently receive education and learning?
- What are the current learning needs for MS Nurses?
- What is the current skillset in MS Nursing?
- How do MS Nurses define their specialty role?

Methodology

Although employing a mixed methods approach, the current research has an overarching influence from the qualitative paradigm. Using a predominately qualitative approach ensured that MS Nurses were firmly at the centre of the research process as the “knowers” of the information that was being sought. The sampling method was purposive. The study took part in two phases. Phase 1 comprised of a cross-sectional electronic, anonymous survey exploring nursing experience, job responsibilities, areas of support and support need, educational strengths, learning needs and skills required to perform the MS Nurse role. The survey consisted of a mix of quantitative responses and qualitative free text (together making it a mixed methods approach) to provide further information and thoughts. Phase 1 attracted 60 participants and was integral to inform further questioning and discussion for phase 2 of the study. Descriptive statistics and thematic analysis were used to analyse the data. Phase 2 was qualitative in style and employed one-on-one, semi structured interviews with 25 individual MS Nurses using a form of focused ethnography called life history. Thematic analysis following the recommendations of Braun & Clarke (2006, 2013) provided a systematic and robust method of data analysis; revealing five key themes, 21 subthemes and many additional findings to assist with defining the role of the MS Nurse.

Significance of the study

MS Nurses work in a dynamic and rapidly evolving area of neurology and have undergone many changes and additions in their role and responsibilities over the last decade. Locally, it has long been recognised between MS Nurses as a specialty of nursing that nurses come to hold close and remain in for a long period of time or move on from fairly quickly after commencing. There is a significant lack of recent research into the role internationally, and little local research in Australasia to support or define the importance of the role. This study aims to provide MS Nurses with the professional support they need in order to understand their function and career options and to provide structure around this complicated nursing role. It is anticipated that the study findings from support and learning needs may form the basis of new programs and mentorships to support and develop the specialty further and promote retention and job satisfaction within the workforce. Additionally, the insights provided to the wider MS community on the nature and breadth of the role may promote understanding and appreciation for the work MS Nurses do and potentially encourage partnerships and collaborations with other HCPs.

Nuances of the report

Throughout this report there will be several terms referred to in context which may require explanation to the reader.

The term “patient or patients” will be used throughout the report, but the terms “client or clients” could apply equally for MS Nurses working in community, organisational or pharmaceutical company roles and is perhaps their preferred personal term. However, the term “patient/s” will be used in this report, as this is a nursing research study and is directly related to the nurse-patient relationship and associated literature on many occasions.

The term person/people living with MS (PwMS) refers to people living with all types of MS. When referring to specific types of MS, the terms person/people living with relapsing

remitting MS (RRMS), person/people living with secondary progressive MS (SPMS) and person/people living with primary progressive MS (PPMS) will be used.

Australasia will be the term used in this study to refer to MS Nurses in Australia and New Zealand, as MS Nurses from both countries already identify as MS Nurses in the region through the peer organisation Multiple Sclerosis Nurses Australasia Incorporated (MSNA Inc).

As a primarily qualitative study, the literature referred to in the report may seem outdated compared to the more recent medical and scientific findings. Unlike scientific and quantitative work, qualitative research texts and terminology very often refer to seminal work, often decades prior, which continue to inform modern qualitative inquiry. As recommended by Braun & Clarke (2006, 2013), qualitative findings will be referred to as “some”, “several”, “most” or “all” to refer to the occurrence of themes in the data, rather than absolute numbers. This is usual accepted qualitative research practice.

Medications have both generic and trade names. In this report, if a medication name is mentioned by a participant it will be kept as referred to by them verbatim in the quotation and not altered.

Overview

The first chapter has provided an introduction to the role of the MS Nurse in Australasia and the significance of the research study. The following chapter 2 will situate the context of the study within current literature and identify gaps in knowledge. Chapter 3 will provide justification and exploration of the methodology, methods, ontology and epistemology used to underpin the study.

The findings for the study will be presented in three chapters to provide clarity and meaning to the different techniques used in the mixed methods design. Chapter 4 will provide the findings from phase 1 of the study, the cross-sectional electronic survey. Chapter 5 will present the five themes and 21 subthemes from the phase 2 semi-structured interviews and

life history analysis. Chapter 6 will discuss the additional findings from phase 2 in regard to support and learning needs for MS Nurses and several unexpected findings from the study. Completing this chapter will be a discussion of the current skillset and a definition of the MS Nurse role to summarise the three findings chapters.

Chapter 7 will conclude the report by presenting a summary of the major study findings and recommendations for clinical practice. Limitations of the research and future research directions will also be discussed.

Conclusion

This study aimed to define the role of the MS Nurse in Australasia in 2020. Using a mixed methods approach in the MS Nurse community, anonymous surveys and one-on-one semi-structured interviews were conducted to develop themes and findings to reflect and define the role of the MS Nurse. The overall finding of MS Nurses as “Conductors of Care” provides a simple insight into a role which is in fact multifaceted, complex and challenging. Chapter 2 will explore what is already known about MS nursing in the literature and introduce the significant gaps in our knowledge about the role of MS Nurses internationally.

Chapter 2- Literature review and situation of current study

As a comparatively new specialty in the field of neurology, MS care has been rapidly evolving and expanding over the last two decades. There has been unprecedented growth in the specialty, with increasing incidence and prevalence of MS (Browne et al; 2014), together with a vast volume of scientific and medical research in the field with new therapies and biomarkers (Cicarrelli, 2019). The disease course is unpredictable and uncertain (Dennison et al; 2011) and has a complex range of disease modifying drugs (DMDs) with significant side effect profiles and safety monitoring requirements (Cree, Mares & Hartung, 2019). The role of the MS Nurse has developed alongside the need for specialist nursing care in a field which has been recognised as complicated and challenging. However, research into the role of the MS Nurse has been scarce and contemporary definitions of the role of MS Nurse are significantly lacking.

This chapter will begin by providing a brief history of MS nursing, position current literature in the specialty of MS and briefly explore other nursing specialties publishing about their roles. This will be followed by a discussion on novice to expert nurses, in an effort to gain an understanding of how expert nurses develop and provide a broader context for situating the MS Nurse role and responsibilities. This chapter will conclude with a summary of the significant gaps in the literature.

MS Nurse history

Over the past century, nursing has striven to identify itself as a profession, elevating the nature of nursing work to be different from medicine, but equally deserving of professional status (Liaschenko & Peter, 2004). The role of the MS Nurse has developed since its introduction in the UK in the early 1990's to now be a well-established component of high-quality MS care (Quinn, Bowen & Leary, 2014). The founding of the International Organisation of MS Nurses (IOMSN) in 1997 was followed shortly afterwards by the Australian affiliate, now known as MS Nurses Australasia Incorporated (MSNA Inc) in 1998, commencing with a small group of members who supported each other in educational and clinical endeavours. Unfortunately, there has not been a formal register of MS Nurses kept

in Australasia in order to identify precise growth and development in the workforce. However retrospectively looking at member numbers since MSNA Inc inception, there has been a steady growth over the last 22 years, culminating in just over 100 current full and associate members in Australasia (mostly nurses but also some allied health professionals).

Attempting to identify a uniform job description for MS Nurses in order to define the role of MS Nurse is fraught with challenge. As recognised internationally, there are no clear guidelines on who can call themselves an MS Nurse, nor any accepted consensus on the training, education and skill level required (Ward-Abel et al; 2014). Additionally, the MS Nurse role has varying titles with many titles being used interchangeably, for example specialist nurse, MS Nurse specialist, MS Nurse, neurology nurse (Meehan & Doody, 2020) and MS Nurse consultant. This has led to the creation of multiple titles for positions that are likely the same job description, which in turn leads to inconsistencies in scope of practice and confusion about career progression. It is difficult to know the boundaries for each role, the job responsibilities or how similar or dissimilar the roles are between services, clinics and organisations.

From texts providing a comprehensive guide to MS care for nurses, it is well documented that MS Nurses have a challenging, complex and varied role that has changed over the last decade from a role of support to that of a highly skilled expert (Halper & Harris, 2016). Halper and Harris (2016) have identified the key domains in MS nursing as clinical practice, advocacy, education and research, with the universal tasks of MS nursing embedded in building therapeutic partnerships, performing comprehensive assessments, formulating treatment plans, initiating and maintaining treatment regimens and evaluating responses to treatment.

The MS Nurse role has expanded considerably in the last decade with the MS Nurse more involved in diagnosis, management and support of patients, playing a significant role in the management of DMDs (Meehan & Doody, 2020) and particularly in terms of adherence and persistence with medications (Burke et al, 2011). The workload has increased considerably with the introduction of each new DMD and the accompanying administration, side effect, safety and logistical monitoring required. As some of the DMD side effects can be fatal,

careful supervision is required and this often falls to the MS Nurse (Abel & Embrey, 2018). In addition, the MS Nurse is the most often consulted HCP in MS care, pivotal to assessing problems, providing advice and co-ordinating care (Mynors, Bowen & Doncaster, 2016) and the preferred source of contact by patients regarding emotional, clinical and educational support (Ward-Abel, Mutch and Huseyin, 2010). In terms of cost effectiveness, MS Nurses have been recognised as playing an important role in avoidance of emergency and hospital admissions with proactive management (Leary, Quinn & Bowen, 2015).

More recently, pressure on MS Nurses is growing as DMDs increase and monitoring becomes more complex, caseloads continue to grow and the numbers of patients increases (Leary, Mynors & Bowen, 2015). As a skilled but sparse resource, it is crucial that the MS Nurse time is managed effectively (Meehan & Doody 2020). With little insight into exactly what an MS Nurse does in their role in present times, this is challenging.

Research into the MS Nurse role

Recent research into the role of the MS Nurse is significantly lacking nationally and internationally. Corry, McKenna and Duggan (2011) employed a literature review to explore the role of the clinical nurse specialist in MS. The investigators identified three key research studies which provided insight into the role of the MS Nurse. The first (Warner et al; 2005) focused on an audit of service change in the United Kingdom (UK) and reported that MS Nurses were an important part of relapse management in MS, worked closely with neurologists and had a role to play in symptom management. The second study (Forbes et al; 2006) evaluated the introduction of MS Nurses into service areas in the UK, demonstrating a reduction in physical and symptom scales in the group with MS Nurse care. The third study (While et al; 2009) also took place in the UK and evaluated the role of the MS Nurse from the perspective of different stakeholders. This study found that practice contributions from MS Nurses revolved around specialist knowledge of the disease, emotional and psychological support, participating in a multidisciplinary team and management of relapses and symptoms.

Other factors identified by Corry et al (2011) from non-research papers identifying aspects of the nurse role in MS included MS Nurses improving patient experiences and quality of life (Harrison & Porter, 2004), MS Nurses providing a holistic link between the person living with MS and the community (Jones et al; 2000), a timely and sensitive service for MS (Shaw, 2006) and the MS Nurse as involved in educational and information roles for patients (Shaw & McMillan, 2008). The literature review highlighted the need for new research into the care MS Nurses provide and to explore how specialist knowledge, skills and expertise can be harnessed by those who require the services. However, the majority of the research into the MS Nurse role is well over a decade old, which is significant because it was in a time before modern DMDs and the additional workload and responsibilities that they have brought to the position.

A more recent report from the UK MS Trust group (Mynors, Bowen & Doncaster, 2016) updated the previous 2014 report on progress towards equitable provision for MS care to every person living with MS in the UK. The report suggests that MS specialty nurses are highly valued by PwMS, working across the whole disease trajectory, providing expert information and decision support. In addition, MS Nurses proactively case manage PwMS and respond to acute deterioration and relapses. Despite increases in the MS Nurse population, the authors noted significant variation across the UK in the caseloads of the MS Nurses. The report also highlighted the need for administrative support to enable MS Nurses to be more effective in their nursing role and skillset. Although the nursing duties and skills between MS Nurses in the UK and Australia are very similar, there are immense differences in the way that MS Nurses are allocated in the UK within clinical commissioning groups (CCGs), Health Boards and the National Health Service (NHS). Australia has no consistent allocation of services for MS Nurses to patient numbers and need, it appears to be driven by individual hospitals and clinics, MS neurologist implementation, funding opportunities and individual business case requests, with no underlying pattern or formula.

A recent report from Australia (MS Australia, 2017) was based on a project to support advocacy and lobbying efforts in the hope of increasing support and funding for specialist MS Nurses in Australia. As part of the project, the MS Nurse workforce in Australia was explored, as well as workload of the MS Nurses, service models and levels of access for

PwMS. The report found there to be a strong case for MS Nurses as a valuable source of patient support and case management nationally. The report also found that MS Nurses played an important role in improved patient acceptance of diagnosis, psychological outcomes and treatment compliance and adherence, with a strong focus on relapse management, DMD support and symptom management.

The most recent research data exploring the role of the MS Nurse is an integrative review from Meehan & Doody (2020), which explored the role of the clinical nurse specialist in MS from the perspective of patients, their families and carers (not the MS Nurses themselves). The authors report that MS Nurses are the best placed in the health care team to meet the complex, variable needs of individuals with MS, their families and carers. Themes developed through the study included the MS Nurse as a longitudinal care provider, a bespoke care provider and an expert resource for PwMS.

Specialist Nurses in general

In attempting to define the role of the MS Nurse and position the role nationally and internationally, it is important to have an understanding of the specialist nurse role in general, as other nursing specialities have preceded the MS nursing domain to create context and understanding around position and role. A specialist nurse focuses on a specific population or area of practice (McCorkell et al; 2015), taking on a leadership role and providing consistency in care (Aspinal et al, 2012). Specialist nurses initiate interventions, support self-care and co-ordinate the multiple disciplines involved in the provision of patient care (Kenny & Wilson, 2012). Often as case managers, the specialist nurse utilises their specialist knowledge of the condition, acting as a central point of contact for patients as well as other members of the multidisciplinary team (Aspinal et al; 2012; Kenny & Wilson, 2012). In addition to their unique skills, specialty nurses can also provide flexible access to care through open referral systems and arrange for patients to be seen in outpatient clinics or their own homes (Aspinal et al; 2012).

It has been suggested that patients who see a specialist nurse have more positive experiences, advice and support with key aspects including the availability of the nurse to

the patient and the ability to liaise between the patient and the medical system (Tarrant, Sinfield, Agarwal & Baker, 2008). Patients value the extra time provided by a specialist nurse and their ability to convey information into an appropriate format for them (Boxhall & Doughery, 2003). As part of the lifelong care of congenital conditions, Nugent (2019) suggests that specialist nurses may fill a key worker role in co-ordinating care, promoting continuity and ensuring the patient has a contact if needed; resulting in fewer admissions, reduced waiting times and improved access to care.

In many other fields the unique and service directed role that specialist nurses bring to the area has been discussed and recognised. The specialist nurse in transplant services provides reviews, phone support, blood monitoring (Perhar et al; 2017). Palliative care patients under the care of community specialist nurses are supported with timely responses, rapid symptom control and faster access to medications (Cooper, 2019). Epilepsy specialist nurses have been credited with improving epilepsy care and driving health care reform, negotiating change across disciplinary, managerial and organisational boundaries and demonstrating leadership (Higgins et al; 2018). In Huntington's disease the specialty nurse role is viewed as essential to patients and their carers for their disease knowledge, person and service knowledge and advice (Wilson & Aubeeluck, 2016).

In breast care, nurse specialists have been recognised as experts in evidence based practice with the ability to problem solve, reflect, analyse and think critically and possess the skills to reflect these aspects back to patients and families; functioning at a highly sophisticated level within a defined patient population (Harmer, 2018). In testicular cancer, the specialist nurse has a role in diagnosis and work-up, medication decision making, further treatments and longer-term care (Dreyer, MacFarlane & Hendry, 2018). The value of the nurse specialist in urogynaecology has been reported by patients as being professional, calm, a source of specialist knowledge, building relationships, providing information and resources and acting as a liaison for patients (Barrasin & Appleton, 2018).

In an increasingly cost driven health service, it can be difficult for specialist nurses to "prove" their worth in monetary terms with much of their work invisible and unacknowledged (Bjorkland, 2004). More recently nurse specialists have been described as

providing optimal return on investment for income generation, patient safety, cost savings and improvements in patient care and experience (Latter et al; 2019). However, there is a lack of understanding of the specialist nurse role and how these nurses support improved patient outcomes (Latter et al; 2019). The MS Australia report on MS Nurses (2017) supports the value of the MS Nurse, yet highlights the contrary funding trends that have not supported their function. This is incredibly frustrating as nursing contributes the largest sector of the healthcare workforce and the nurse's interaction with patients provides enormous potential to improve the patient experience and outcomes of care (Harmer, 2018). At present there is a profound mismatch in general between the specialist nurse workforce and the rising demand (Lawler, 2020). The area of MS nursing care is no exception.

Expert and novice nurses

In order to appreciate the specialist nurse role, there needs to be an understanding of how nurses become experts in their field and in nursing in general. This section will briefly explore concepts of the "expert nurse" in clinical practice.

The term "expert" in nursing is applied to those who seem to be knowledgeable in their profession and at the pinnacle of their career; recognising who these expert nurses are is important for the professional and personal development of early career nurses (Thornley & West, 2010). The seminal work of Patricia Benner (1982) is vital to understanding the five stages of nursing proficiency; from the initial novice, advanced beginner, competent, proficient and expert nurse and how the Dreyfus model is useful to understand each stage of development. Each component of the Dreyfus model as Benner (1982) applied it to nursing will now be discussed briefly.

The *novice* nurse has no experience in the situations they are asked to perform tasks and have not yet developed discretionary judgement. The *advanced beginner* can demonstrate marginally acceptable performance as they start to formulate guidelines for their actions. Once at the level of *competency*, typically after two to three years' experience in the job, nurses begin to see their actions in terms of long-range goals or plans and they are

characterised by a feeling of mastery. The *proficient* level nurse perceives situations as wholes and knows what to expect in a given situation and modifies plans and responses, holistically understanding a situation. At the *expert* level, the nurse has an intuitive grasp of each situation, recognises problems quickly and acts decisively, seeing a situation in its entirety.

Part of becoming an expert nurse is learning to “read” the patient, instinctively combining experience with scientific knowledge as clinical knowledge and critical thinking increases and progresses (Benner, Tanner & Chesla, 1997). Additionally, an expert nurse is characterised by engaged practical reasoning which relies on mature and practiced understanding and a perceptual grasp of similarities and differences in particular situations, being comfortable in emotional involvement with patients and their families (Benner, Tanner & Chesla, 1997). The time since Benner’s research has recognised that intuition in nursing practice exists and has been established as a source of knowledge useful in critical thinking, from novice to expert nurse (Miller & Hill, 2018). Importantly, as new nurses gain more insight and knowledge throughout their careers, they become “seasoned” nurses and mentors for the next generation (Davis & Maisano, 2016). This context is important to explore in the role of the MS Nurse in Australasia and how career milestones develop and progress in MS nursing.

The gaps in the literature

Although there has been an increase in nursing literature supporting specialist nurses generally in many different areas of practice, there is a significant lack of recent research into the role of the specialist MS Nurse in modern times. Following on from a major MS Nurse research boon exploring the role in the early to late 2000’s in the UK, the last decade has seen little progress, particularly when one considers the advances that MS care has taken, and the changes seen in clinical practice. Additionally, there is a great deal of title confusion in the MS Nurse field with many titles used interchangeably with little understanding of what they actually mean. There is also a lack of literature exploring novice to expert roles in MS nursing and how nurses could be assisted to progress through the levels and attain career milestones in the specialty.

This research study aims to define the MS Nurse role in Australasia as a way to develop key insights into the role in the current environment of heavy workloads, increasing numbers of patients, new treatment options and rapidly developing science. Although there has been recent research into the role of the MS Nurse from the perspective of patients and carers (Meehan & Doody, 2020), the advantage of the current study is that the participant population are MS Nurses themselves who are performing the role on a daily basis. It is anticipated that the study could be replicated in other regions in order to further the understanding of MS Nurses internationally. In the International Year of the Nurse and Midwife, this report also celebrates and acknowledges the role of MS Nurse in the community and the unique contribution they make to patient care and quality of life.

Chapter 3: Methodology and Methods

This chapter will discuss and justify the research paradigms chosen for the current study, the ontological and epistemological framework employed to guide the study and the overall research design and study methods. The roles of study rigour, ethical considerations and reflexivity in the current study will also be discussed.

Mixed Methods Research

Mixed methods research (MMR) is a combination of quantitative and qualitative research, providing a scientific base for practice in the quantitative elements, but also integrating the richness of qualitative enquiry (Younas et al; 2019). MMR in nursing research recognises the need in nursing to generate data from different perspectives (Doyle, 2015) but is really a hybrid collection of assumptions (Bressan et al; 2016). In this research study, the quantitative component of the study provided only a small part of the data collection and analysis in phase 1, predominately in demographics, job description and tasks, support and learning needs of MS Nurses. The great majority of the study employed the qualitative paradigm to deeply explore the uniqueness of MS nursing and illuminate key aspects (Doyle, 2015). The great advantage of using MMR in this study was to use the contrasts and comparisons as a form of triangulation of different perspectives (Bressan et al; 2016) on similar issues between phases 1 and 2.

The quantitative paradigm within phase 1 of the study

The quantitative paradigm is based on a probabilistic view of reality known as positivism or post positivism (Patton, 2014). Inherent in this paradigm is the assumption that there is an objective reality which can be discovered (van Griensven, Moore & Hall, 2014), being free of subjectivity from the researcher. This viewpoint suited the first part of the phase 1 data well, looking to uncover demographic and task orientated data relating to the role of the MS Nurse.

The qualitative research paradigm as the overarching paradigm for this study

The majority of the current research employed the qualitative paradigm during most of phase 1 and all of phase 2 of the study, and as such will be explained in detail in order to understand the methodology and methods. Qualitative research as a paradigm 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). Qualitative research makes the world visible, studying in the natural setting to make sense of and interpret phenomena in terms of the meanings that people bring to them (Denzin & Lincoln, 2000). 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. With roots in gaining insights and deep understanding into the experiences of people, the qualitative paradigm suits the study aims of the current research well. The research questions required a methodology that would gain deep, rich insights and understanding of the experiences of MS Nurses working in the specialty.

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 care system. As the current study investigators are both experienced registered nurses, one with significant practice in MS (TB) and one with extensive practice in mental health nursing and life history research (JP), they are ideally suited to exploring the nurse role.

Ontological and Epistemological Perspectives

In qualitative research the research design must clarify the contributions of epistemology, methodology and methods (Carter & Little, 2007), and therefore an understanding of ontology and epistemology is required. A detailed perspective about the views of the investigator in this field can be found elsewhere (Burke, 2019), but a summation is provided below.

The source of knowledge to answer the research question was not going to come from books and articles, but from the “knowers” (Munhall, 2012); the MS Nurses working in the

specialty of MS. Talking to these informants allowed construction of knowledge to learn about their lived world (Kvale & Brinkmann, 2007). This provided the base for knowledge construction.

Ontology

Ontology refers to the nature of reality and what there is to know about the world (Ormston et al., 2014). The ontological beliefs used to support this study were in line with *constructivism*, centred on the world being context specific, co-creating knowledge between the researcher and study participants, being open to revision and possessing multiple realities. 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). Thus, an ontological foundation of constructivism and relativism was applied to the current study, appropriate with the study values.

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. *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 (the MS Nurses) understand their experiences, but also understanding that this truth may not be universal to all members (Faraday & Plummer, 1979).

Methodology

Methodology refers to the framework 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). Although various forms of both quantitative and qualitative methodology were considered for this study, a cross sectional survey design was chosen for phase 1 of the study and the qualitative method of focused ethnography, life history, was chosen to answer the research question in phase 2 of the study. As an underused methodology in nursing (Burke & Patching, 2019), ethnography and life history will be discussed in further detail to provide background and context for the reader.

Ethnography is a research methodology which involves the process of learning about people by learning from them (Roper & Shapira, 2000). Ethnography involves key informants who represent the culture under study discussing their lives, so that others can better understand the culture (de Chesnay, 2014). In the current study, this is the MS Nurse community in Australasia. Nursing studies using focused ethnography have been used in a variety of areas (Ensign & Bell, 2004; Garcia & Saewyc, 2007; Haylen & Fisher, 2014; Haylen, 2015; Burke, Vucic & Patching, 2019).

Ethnography is holistic, contextual and reflexive (Boyle, 1994) ensuring an excellent fit for the epistemological foundations and the broader goals of this study. Ethnography has been adapted for use in different settings, depending on the goals of the research and is based on the concept 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 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). The life history method was chosen as the most appropriate design for this study for the purpose of identifying important themes experienced by MS Nurses which may also be experienced by their peers (Field & Morse, 1985). 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, which is suited to understanding an individual MS Nurse's entire journey.

The purpose of the life history approach in the current study was to collect a focused history around each MS Nurse's experiences in nursing to reflect the cultural and social contexts of each participant. They were to approach their life history in any way they chose, not necessarily in chronological order or centred only on their MS experience, as recommended by DeChesnay and Fisher (2014). In life history, the researcher and the participant come together as collaborators, composing and constructing a story (Atkinson, 1998), also consistent with the ontology and epistemology of the study.

Study methods

Sampling: Phase 1 surveys

Purposive sampling was used to target nurses working in the specialty of MS. The study was publicised through the MSNA Inc network by email with an attached flyer (Appendix 1). Snowballing recruitment within the MS Nurse community was also encouraged for MS Nurses who were not MSNA members, so that they could also be included. Study recruitment numbers were higher than expected with a total of 60 participants. As there is no formal register kept of MS Nurses in Australasia, it is not possible to know exactly how many are currently practicing, but it is likely to be approximately 80-90 from MSNA Inc membership records. This represents a high response rate to the survey of between 67-75%.

Sampling: Phase 2 interviews

The study was once again publicised through the MSNA Inc network about a month after phase 1 was completed, with a single flyer sent to members by email (Appendix 2). The response rate from this strategy exceeded expectations with a total of 25 participants, so no reminder emails were required. Snowballing recruitment within the MS Nurse community was also encouraged and several participants were as a direct result of this strategy.

An abbreviated table of demographics for the enrolled sample taking part in the study interviews is shown in Table 1. Many details could not be included due to the small numbers of MS Nurses in Australasia and the demographics possibly revealing their identity. Instead of the usual demographics, only the setting of their practice is included as it provides context to the findings.

Pseudonym	Participant number	Setting
Sue	01	H /C
Lillian	02	H
Ruby	03	H
Orion	04	H
Sarah	05	H
Grace	06	C
Liz	07	H
Isobel	08	H
Dawn	09	H
Sam	10	H/C
Newera	11	H
Nim	12	C
Rosie	13	H
Flo	14	C
Elizabeth	15	C
Maggie	16	H
Charlotte	17	C
Olga	18	H
Mary	19	H
Win	20	H
Leroy	21	H
Lesley	22	H
Zorro	23	H
Gerty	24	H
Maureen	25	H

Table 1. Enrolled study sample into phase 2 interviews showing workplace setting. H= hospital or clinic setting C= community or organisational setting

Data Collection: Phase 1 surveys

Phase 1 of the study utilised a cross-sectional design to obtain an overview of the MS Nurse community in Australasia during February of 2020. The survey was designed specifically for the purpose of this study, as no validated surveys had been reported previously in this field. The survey was open for a period of 4 weeks after the initial flyer

was sent to MSNA Inc members by the MSNA Inc Secretary and provided a direct temporary link for MS Nurses to go straight to the survey. A reminder email was also sent out at week 2 and week 3, with the final reminder providing a deadline for survey completion at the end of week 4.

For phase 1 of the study, the final instrument comprised a survey with 46 individual questions, which was then entered on to the SurveyMonkey platform as an anonymous electronic survey. Many of the questions used a Likert-type scale to assist with answering the survey quickly and efficiently, most categories also had an “other” section for free text to add descriptions or answers which were not included as an option. The survey also included several qualitative response questions with free text where rich detail was provided by participants. In addition, open categories at the end of the survey provided participants with an opportunity to report on other areas of MS nursing they felt needed attention or to provide further clarification about their role.

The survey captured general information relating to the demographics, work history, current job description and role, tasks, skills, educational status, learning needs, support systems and support needs of MS Nurses. Designed consciously as an anonymous survey, it is hoped this method facilitated an honest report of perceived needs and areas of support without participants feeling the need to report what was expected of them. The information provided by the participants in phase 1 provided a platform for the Investigators to develop more specific topics for phase 2 of the study with the one-on-one semi-structured interviews, in order to acquire deeper insights and explore current issues.

Data collection: Phase 2 interviews

The phase 2 one-on-one semi-structured interviews took place over April and May of 2020 and consisted of 25 individual interviews. The interviews took between 40 and 120 minutes in duration (with an average of 56 minutes) at a time convenient for both

participant and researcher (TB). Initially, face to face, semi-structured interviews in person were the planned study design for phase 2 of the study. However, due to corona virus disease 2019 (COVID-19) restrictions in Australasia beginning the week the interviews were due to commence, the study design was amended to incorporate virtual interviews for all study participants. The Skype and Zoom platforms were offered to study participants with the appropriate password protections in place. Interviews were audio-recorded using a Dictaphone for later transcription.

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). The interviews all took a unique path following the direction the participant wished to take with occasional questions from the investigator to explore further.

At the commencement of the virtual interview, participants were provided with a verbal overview of the study, outlining the study aims. Each participant was invited to tell their life history with particular thought to the question "What is your lived experience of being an MS Nurse?". This approach ensured the information gathered was consistent, rich and participant centred. Reflection questions (Appendix 3) were provided prior to the interview to study participants which gave some direction to the information being sought. This process, as suggested by Patching and Lawler (2009), allowed the participants to see the style and depth of the information required. Participants were instructed that they could use the reflection questions to think about their nursing life, that they could use some of the questions, or they could elect not to use these reflection questions at all.

Even though the interviews became virtual interviews instead of in-person, they still retained many of the qualities of in-person interviews that were sought for the study. There was a great deal of connectedness and rapport on the virtual platform which was unexpected prior to the interviews. The interviews were scheduled at a mutually convenient time and prepared for as a researcher would for an in-person interview. That is, considering seating arrangements (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. However, this strategy was not required as MS Nurses were eager to keep exploring their role. Often only time limitations from other demands led to the interview concluding.

Data Management: Phase 1 surveys

The survey data was initially reviewed to assess for completeness, outliers, patterns and trends. The SurveyMonkey® platform provided data in several formats to download for the investigators to analyse. Invitations from the SurveyMonkey team to upgrade to use their in-house analysis were not utilised, the study researchers preferring to do the analysis themselves. Data was provided in a selection of descriptive statistical and graph formats for the quantitative component, as well as written text for the qualitative sections. The qualitative components were managed by the study investigators using the same methods as outlined below in the phase 2 interviews.

Data Management: Phase 2 interviews

Following suggestions for sound qualitative research management from Tuckett (2005), good organisation and a systematic management of the data was key for later analytical diligence in the study. There was an overwhelming amount of data from the transcripts and also from the coding process. 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” (early thoughts and impressions from the data), coding, story excerpts and quotes as advocated by Plummer (2001).

Interviews were recorded using a Dictaphone and transcribed by TB as part of the technique of total immersion in and familiarisation with the data, as recommended by Braun & Clarke (2006, 2013). All interviews were transcribed completely within a day or two of the interviews to retain as much detail as possible. Interviews were transcribed into a half page vertical Word document for coding to be applied on the right side of the page during the data analysis phase. An electronic copy of each interview transcript was stored on a

password-protected computer under a study number and pseudonym for each study participant.

Field notes are often recommended when performing research interviews (Tuckett, 2005) and involve writing up observations and comments on impressions and descriptions of participants and the study process afterwards. They can also be useful as an early form of data analysis. Field notes were kept by the interviewer (TB) to help remember details later in the analytical process and also provided a platform to direct future data collections; for example, questions or phrases which performed particularly well to be included in subsequent interviews.

Using electronic technology both with data collection methods and in transcription, care needed to be taken to prevent compromising participant confidentiality with lapses in data security. Computer security was maintained on all hard drives, strong passwords were used for computers and devices, firewalls in hard and software, soft copy and hard copy information were deleted appropriately. In addition, participant numbers and pseudonyms were used to deidentify the data and any potential identifiers (workplaces, city of residence, other staff members, family) were removed from the transcripts.

Data Analysis: Phase 1 surveys

Descriptive statistics were used to examine the quantitative component of the survey data and characteristics of the study sample. Data were arranged as categorical variables, counts and percentages. For the qualitative components of phase 1, analysis began with reading through the text responses and then following the Braun & Clarke (2006, 2013) methods for systematic thematic data analysis. These methods are outlined in detail below for the phase 2 analysis. Several codes were developed during phase 1 and candidate themes started to take shape leading up to the interviews in phase 2. However, there was still a considerable amount of deliberation and change to candidate themes at this early stage.

Data Analysis: Phase 2 interviews

The data analysis strategies and tools used in the interviews have been detailed extensively elsewhere (Burke, 2019 p 91- 110) and will therefore only be summarised in this report.

Thematic analysis following the recommendations of Braun & Clarke (2006, 2013) was chosen as the method to best answer the research questions, following a robust and systematic method.

Thematic analysis involves looking for patterns in participant experiences across an entire dataset and allows a high level of interpretation. Thematic analysis was also congruent with the research ontology, epistemology, and overarching methodology of focused ethnography/life history and with the other research methods chosen in the study design. The various components of the research design fit together well to provide a robust framework for operationalising the study and meeting the study goals.

Fundamentally, 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). As an adaptable method, thematic analysis is inductive, the data are examined from the “bottom up” and coding and theme development are directed by the content of the data. This study was not based on any pre-determined theories but shaped by the experiences of the individual participants and the group as a whole, from the emic perspective. Furthermore, 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. Both latent and semantic interpretations of the data were used in this study.

The major elements of the Braun and Clarke (2006, 2013) process of thematic analysis used in the current study are outlined below.

1: Familiarisation with the data

This phase involves reading and re-reading the transcribed interviews becoming immersed and intimately familiar with the content. Transcribing the interviews personally also promoted deep engagement and connection with the data from an early stage.

2. Generating initial codes:

The second phase involved generating succinct labels called “codes” which identify important features of the data that might be relevant to answering the research question. The researcher codes the entire dataset, working systematically identifying interesting aspects that may form the basis of later themes.

3. Searching for themes:

The focus of the analysis 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 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. A key component of the phase is developing the scope and focus of each theme.

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. A name for each theme is developed, ideally being both informative and succinct.

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.

Thematic analysis is typically a recursive process, with movement back and forth throughout the process. 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). As the interviews were all flexible and interactive, different issues came up in each conversation, which were not necessarily discussed with other participants. Researcher judgment is crucial to determine what constitutes theme significance (Braun & Clarke, 2006).

Collating and organising the themes and subthemes 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 thematic maps which were used in data analysis for the current study. A thematic map is essentially a visual aid, which uses a drawing to summarise, define and name themes and subthemes and the links between them. It is simply a visual representation of how themes and subthemes may fit together to tell the story and were used extensively in the data analysis for this study as a record of theme progression.

Frameworks for the study

A conceptual and operational framework for the study was based on previous work using the same methodology (Burke, 2019, p112-114) and will only be mentioned briefly here to provide context. The frameworks chosen for conceptual and operational structure considers 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 helped to ensure consistency in the study process and consideration of all the necessary components of high-quality qualitative research and informed the methods outlined in this chapter.

Methods: Ensuring rigour in the study

Key strategies to ensure study rigour in this study with an overarching qualitative paradigm included transcribing interviews personally by the interviewer (TB) and re-listening to the original audiotapes to stay as connected to the original data as possible. Additional elements supporting rigour included transparency (robust data analysis method, reflexive

diary kept), triangulation (review of themes with both study investigators based on data, MMR component to cross-reference), credibility (peer debriefing of themes with MS Nurse experts for “fit”, prolonged engagement in the field of MS, direct use of quotes to demonstrate themes) and transferability (thick descriptions, participant quotes). Additionally, selecting a robust and systematic method in thematic analysis such as the Braun & Clarke (2006, 2013) process was crucial to maintaining rigour in the study.

Methods: Data saturation

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). Whilst the concept of applying data saturation in qualitative research is challenging (Braun & Clarke, 2013), there are some general principles which indicate that enough data has been collected. These principles 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). An alternative term to data saturation in qualitative research has been suggested by Malterud et al (2016) and involves “information power” a model which considers 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. The participants in the current study were from diverse nursing and regional backgrounds, worked in different settings such as clinic and community and provided specific and high-quality insights; meeting the goals of the study, answering the research question and providing excellent “information power”.

Information power in the current study yielded over 500 individual codes from the raw data. No new candidate themes arose after the twelfth interview, but interviews continued in order to respect the MS Nurses who already had volunteered for the study and to honour their personal stories. Although no new themes emerged from that time, ongoing participants provided deeper insights to the existing data that was exceptional and integral to the richness in the final thematic analysis. Once the volunteers were exhausted at 25 participants, study recruitment was deemed complete.

Methods: Ethical considerations

The concept of ethics is intrinsic to the constructivist epistemology because of the inclusion of participant values in the research (Lincoln & Guba, 1985). The usual process for the ethical conduct of studies was followed in line with the University of Notre Dame, Australia guidelines. Ethical approval for the study was sought and granted by the University of Notre Dame, Australia, Human Research Ethics Committee (HREC) approval number: 019162S. The study was approved as a low-risk study.

The 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) and a flyer for both survey (Appendix 1) and interview (Appendix 2) study participation. As per the requirements for study approval, a consent form was provided to each phase 2 participant and signed prior to any study procedures taking place. Due to not being able to meet in person, the consent forms were signed by the participant first, sent to TB, signed by the investigator and returned to the participant by email. As an added protection for the participants, the PICF was sent a few days before the scheduled interview to avoid the situation where participants may have felt obligated to take part on the day of the scheduled virtual meeting. This arrangement also provided participants the opportunity to ask questions, consult significant others and think about their participation ahead of time. Participants were free to withdraw from the study at any time, and for any reason. No participants requested to withdraw.

An area identified at the beginning of the research process as being potentially challenging to the ethical conduct of the study involved maintaining participant confidentiality throughout all methods (transcriptions, coding, analysis). Confidentiality for the study participants was essential, particularly as some stories involved family members, friends or HCPs directly. Participants were encouraged to select a pseudonym to protect their identity. The names of significant others, HCPs and workplaces were all excluded from the transcripts, as well as potentially identifiable data such as birthplaces and towns of residence.

No study participant required additional emotional care through the research process, and many participants expressed gratitude for the positive experience the interviews had provided them, to have their voices heard. All participants in the interviews were followed up to express gratitude for participating in the study and provide an opportunity to check on their progress after the interview. 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 HREC or to the investigators.

Methods: Reflexivity

In this particular study the researcher who performed the interviews (TB) is an MS Nurse in Australia and was already known to many of the study participants, but not all. This situation required a plan for personal reflexivity. There were positive impacts on the study due to TB's experience as an MS Nurse for over 15 years. Firstly, with clinical knowledge of the disease and experience as an MS Nurse, building rapport with the study participants and developing a trusting environment felt natural and unforced. Participants reported feeling comfortable and free to discuss any issue they wished. As a consequence, discussions relating to sensitive issues, such as relationships, mental health, workplace issues and areas of potential need were able to take place. Leading into data analysis, this clinical experience was also optimised to see nuances in the data that may not have been discovered by a researcher with no clinical MS experience. The MS terminology that participants used in their life history was also able to be situated appropriately and understood. This was an important feature as ethnography relies strongly on naturally occurring language of the participants in the field (Holloway & Todres, 2003).

It is also possible that many years of experience working as an MS Nurse in the field (TB) may have constituted a form of fieldwork in ethnography, where extended participation and observation in a culture occurs, extending the findings of the study. This could be viewed as both positive (seeing nuances or contextual elements in the data) and negative (seeing things that are not present in the data but had been experienced by the researcher). To combat any negative effects, there was a constant back and forth between study subthemes and themes with the study data to ensure cohesiveness and presence. The use of participant quotes to directly support each subtheme and theme was also utilised

throughout the study to demonstrate connections. Regular discussions regarding the developing findings with the co-investigator (JP), who is not an MS Nurse, also assisted this process.

During the study, functional reflexivity was constantly assessed to confirm that the methodological paradigm and methods was serving the study well and no alteration was needed to the data collection methods and analytical methods as the study progressed.

Reflexive analysis involves consideration of how the patterns and themes arose from the data. Once every candidate theme was developed, the original data was consulted to ensure that the themes were firmly embedded in the study data and not researcher thoughts and opinions. If a candidate theme could not be supported entirely by participant quotes and stories, it was discarded to ensure an inductive, data driven analysis.

Summary

Phase 1 of the study employed a mixed methods approach to gain an overview of the MS Nurse community in Australasia, with particular attention to demographics, job description and tasks, current role, support strengths and needs, educational strengths, learning needs and specific skills developed in the MS Nurse role. Phase 1 consisted of quantitatively based descriptive statistics and a component of qualitative responses which produced deep and rich insights into the current status of MS nursing in the region. Responses from the phase 1 surveys also helped to inform the direction of the phase 2 interviews by providing information on contemporary issues and areas of interest to explore further. The methodology chosen for phase 2 of the study was a form of focused ethnography called life history. Due to COVID-19 travel and visitation restrictions during the course of the one-on-one semi-structured interviews, a virtual platform using Skype and Zoom was used to explore the working lives of MS Nurses. These interviews unearthed an extraordinarily deep and insightful exploration which progressed to develop five themes and 21 subthemes to help define the role of the MS Nurse in Australasia. These findings will be discussed in Chapter 4.

Chapter 4: Survey findings phase 1

The aims of phase 1 of this study were to help determine the current skillset of the MS Nurse by identifying areas of strength in education and existing support systems and also to understand the current learning and support needs, so that appropriate educational and support programs could be suggested to address these areas of unmet need.

Additionally, the free text answers identified areas to explore more deeply during the one-on-one phase 2 interviews and also contributed towards the development of codes and candidate themes towards a role definition for MS Nurses. Using a mixed methods approach, phase 1 consisted of 46 questions with some quantitative responses (Likert-style answers, pre-populated boxes) and qualitative style free text responses.

For phase 1 of the study, an anonymous questionnaire survey was set up electronically on the SurveyMonkey® platform and used to capture general information relating to the skillset, educational status, learning needs, support systems and support needs of a purposive sample of MS Nurses in Australasia. As discussed in the previous chapter, the study was publicised through the MSNA Inc network, with two reminders during the month-long window for participation. Snowballing recruitment within the MS Nurse community also alerted volunteers to participating in the study. As an anonymous survey, it is hoped this method facilitated an honest report of perceived needs and areas of support without participants feeling the need to report what was expected of them. A total of 60 of MS Nurses responded to the survey, significantly more than anticipated before the study commenced, representing a high proportion of MS Nurses in the Australasian region. The average time taken to complete the study survey was 22 minutes.

Key demographics of the sample

A total of 80% of the phase 1 respondents (N=48) were aged over 41 years, and only 10% (N=6) were aged under 30 years, suggesting an abundance of life and nursing experience in

this group and an area generally attracting more mature nurses. The great majority of participants were female, with only 4 males participating. Most of the responding MS Nurses lived in Western Australia (WA), followed by Victoria and New South Wales (NSW). No responding MS Nurses lived in the Australian Capital Territory (ACT) or Northern Territory (NT). Six participants were from New Zealand (NZ). Figure 1 demonstrates the geographical spread of participants in the study.

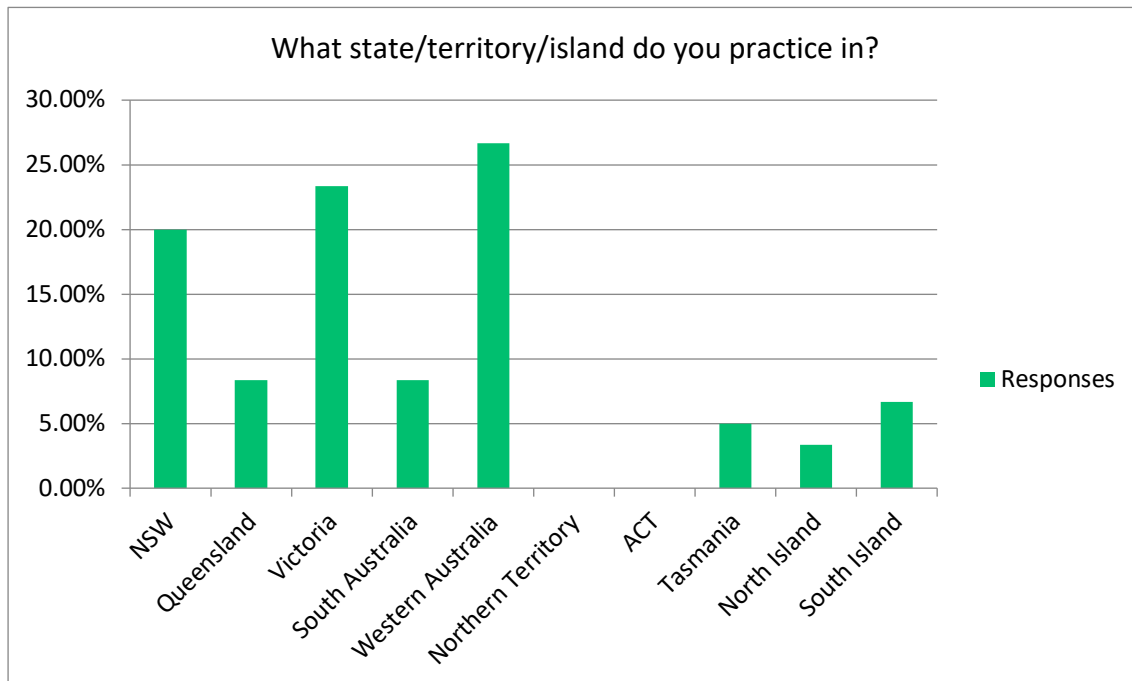


Figure 1. *State, Territory or Island of practice for MS Nurses participating in phase 1 of the study*

The majority of MS Nurses were working part-time hours over one to five days per week, with 35% working full time and 1 participant working casually. No participants were retired. Almost all participants (N=57) were currently working in MS care, with 65% working in a hospital clinic, public (55%) or private (10%). The community (27%) and MS organisations (32%) were well represented. MS Nurses currently working in the pharmaceutical industry were also represented with 4 participants.

Education and experience

Over half of MS Nurses had achieved a nursing Bachelor degree as their highest form of education, and 8 participants had achieved a Masters level in nursing. Over two thirds of MS Nurses had two or more certifications or extra courses since graduation, suggesting a well-educated and engaged group. The majority of MS Nurses came from a neurology background (N=25), a natural flow as MS is a subspecialty of neurology. Nurses came into MS from a wide range of diverse backgrounds; including surgical (N=18), community (N=16) and intensive care (N=13). Almost two thirds of participants currently work as part of a team, with N=25 working specifically in a multidisciplinary team. Nine nurses worked independently on their own.

MS care experience

MS Nurses tended to be involved in the MS specialty for a long period of their career, with over half of study participants in the field for 11 years or more. Only 15 participants had been involved in MS care for less than 3 years. This suggests a loyal workforce who often remain in this specialty for over a decade. Half of MS Nurses participating in the study have worked in their current job in MS for over six years.

The majority of MS Nurses were categorised as a Registered Nurse in their job description (28%), followed by Clinical Nurse Specialist (24%), Clinical Nurse Consultant (15%), Registered Nurse Clinical (14%) and Clinical Nurse Research (10%). Interestingly, eight MS Nurses categorised as a research title, perhaps reflecting the large volume of research currently in MS care and also a source of funding for the MS Nurse role. There were two MS Nurses identifying as a Nurse Practitioner.

All study participants reported having experience in adult MS care, 46% experience with adolescents and 12% with children under 12 years of age. Most MS Nurses work with people living with relapsing remitting MS (RRMS) (93%) and progressive MS (90%). Interestingly, only half of study participants had experience with severely progressive patient care (wheelchair dependant) and only N=16 with palliative care. This could be

reflective of the workforce working primarily in hospital clinics and perhaps the difficulties in severely progressive or palliative patients being able to attend these appointments and being more likely to be managed in the community.

Responsibilities of the MS Nurse

Participants were asked to tick boxes that applied to all of their current work responsibilities in a pre-populated list. The frequency of these responsibilities is reported in Table 2.

Reported by almost all MS Nurses (70% or greater)	Reported by most MS Nurses (51-69%)	Reported by some MS Nurses (25-50%)
Telephone advice	DMD treatment escalation	Inpatient consults
Symptom management	DMD decision making	MRI reporting checks/appointments
Newly diagnosed education	Triaging relapse	Collecting data for research
Family and friend support	DMD monitoring blood results	Visiting patients at home or work
DMD initial education	DMD initiation of blood tests	Discuss new research projects
Education of other MS team members	Nursing consults clinic	Reporting serious adverse events
Psychological support for patients		Entering or managing research data
Educate general healthcare team		Supervision of other nurses
		Maintain patients in research/trials
		Neurological assessments

Table 2. Frequency of job responsibilities reported by MS Nurses

Participants were also encouraged to list responsibilities that were not on the pre-populated list as open-ended text responses. These responsibilities included assisting with the National Disability Insurance Scheme (NDIS), uploading reports, managing compassionate use drugs, accounts and invoicing, ethics submissions and co-ordinating prescriptions.

Another way to express the same data, other than frequency of occurrence, was to examine the job responsibilities from the perspective of demonstrating direct and indirect nursing care to the patient. This helps to get a feel for how much time is spent in the role directly caring for patients and is shown in Table 3.

Direct care	Indirect care
Telephone advice	Family and friend support
Symptom management	Education of other MS team members
Newly diagnosed education	Educate general healthcare team
DMD treatment escalation	Entering or managing research data
Psychological support	Reporting serious adverse events
DMD decision making	MRI reporting checks/appointments
DMD monitor bloods	Supervision of other nurses
DMD initiate bloods	Collect data for research
DMD initial education	Initiate discussion on research
Triage relapses	Maintain patients in research/trials
Clinical outpatient consults	
MRI report checks	
Home/work visits	
Neurological assessment	

Table 3. *Direct and indirect nursing care responsibilities of MS Nurses*

Collaborations with other HCPs

In order to obtain insights into the MS Nurse role of providing support, advocacy and care co-ordination, information was sought from the participants on their patterns of referral or seeking help for patients from other HCPs. Most study participants were likely to refer to physiotherapists (86%) and Continence Nurses (78%), reflecting the common symptoms seen and screened for by MS Nurses in motor/sensation and bowel/bladder issues. More than half of the participants were also frequently referring to Occupational Therapists (69%), Psychologists (64%) and Social Workers (54%). The frequency of partnership with these key HCPs in MS may represent an area for future collaboration with MSNA Inc and also individuals for further support, education and research. It also highlights the MS Nurse as the Conductor of Care, referring frequently to improve outcomes for the patient and recognising their scope of practice. This will be discussed further in the following chapter.

Areas of Confidence in MS nursing

Identifying areas of practice confidence in MS Nurses provides insights into the current skillset of the MS Nurse and where their particular areas of strength are most prevalent. Participants were asked to mark in a pre-populated list the areas of MS nursing that they felt confident in practicing with patients. Table 4 outlines these responses.

Area of higher confidence (>70%)	Areas of intermediate confidence (50-70%)	Areas of lower confidence (<50%)
Bladder	Psychology in general	Suicidal thoughts
Bowel	Allied health involvement	Current research
Identify Relapse	Sexuality	Rehabilitation
Relapse management	Pregnancy	Tremor
Depression	NDIS	Menopause
Anxiety	Spasticity	Palliative care
Sleep	Gut/Diet	Post-Traumatic Stress Disorder (PTSD)
Sensation symptoms	MS Australia	
Motor symptoms	Employment issues	
Visual symptoms		
Balance symptoms		

Table 4. *Areas of confidence in practice for MS Nurses.*

These areas of MS nursing practice confidence relate well with the frequency of these symptoms/issues appearing in MS clinical practice (Ben-Zacharia, 2011). The more common symptoms are related to higher confidence levels in MS Nurses, whilst less commonly seen issues are reflected with less confidence. This suggests that the MS Nurses feel more comfortable with the areas they are more experienced in, a natural phenomenon.

There are many opportunities suggested herein as learning opportunities for MS Nurses, especially in the areas of lower confidence such as managing suicidal thoughts and PTSD, understanding current research, managing rehabilitation, treating tremor, dealing with menopause and palliative care issues. For example, workshops at the annual MSNA Inc conference, at pharmaceutical company sponsored MS education days, MSNA Inc initiated mentoring groups, webinars or resources addressing specific areas.

Current sources of MS Nurse education

Generally, MS Nurses were either satisfied (59%) or very satisfied (14%) with their current level of education. Others were neither satisfied or dissatisfied (19%) or dissatisfied (8%). There was no pattern in regard to length of time in the specialty or of experience. No participants reported being very dissatisfied. These findings suggest that the majority of MS Nurses are satisfied with their current education, however, there remains a small group who require additional learning and skills development.

The majority of MS Nurses acquired their education as self-directed learning from books and articles (90%) and the internet (80%). MS Nurse meetings were also popular sources of education, from the annual MSNA Inc conference (90%), followed by MS Nurse meetings in their own state (85%) or nationally (83%). Education from other HCPs (68%) and neurologists (65%) were also popular sources of furthering education. Common websites for self-education included the MSNA Inc website (65%), the MSRA website (48%) and the IOMSN website (43%).

Conference attendance was also a popular way for MS Nurses to network and learn, both from national and international experts and from colleagues and peers. The MSNA Inc annual conference is held each year in a different state of Australia/NZ. Almost half of all participants (47%) had attended 6 or more MSNA conferences, supporting previous findings of MS Nurses staying in the specialty for a long duration. Six responders however, had never been to an MSNA conference and a further six participants had only ever attended one conference.

International conferences were a different scenario, with over half of MS Nurses never to attend either of the two primary international MS conferences, Consortium of MS Centres (CMSC) or European Committee for Treatment and Research of MS (ECTRIMS) annual conferences. These opportunities are excellent sources of education with specialised MS Nurse pathways and special interest groups for more focused learning at both settings, providing self-development opportunities which are often not available in Australasia. In addition, both events host MS Nurse networking events to meet peers from other countries

and discuss hot topics in MS nursing around the globe. Interestingly, funding for conference attendance is overwhelmingly from pharmaceutical company support (84%), followed by funding from workplaces (29%), scholarships (12%), self-funded (11%) or from being awarded a prize to attend (9%). This evidence demonstrates that pharmaceutical companies are great supporters of MS Nurse education in Australasia and their support is crucial for MS Nurses to receive education and learning support opportunities for conferences, both in Australasia and abroad.

Advanced Practice Skills

Participants were asked to rate their feelings of competency in several areas of advanced practice skills involved in MS care using a pre-populated list. The majority of MS Nurses rated themselves as competent in DMD initiation of oral medications (85%), injectable medications (79%) and biologics (68%). Fewer MS Nurses regarded themselves as competent in assessments for depression (50%) and administration of infusions (41%).

Reflecting the synergy between research and clinical care in MS, several MS Nurses rated themselves as competent in common MS research tools such as 9-hole peg tests (52%), Paced Auditory Serial Addition Tests (PASAT) (43%), and Single Digit Modality Testing (SDMT) (39%). Interestingly, leadership was also a strong area of competence, with 54% of participants rating themselves as competent in this area. Skills such as venepuncture (52%) and IV cannulation (30%) are becoming more popular as DMDs develop and blood tests are needed more frequently, as well as a need for these skills in research studies. Highly specific areas of advanced learning in MS care were also rated by some nurses as competent, including Expanded Disability Status Scale (EDSS) (20%) and advanced neurology assessment (11%). This indicates that MS Nurses are keen to expand their learning and attempt more advanced skills and could represent an area of future development and education.

MS Nurses were also asked to list other skills not mentioned in the pre-populated list that they felt competent in related to their role. These open-ended text responses included reflective listening, pain management, catheterization and continence care, managing respiratory support, gut support, expediting issues to experts appropriately (referrals) and

managing career burnout. An area which attracted multiple similar responses in this area was counselling, ensuring holism and “humanising the medical world”. These areas provided topics for discussion in the phase 2 interviews: holism, listening, explaining, educating patients, leadership, support, DMD management and counselling.

Confidence in concepts in MS nursing

Once again, understanding areas of strength helps to determine current skillsets of MS Nurses. Participants were asked to tick applicable areas of a pre-populated list of concepts of MS that they felt confidence in terms of both knowledge and understanding. Table 5 separates these concepts into areas of greater confidence, of intermediate confidence or areas of less confidence.

More confidence (>70% rated confidence in)	Intermediate confidence (41-70% rated as confident in)	Less confidence (40% or less rated as confident in)
MS definitions/phenotypes	Adherence issues	Stem cell therapies
MS diagnostic criteria	Risk/benefit profiling	Research terminology
DMD modes of action	Gender differences	Research ethics
Epidemiology	Psychosocial aspects	End of life planning
Diagnosing a relapse	Evidence based research	Ethnocultural issues
DMD monitoring	Emerging/new treatments	
Diagnostic tests	Complementary therapies	
Advocacy for patients		
Pathophysiology		
Organisations in MS		

Table 5. Areas of confidence felt by MS Nurses in concepts relating to MS.

The areas of less confidence listed in Table 5 represent opportunities in concept areas to develop educational and support tools to promote confidence for MS Nurses. These could

be provided by MSNA Inc through the annual conference or as webinars or other online educational resources in coming years. Concepts of research reflected here could be an ideal opportunity for the recently convened new research subcommittee of MSNA Inc to be tasked with addressing these unmet specific needs in research. Emerging and new treatments (including stem cell therapies), end of life planning and ethnocultural issues also represent ideal areas for future educational focus.

Developing skills for the future

Utilising an open-ended text format, study participants had many suggestions for skills they felt they need to perform or extend their role but were currently lacking education and support in acquiring. Several of the key areas which attracted many similar responses in acquiring skills included:

- Neurological examination and assessment
- MRI interpretation
- Pathophysiology and immunology of the disease
- Sexual dysfunction
- Suicide and PTSD assessment and management

Other areas not mentioned as commonly as those above, but still highly relevant to MS nursing practice include research statistics and evidence-based research, psychological support for progressive MS patients, medication escalation and treatment footprints, palliation, continence issues, tremor and spasticity. Some of these topics have come up repeatedly throughout the survey already in other questions and formats. This highlights the advantage of using a mixed methods design and employing triangulation to ensure the study findings are sound and consistent.

In the area of pathophysiology, this participant quote was particularly simple yet insightful, as it touches on one of the core values of MS Nurses acting as advocates for their patients by developing their own knowledge further in order to assist the patient journey:

Participant quote (PQ): I feel I need to develop and extend my knowledge so I can easily translate it in a way that makes sense to a patient.

Support for MS Nurses

This section began by looking at how often MS Nurses enjoyed going to work. Over three quarters of respondents enjoyed going to work the majority of the time, either most days (51%) or every day (25%). A further 22% enjoyed going to work only sometimes, and 1 responder rarely enjoyed going to work. These findings suggest that *most* MS Nurses enjoy their role.

For those participants who enjoyed going to work, further information was sought to understand the reasons why, using a pre-populated list. These reasons included:

- Job satisfaction/making a difference in the lives of others (88%)
- Taking care of people (87%)
- Feeling confident educating patients and families (73%)
- Learning new things (72%)
- Working as part of a team (70%)
- Professional development (67%).

The following quote from a study participant in the free text area highlights how core nursing concepts of support and education can improve patient journeys, but also simultaneously assist in MS Nurse job satisfaction.

PQ: It's really rewarding when I'm talking to someone with MS, or their families, and you can see they don't really understand what is happening or what they are supposed to do next. Then, you explain it in a different way, and you can see it 'click' for them; they are starting to understand what's going on and what they should do next. I feel that inspiring hope and

confidence for people with MS to take charge of their own lives is a large part of our role as MS Nurses.

An alternative to taking care of people was the opportunity to empower, which in turn improved this MS Nurse's own satisfaction in their specialty role and helped patients regain control.

PQ: Rather than the sentiment of taking care of people...I prefer to "empower" people rather than take care of them...I'm hoping with my knowledge they would be able to know how to independently seek assistance and feel as if they were somewhat in control of their lives.

For those MS Nurses who did not enjoy going to work every day, further information was sought to explore the reasons why this might be happening. The first part of this exploration involved participants ticking a pre-populated list of possible reasons why. The most common reasons were:

- Frustration from work colleagues (29%)
- Low team morale (29%)
- Lack of respect (24%)
- No freedom to develop the role (20%)

The free text answers provided a place for respondents to express their concerns in their own words. There were several themes repeated from MS Nurses, including perceived barriers from management to job enjoyment.

PQ: When management changed...I was then restricted and blocked from giving best practice and asked, "what benefit do you bring to the organisation?" as the needed work didn't actually meet the KPIs for NDIS".

Overall, the majority of participants felt emotionally and mentally supported in their workplace (73%). However, 27% did not feel this support at all and this will be addressed in

greater detail below. For those respondents that did feel emotionally and mentally supported in their role, this consisted mainly of having access to debriefing sessions and being able to talk to colleagues about difficult or challenging patients. Others had access to clinical supervision, felt purpose within a team and greatly value and were fortunate to have an invested and effective manager/team leader. Examples of this included a manager debriefing, listening, appreciating, supporting, looking after the mental health of MS Nurses and supporting professional development, skills and learning.

For those not so fortunate to be working in an environment that they felt emotionally and mentally supported, the effects were profound. There were many comments in this section, leading to strong themes that were repeated throughout this group. The comments consisted primarily of increasing workloads with no support or resources to cope, too many patients to care for, feeling burnt out with no recognition of this or support from others, lack of opportunities to debrief about challenging and difficult patients, lack of wellbeing support from organisations, lack of respect for the specialised MS Nurse role and knowledge, lack of connection with other MS Nurses or similar organisations and lack of ethnocultural support.

Overwhelmingly, participants responding to this category felt burnt out and inundated with work and tasks they felt they could never catch up and complete. This quote expresses the concern this feeling could incite:

PQ: I feel I must continually complete tasks to get patients onto DMDs and do all that needs to be done. This has caused me to feel a lack of connection and joy for helping people with MS to manage...there are so many tasks and processes involved in everything that I feel I cannot give the time and presence that I would prefer to give to patients when I interact with them.

This highlights areas where possible support packages or development programs could be instituted, for example mentoring programs for isolated nurses or those working independently to provide collegial support and help with decision making. Mentoring could also assist with providing avenues for debriefing. Of course, issues to do with high

workloads need to be addressed more locally at the workplace, but support systems within MSNA Inc or other nurse organisations could also help in emotional support, practicing coping skills or by providing support to MS Nurses who need to address management with their concerns. Wellbeing support programs may also be another opportunity to pursue more generally for MS Nurse emotional and mental health support.

Respondents were then asked what the “perfect” emotional and mental health system would look like for them. Aside from the obvious answer of decreasing workloads and patient numbers that they care for, responses fell into two main categories; strengthening teams and looking after mental health. Additionally, these findings were enriched from the group that did feel emotionally and mentally supported in their workplace and the practices that were in place already for this to happen.

Strengthening teams

- Supporting health and safety of team members
- Focus on whole team, not self
- A forum to voice concerns without judgement
- Assistance from other team members when workloads increase
- Working together for a common goal
- A culture of honesty, care and appreciation
- A team that builds and respects each other to encourage growth
- Collaboration on shared patients

Looking after mental health

- Access to both formal and informal debriefing
- Clear and accessible clinical support, especially when dealing with difficult situations
- Counselling sessions and support when needed
- Maintaining work/home life balance

Participants were also asked about physical support in their workplace (for example, workspace, adequate supplies, physical needs met). A total of 74% of participants felt well

supported in this regard, however 26% did not feel well supported at all. For those feeling well supported, this manifested in comfortable, private and quiet workspaces with ergonomic desk/chair support, having their own computer, having windows to see outside, an opportunity to personalise their workspace and free car parking on site.

Areas where a lack of physical support became an issue included personal work comfort factors such as lack of desk space, lack of ergonomic seating and support, no space to store equipment, and working in an overcrowded and noisy space. Lack of privacy for difficult or sensitive phone calls with patients was also a concern. Exhaustion from unpaid or unrecognised overtime, no support for breaks and being overwhelmed from the sheer volume of patients led to feeling physically drained and therefore unsupported. Some participants also felt that their workplace granted workspace much more readily to doctors than to nurses to perform their roles.

The “perfect” physical support space was expressed in free text responses and these included having a comfortable desk and chair, air conditioning, basic tools to do assessments, access to parking and transport, personal alarms, and something as simple as receiving a tea or lunch break to recover and refuel. An area for privacy for difficult phone calls with patients was also high on the wish list, as well as several respondents wishing to work in a multidisciplinary team to provide support to each other. As documentation and paperwork seem to be increasing, help with administration tasks and being issued a workplace computer were also sought after by several participants. A physical wish for more time to do the necessary work and more time to link into allied health and make connections was also shared.

In the area of spiritual support, 53% of participants felt that this was not important to them in their MS nursing role, but 47% of participants felt that it was. Spiritual support could mean anything spiritually of value to the MS Nurse, not just religious support, but any interpretation of spirit they wished to use. When asked what the “perfect” spiritual support system looked like, this captured some aspects of emotional support already mentioned above, mainly in the form of feeling supported across all domains of the workload. Other responses included providing more time for self-care and love, spending some time in

solitude, and the most common, being able to debrief about patients to go home with a lighter heart.

Once again, there are many opportunities for learning and support programs for MS Nurse organisations to engage and support their members in these categories. This could include mentoring and one-on-one support, especially for remote or independently working MS Nurses. More formal workshops or sessions at conferences dealing with debriefing issues and counselling, clinical supervision or support opportunities could also be beneficial. Perhaps a new sub-committee for MSNA Inc focused on member wellbeing to specifically address issues of support across all domains discussed here could be considered, as it is likely to be of great benefit.

Skillsets and role in MS Nursing

There were some interesting free text responses in the form of comments to various questions about the skillsets and role of MS Nurses throughout the survey. Perhaps this quote sums up a foundational skill of MS nursing and indeed other chronic health care, which is currently under threat from high workloads and pressure.

PQ: I enjoy creating relationships with MS patients and helping them through their journey...(although) because the workload is so task heavy and burdensome, I feel that I cannot allow time to really enjoy the interactions; every time I do a great job helping a patient, I come back to my desk and feel overwhelmed with everything that I did not get done because I was helping a patient.

MS Nurses develop special skills managing chronic illness and sometimes the value of “holding back” and not going in with the full complement of these skills is actually *one* of these unique skills.

PQ: Recognising when to act and when to step back or simply take a pause when caring for a client. To allow them to come to terms with the changes that occur in their life from the

impact of MS and to recognise when a hug or a kind word may be required instead of an injection or an assessment.

How MS Nurses see themselves

There were many opportunities for free text responses throughout the survey. These short, impactful quotes demonstrate some of the ways that MS Nurses saw themselves in the role, and provided a platform for the phase 2 one-on-one interviews to develop deeper insights:

- *I am blessed*
- *The early years are foundational and a springboard*
- *It can be lonely*
- *Such direct, hands on care*
- *There is no time for further education and understanding of MS. Time only to get the job done*
- *It's a heavy load*
- *Those new to MS are left to struggle in such a complex and chronic condition*
- *Each patient brings their own needs and life experience*
- *Having experience in other nursing areas bring extra insights into the holistic care of each patient*
- *Many opportunities for support are within the MS Nurse community*
- *MS Nurses develop social and personal skills*
- *I have educated my clients on a daily basis, but I also recognise that they in turn have educated me.*
- *MS Nurses should be held in respect for the expertise and knowledge he/she brings to the role. This can make the difference to a positive or a negative journey with MS.*

Areas to explore more deeply in phase 2

Several points were raised in the survey responses and particularly the free text responses became an area of deeper exploration in the phase 2 one-on-one interviews. The

demographic data revealed that most MS Nurses had been working in the MS specialty for a long time and came from a wide range of diverse backgrounds. These backgrounds including surgical, community, intensive care, oncology, rehabilitation, cardiology and respiratory and all likely have a place somewhere in modern MS care with recent developments and monitoring needs for patients. As part of the life history of MS nursing, phase 2 participants told of their backgrounds before coming to MS care and of the benefits and transferable skills they brought into the new role.

Whatever MS Nurses were officially called in their job descriptions, their roles were remarkably similar. There was a tendency towards “clinical” in the title, whether as a registered nurse clinical, clinical nurse specialist, clinical nurse consultant, or clinical nurse alone. A higher than expected occurrence in “research” was noted, with eight MS Nurses having “research” in their job title. This may have implications for education and support in the future, but also recognised the role MS Nurses have in research in the modern day. This was further supported by the high figures for nurses performing research tasks in their daily responsibilities. This included collecting and entering research data, maintaining patients in research trials, recording serious adverse events and discussing current research with patients.

MS Nurses put a lot of value on their own education, as evidenced by their dedication to self-directed learning as their primary source of education. Attendance at the annual MSNA Inc conference was also a popular way to learn and stay in touch with colleagues. Learning needs were questioned further in phase 2 of the study.

There were several quotes in the free text responses of the phase 1 surveys that touched on possible distinctive features of MS nursing which were also explored more deeply in phase 2 and went on to provide additional findings in the study.

PQ: MS Nurses are absolutely critical to the wellbeing of people with MS and we need to ensure that all patients have access to them, no matter where they reside or what MS centre or neurologist they see. We need to focus on safeguarding this important role into the future.

PQ: I'm proud of this role and the areas that are 'ours'.

PQ: I found my 'niche' in MS nursing for many years. The teamwork and team leader made all the difference and allowed our endeavours and our energy to focus on the patients and their care.

PQ: Recognition of the multiple layers that the role has, awareness of the importance of the MS Nurse not only to the patient but HCP, medical and charities throughout Australia...we have always been seen as needed, but not seen as the role we are.

PQ: Evaluating our role and giving others the understanding of that role will empower the nurse and give recognition of standing in the pivotal and challenging path of a person with MS.

Candidate themes for later data analysis

Candidate themes are themes at a very early stage of development in data analysis (Braun & Clarke, 2013). Some candidate themes go on to become definitive themes or subthemes in the final analysis, some are discarded or some merge to form another theme. Candidate themes are not usually mentioned in the final study report, but in this case, they will be acknowledged because they tell a story of the phase 1 qualitative data analysis before proceeding to phase 2 interviews where they could be explored further. Informally they are the phase 1 study findings ready for further development in phase 2.

- *Candidate theme: "People Person"*
 - I make a difference
 - Taking care of others when they need help
 - I empower
 - Hands-on care

- Social connections
- Collaborations with allied health
- Working in a team
 - *Candidate theme: I am a learner*

- Learning new things
- Self-directed learning
- High conference attendance
- High meeting attendance

- *Candidate theme: I am a Teacher*

- Feeling confident teaching patients
- Educating family and friends
- Educating other nurses
- Educating other members of the health care team

- *Candidate theme: Value in professional development*

- Develop role
- Creativity in role
- I feel respected
- Working independently

- *Candidate theme: Self-directed learner*

- Internet
- Books and articles
- Conference attendance
- Meeting attendance

○ *Candidate theme: Manager and organiser*

- The medical system
- Employment
- Appointments and tests
- Symptoms
- Relapses
- Medications
- Education
- Support

○ *Candidate theme: Special skills*

- Reflective listening
- Humanising the medical world
- Negotiating the health care system
- Venepuncture
- IV cannulation
- Basic neurological assessment
- Advanced neurological assessment
- EDSS assessment
- Visual acuity
- Cognitive tests
- Suicide assessment and intervention
- Depression screening
- Anxiety screening
- Continence care
- Gastrostomy care
- Spasticity care
- Relapse assessment

- *Candidate theme: Medication Managers*

- Initial DMD discussions
- DMD escalation discussions
- DMD initiate blood tests
- DMD monitor blood tests
- Prescription management
- Compassionate use medication management

- *Candidate theme: Special social and interpersonal skills*

- Pausing/recalibrating/holding back
- Knowing when to step in

- *Candidate theme: Empathy and kindness/holistic care*

- Humanising the medical world
- Listening
- Problem solving

- *Candidate theme: Support Sources*

- Medication support with starting and side effects
- Educational support with new diagnosis, symptoms, ward consults, educate other HCPs
- Physical support with symptom management, triaging relapses, telephone advice, neurological assessments
- Emotional support with newly diagnosed, family and friends, home visits
- Hidden support in reports, research, checking MRIs, reporting SAEs

- Neurologist support with calls, education, checking up reports, decision making, research
- How-to support navigating NDIS, newly diagnosed, symptoms
 - *Candidate theme: Sources of Hope*
- Direct, hands on care enhancing and promoting hope in patients
- Recent drug advances promote hope in the nurse who passes this on to the patient
- Patients need hope

PQ: This is an incredible field of work to be involved in. Changes in treatment options over the last few years have been amazing and made work exciting and satisfying.

- *Candidate theme: Barriers to the MS Nurse role*
- Lack of appreciation
- Lack of time
- Lack of resources
- Lack of support from management
- Lack of respect
- Lack of recognition of role
- Too much stress
- Too many patients
- Too much work
- Too many tasks
- Too much paperwork

PQ: Since the advent of NDIS, the organisation I work for has devalued the role of the MS Nurse as it is seen as "less" as it is not directed towards nursing tasks such as catheter and wound care. We have lost very experienced and valuable MS Nurses due to low morale in the workplace.

PQ: I care deeply about the clients I see and try my utmost to be their advocate to ensure their needs are met but this is becoming more difficult as time constraints are placed on staff, workloads increase, and education opportunities dwindle. Care is now focused on the amount of income based on NDIS funding plans.

PQ: Institutions struggle to recognise the importance of what an MS Nurse does...(they want) concrete figures and justifications. It can be difficult to describe what we do that makes a difference.

- Candidate theme: Feeling burnt-out
- Burnout was a factor in many responses throughout the survey, presenting repeatedly, directly or indirectly.

PQ: This job has a time limit...after a while it is better to move on to another role or move to something different to stay fresh, challenged and motivated.

PQ: The MS Nurse role is undervalued.

- Candidate theme: Overwhelming

PQ: I feel overwhelmed at times- I'm the only nurse in my workplace and it's very busy. My role is extensive.

PQ: This role has changed so much in recent years with no 'official' discussion of how these changes 'fit in' with my current work schedule and workload (that is, more jobs for me without checking if I can manage it). The neurologists rely on us to do so much to support them as well as the patients. I don't think this is recognised enough...more, more, more with no more resources to help us with the load...I don't think they (neurologists) actually know what we do except fix the problems for them, so I'm glad the definition is happening to bring light to what we do.

- *Candidate theme: Collegial support*
- Support from MS Nurse colleagues important
- Seeking collegial support on bad days
- Searching for answers using colleagues and their experiences

PQ: It's important to be able to reach out to our colleagues, both within our place of employment and those working in our specialty.

PQ: I love this role and the MS Nurse connections I have developed as a result of being part of the MSNA membership over many years. The interstate connections are incredibly special to me. The MS Nurses have kept me 'sustained' working in this field ...I always know there is someone to reach out to for advice and support if I really need it.

- Also consider the comment that felt there was a "clique" in the profession:

PQ: I don't feel well supported by the MS Nurse community. It feels like there is an 'in crowd' and it's hard to gain professional entry into such a crowd.

- And perceived inequality in access to conference educational opportunities:

PQ: MS Nurses should be given equal opportunities to attend events such as ECTRIMS, as this experience will ensure a more positive attitude amongst colleagues. Some individuals have been lucky to attend annually whilst others have never had a chance. Some nurses selfishly hold their knowledge to themselves without sharing with others and this does not assist the newcomers to the field of MS...and does not assist them to care for their patients to ensure best outcomes are met.

○ *Candidate themes: Team Support*

- Good team support and a good manager makes it easier to go to work
- Common purpose
- Support with difficult or challenging patients
- A platform to debrief

Candidate recommendations: Keys areas identified from phase 1 surveys where educational programs could assist in developing competence and confidence in MS

Nurses:

- Neurological examination and assessment
- MRI interpretation
- Pathophysiology and immunology of the disease
- Sexual dysfunction
- Suicide and PTSD assessment and management
- Assessments of appropriate workloads
- Understanding current research in MS
- Research terminology and ethics in general
- Rehabilitation
- Managing tremor
- Managing menopause
- Palliative care and end of life planning
- Understanding stem cell therapies
- Ethnocultural issues
- Paediatric and adolescent care
- Care of severely progressive patients

Candidate support recommendations: key areas where developing support programs could assist MS Nurses in their role and to maintain physical, emotional and mental wellbeing:

- Debriefing outlets
- Clinical supervision
- Mentoring and direction for new nurses
- Support for isolated nurses or those working independently
- Forums to discuss management of challenging cases
- Education in key areas identified above
- General health and wellbeing support
- Methods to make connections with other MSNs
- Building strong and respectful team environments
- Identifying, managing and preventing burnout
- Prioritising: managing high workloads and competing deadlines
- Maintaining work/life balance
- Managing stress and anxiety

Summary of key areas to explore more deeply in phase 2 one-on-one interviews:

- Extended roles - a good thing for skills development or takes away from nursing?
- Support for nurses - what is lacking, what is good, what works for you
- Education strong points, what works well for you, how do you learn best?
- Education needs - what is lacking, what do you need?
- Holistic care - the meaning of and the actions of
- Humanising the medical world
- Obstructions/barriers to the role
- Responsibilities
- Current skills
- Skills you would like to develop and why
- A bad day/a good day/ a great day
- The role (or not) of research in your daily MS Nurse life

Conclusion

The phase 1 survey findings provide an overview of the current MS Nurse population in Australasia, and a snapshot of MS Nurse responsibilities, tasks, skills and positions in 2020. Additionally, MS Nurses have reported on their current support strengths and needs and current educational strengths and learning needs. Several key areas to develop support and education programs for the future have been identified and discussed in the study findings. It is hoped that by supporting unmet needs, MS Nurses will be able to extend their practice, fostering career development. Additionally, by providing appropriate support to practice well and to acquire or maintain personal physical and mental wellness, that there will be retention of skilled and experienced MS Nurses in the workforce as the need for MS Nurses continues to grow.

The findings from phase 1 also partly informed the questioning for the phase 2 one-on-one interviews and provided an abundance of opportunities to explore the role more deeply in many aspects; such as how MS Nurses work, what forms the core of their nursing ethos, how they care for patients, what makes up a typical working week, the values they hold close, the things they do particularly well, areas of MS nursing which may be niche or unique, the areas that comprise support, what advocacy for patients looks like and many more concepts. Chapter 5 will present and discuss the final study themes arising from the phase 2 one-on-one interviews and provide an overview of the MS Nurse role, the variety of activities that an MS Nurse performs in their daily practice.

Chapter 5: Thematic findings phase 2

This chapter will discuss the themes and subthemes developed from the phase 2 one-on-one interviews, which contribute significantly to defining the role of the MS Nurse in Australasia. In total there were five themes and 21 subthemes identified which explore the work of MS Nurses, defined as individual concepts, but all connected and often working in synergy. Participant quotes will be presented in *italics* identified with their chosen pseudonym. A **central organising concept** will be established for each theme to provide clarity in the inclusion and direction of each area of focus. Table 6 shows the themes and subthemes identified in phase 2.

Theme	Subthemes
Theme 1: Holistic Healers	<ul style="list-style-type: none">• Patient centred care• Changing pathways• Situating hope• Leading teams for multidisciplinary care
Theme 2: Sources of Support	<ul style="list-style-type: none">• Setting up the long-haul partnership• Being the balm of calmness• Enabling self-management, independence and empowerment• Advocacy• Supporting Neurologists
Theme 3: Disease and Symptom Educators and Managers	<ul style="list-style-type: none">• Education and setting the scene• Relapse management• Symptom management• Adding value with home visits and community care
Theme 4: Medication Managers	<ul style="list-style-type: none">• Initial decision making and treatment switches• Drug safety monitoring and side effect management• Adherence and persistence• Logistical organisation

<p>Theme 5: Professional Development Advancers</p>	<ul style="list-style-type: none"> • Building networks with other MS Nurses • Dynamic consumers of self-development and learning • The rise of MS Nurse clinics • Commitment to research
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Table 6: Themes and subthemes from phase 2 one-on-one interviews

Theme 1: Holistic Healers

The theme of “Holistic Healers” symbolises MS Nurses recognising the patient across mind, body and spirit. It describes how MS Nurses grow to understand individual patients; what shapes their belief and value systems, what they already know about illness and/or MS, the things that may have happened previously in their lives to influence how they process information and make decisions in the present. It is about really taking the time and committing energy into each and every patient in order to be able to assist them on their MS journey and to live their best life possible. It is about recognising that it is not just their physical ailments that need to be treated, but also the psychological impact; what they are feeling and how they are feeling it.

The **central organising concept** of this theme is the fundamental nursing lynchpin of holistic care; of considering all the various parts of an individual and also looking at how all the parts come together to make the whole. At times, this could be extremely complex and demand considerable skill by the MS Nurse to uncover, unravel, assess and plan. Often, it was the basic ethos of kindness and compassion which did the healing, considering all needs of the patient and giving them priority, being interested in more than just medications and relapses.

Holistic Healers comprises four subthemes which will explore the concept of holistic care in greater detail:

- Patient centred care

- Changing pathways
- Situating hope
- Leading teams for multidisciplinary care

Holistic care is derived from philosophies of holism and humanism and recognises each person as a whole, acknowledging interdependence of varying aspects of that whole (Jasemi et al; 2017). Holistic health care professionals consider the whole person within the context of the environment and understand the mind, body and spirit, basing their practice on openness, equality and mutuality (Jasemi et al; 2017). Frisch & Rabinowitch (2019) believe that holistic *nursing* care defines a disciplinary practice specialty, where nurses practice patient and family centred care, grounded in the principles of caring and healing. An integrated review by these authors explored the consensus of holistic nursing in the last few decades, concluding that holistic nursing attends to the complexities of the human experience and looks at whole person care. Holism in nursing requires an understanding that intuition, subjectivity, the value of the individual, caring, warmth and compassion need to be retained (Sarkis & Skoner, 1987).

Additionally, to be truly holistic, nurses need to practice a concept known as presence. This was explored by Hessel (2009) as an elusive concept which has been recognised as advantageous to the patient experience. It involves being with and attending to another, getting involved, strengthening connections between nurse and patient, uncovering therapeutic benefits for healing and recovery. Presence connects the nurse and patient through sharing the human experience and the benefits of this connection can be reciprocal. Inclusive definitions of presence are difficult, but Hessel (2009) believes presence in a holistic exchange takes place through active listening, attentiveness, intimacy and therapeutic touch, spiritual exploration, empathy, caring or compassion and recognition of the patient's psychological, psychosocial and physiological needs.

MS Nurses used these techniques on a daily basis, every MS Nurse interviewed in the study talked about concepts of holistic nursing in regular practice, no matter what their work setting. It could not be separated from being an MS Nurse, so bound was this connection. The concept of presence was also deeply felt by the MS Nurses; a commitment to listen, to

put the patient first, to administer a well-placed hug or nod and to demonstrate empathy, compassion and kindness. It was viewed by all MS Nurses as fundamental to the role.

Whenever I see a patient, I really check-in with them...you intuit if they are holding it together...I take a pause with them to think and breathe and then say...how do you feel? Back on them with a re-set, even for patients coming in for a long time. If they are really struggling, I keep them on close follow-up. Liz

Taking that time at the beginning of the journey is priceless, taking the time without rushing, making them see that they are not in this MS journey on their own, if you don't do that well in the beginning, then it is a disservice to them for their journey. Mary

Holistic care in MS was also seen as something that was about much more than just medications and therapies. It encompassed symptoms, relapse management, mental health care, fears, tuning in to things that could be causing worry but were difficult to articulate.

(Often for the first time) we tell them if they can't get it into words, it's OK because we understand...there's a name for it, like brain fog or the MS hug...I have heard it all before, you are not alone. There are lots of things we can do besides medications, there are lifestyle changes that can improve things. I knew everyone's name and I made them feel special by going out of my way...a willingness to go into bat for people. Nim

Subtheme 1: Patient centred care

More than mere bodies and minds, patients have complex lives, and many stories about why they are now our patients (Lazenby, 2017). Part of understanding this journey they are on is to put them and their case at the forefront of care and put aside the busyness of nursing care to be there for that person. We have to imagine what patients would do for themselves if they had the will, knowledge or power to restore or promote their health (Lazenby, 2017). MS Nurses do that by situating the patient firmly in the centre of the health care plan.

We are trying to empower their ability to have strategies and resilience...whereas in the wards they are fast and paced...in MS nursing we make it look like there is time for everything and slow it down...to be stronger on the other side. Sue

I talk patients through what is best for them using a holistic approach, not just what is convenient for them or if they are scared of needles, much deeper than that. It's emotional support...where are they getting stuck...not knowing what to do...and including their family and friends in this, too. Elizabeth

One MS Nurse felt that her nursing care was more patient focused than team focused at times, on one occasion suggesting alternatives to an allied health worker with an unreasonable exercise prescription for a patient. Another MS Nurse felt that her strong stand on research ethics sometimes put her at odds with her research colleagues, who just wanted to enrol more patients in a research study, even if it wasn't in the best interest of the patient at the time. She always won the battle.

I step in if patients are not keen to participate in research, they don't always want to. If it isn't right, I step in. If it is ethically wrong and goes against the grain of patient centred care, I will step in. Liz

Sometimes, nurses in general focus too much on the medical task first, missing out vital information by not sitting and listening and observing (Donnelly, 2018). Most MS Nurses in the current study echoed the importance of listening, of not just *not talking*, but really listening and observing everything about the patient. This included the tone of voice, the pace of the voice, the non-verbal cues. As Nightingale (2018) reminds us, observational skills are the core of the nurse's work, it is for the sake of saving lives and increasing health and comfort. It takes skill to focus narrowly on a problem and to observe the broader context at the same time (Donnelly, 2018). Many MS Nurses felt that this was at the core of their nursing skills and something that they excelled at.

Definitely listening...if you become judgemental or are more reactive listening than receptive listening, you don't get to the bottom of the problem and you lose that trust...the patient should be at the centre. Newera

MS Nurse communication is mostly listening...and less talk...often when you are nearly wrapping up at the end...something meaningful comes up as the last thing...the thing they wanted to say at the beginning but had to work up to saying it. Lillian

I think as nurses we are do-ers and you have to fix it, you have to have an answer, but in MS there really are sometimes no answers...we have had people in great distress recently and you start the call and worry...but you listen and let them vent...and by the end of the conversation they have often fixed it themselves, you just had to listen. Zorro

Home visits from the MS community nurses could be enlightening and much more information could be gathered about a patient during home visits. Being able to observe the patient away from the clinic allowed MS Nurses to have a more honest account of the patient's life and was able to highlight particular areas of struggle that may have been missed in the faster paced clinic environment, allowing truly holistic care. Home visits will be discussed in further detail in Theme 4, Disease and Symptom Educators and Managers.

Going into people's homes increased their comfort level, they felt more connected there...it was nice if I could see a newly diagnosed patient in their home, especially if they were uncomfortable in clinic seeing the more progressive patients there...you could see if they were struggling and you could see family relationships which you didn't see in clinic. Nim

Many MS Nurses spoke about the importance of meeting patients where they are at in the disease journey, rather than following a predetermined agenda of where patients should be at or forcing them to fit into an existing template of care. True presence creates the opportunity for nurses to go where the patient is in life, to learn about the experience of health, defined and lived working with patients as they choose the meaning of the situation (Melnechenko, 2003). This was seen as a pivotal part of the MS Nurse role. A major part of

this strategy was working out what the patient's understanding was; regarding all aspects of care, rather than just assuming patients were at a certain stage at a certain time.

I would ask specific questions designed to tell me where they are at in their thinking...and then we would talk about that (and not necessarily where I was headed). Lillian

I can remember one day with violent weather, rain and winds and I had a 90-minute drive out of the city to meet a new patient for injection training. I even drove through flooding to get there. I started to get the first injection ready and I detected things weren't quite right...I looked at her and said "you aren't ready for this, are you?"...she burst into tears...so we agreed to just play for today and we try again later. A huge disappointment to me in the circumstances, but I smiled at her and we had a moment together. You have to put the patient and where they are at first. Flo

Mary reported how she changed her communication techniques between patients in order to get the most out of every encounter and to encourage the connections that she believed led to more holistic care and meeting patients where they were at. Orion felt strongly that understanding a patient's background had the power to influence future care.

It is very individually driven...I might say to the truckdriver who comes in and says nothing is wrong, everything is right..."so, how are you really going mate, what's been happening, how is this, how is that"...and then the next patient might be a more formal Mrs Smith needing a more direct approach...I want them to know right away that they can connect with me, tapping into what that person needs at that time. Mary

With the newly diagnosed, I arrange a second visit where they can bring a friend or family member, we have a pow-wow of the nuts and bolts of how they feel...I really want to understand their background...what they understand...seeing where they are at. Orion

Lillian discussed the difficulties in supporting young women with severely progressive disease and also supporting their families and carers. Lillian described dropping small hints along the way to deliver information in parts which could be accepted before moving on;

she described it as a “*togetherness disease*” which necessitated “*tender conversations*” to keep the patient firmly centred in their own care in the most difficult of situations.

In progressive disease there can be many elephants in the room that have to be talked about...it is a very tender conversation with a few hints dropped and perhaps going over 2 to 3 visits...it is a togetherness disease, as it should be. It is about tender conversations. Lillian

MS Nurses were often keen to take as long as the patient needed in the beginning for them to feel comfortable working out what their new body looked like. Not fitting a proforma agenda of care, fitting the needs of the patient instead.

I recently had three, one-hour sessions just to start and work out which treatment the patient should go on. But that’s what they needed. Putting time in earlier pays rewards later, creating a relationship. Dawn

Often I would say to new patients “I’m taking you on a very quick tour through Europe and some areas we will come back to and stay there for a while...we will go back to the locations you need to again and we can do that anytime you need to. It takes the pressure off a person. Lillian

Subtheme 2: Changing pathways

This subtheme is about changing the pathway for a patient in order to improve their quality of life, about taking extra steps to produce a change. This change could be in terms of adherence to medications, accepting help from other therapists, looking at the disease differently, changing behaviour on any level. It is about digging deeper than the surface issue to bring about this change. Anything that leads to change in the more negative path they were heading down, to a path of more positivity, more benefits and a better quality of life.

The new drugs brought about change...I was one of the first injection training nurses and this opened up new pathways into holistic care...we finally had something we could do...we

could then help with other things and change their individual pathway with things like psychological help to stop them spiralling. Sue

Digging deeper and finding what is worrying them...for those struggling to walk safely, take that extra time to talk to them and break down the barriers by considering a scooter or wheelchair...the world could open up around them...later they say, "why didn't I do that years ago?". They have a certain perception (but we can change that for them). Nim

I like that we have gone from the past tragedy of MS to what MS is today...it is extraordinary. My favourite part about my role now is offering hope and challenging all the myths. It is myth busting...the patient coming in with preconceived ideas and coming to see me puts them on a new pathway of their thinking. They would come in down with a low mood and you tell the possibilities and expressing hope yourself...they walk out the door a different person...children, career.... it's not the same, but you can do this. Maureen

We change pathways for people through shared decision making and ongoing support... we do this by supporting people through life changing decisions such as family planning, career choice and employment. We listen, understand and validate their fears. Maureen

A major concept here was also changing pathways by making it common place to discuss things that may not be able to be improved. This was referred to by an MS Nurse as being prepared to go where others in MS care are too scared to go and really tackle the things that cannot be easily fixed. Sometimes just the discussion with the MS Nurse changed the pathway. Somebody understood.

A neurologist was disappointed I had items on my care plan that couldn't be fixed...but this is the real difference with MS Nurses, we explore areas that can't be fixed, we talk about it with the patient and see how we can manage it better. Isobel

When patients are not feeling good, despite the MRI being stable and medications all good...we need to discuss that...I take extra time and try and meet them at their home with

their family...I create a deep connection in the community...we want the best chance for this to work out for them. Sam

We are the vessels of reason...we can change fear into hope, change tears into joy and change weakness into strength. Sue

Subtheme 3: Situating hope in holistic MS nursing care

Linda Morgante was an American MS Nurse leader who became well known for her belief in the concept of hope being an essential component of living well with MS. Linda passed away in 2007, but her legacy of work to inspire and encourage nurses from all over the world to instill hope in MS care certainly lives on. The concept of hope touched the working lives of every MS Nurse participating in the study in some way.

“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)

Previous work on the lived experience of people living with relapsing remitting MS has identified the presence of various types of hope in the patient journey - functional hope (retaining functional capacity), restorative hope (going back to pre-MS function), curative hope (hope for a cure) and defiant hope (the fighting spirit to battle MS) (Burke, 2019). Most MS Nurses in the current study agreed that the concept of hope in MS care was not just about encouraging or sustaining hope in patient lives, but more about situating the right amount of hope for each individual patient, based on their holistic assessment. It is about considering the individual circumstances for each person; their disease state, their support systems, their health beliefs.

I feel like part of a healthy mindset is being able to look towards the future with positivity and optimism...our care is for hope of improving quality of life rather than fear of what will happen if they don't. Elizabeth

Hope is a bit like a placebo...I have a patient in a terrible situation who will pull through now because of the hope we have instilled...if we take away hope he could give up and (with a young family) we don't want that to happen. Liz

Balancing hope with realistic expectations can be fraught with challenge. The fact remains that there is no cure for MS, although there are highly effective DMDs, there is not a drug that will work for everyone. The other fact is that even with good relapse control, there can be deterioration in function over time as a progressive neurodegenerative disease, despite our very best efforts and careful monitoring. So, how to situate hope in this setting?

An MS Nurse participating in the study felt that nursing education from the beginning should centre on the fact that we have treatments, but that eventually the effect may diminish or recovery from relapses may not be as great. She felt it was important not to overstate hope in this situation, and believed it was up to each nurse working holistically to gauge when this discussion should take place, but as early as reasonably possible in the disease.

As an MS Nurse, we should incorporate discussion about the natural progression of the disease, but we have to be careful not to demoralise them...we want to maintain hope but also let them know that each relapse may not have complete recovery...their expectation may be too great if we don't say that. Newera

Hope is important at every stage of MS care, whether it be at the time of diagnosis, treatment selection, relapse care or even recommending a rehabilitation strategy or piece of equipment. Most patients crave for a crystal ball to have certainty. No one knows what a person's MS disease trajectory definitely looks like. As MS Nurses we draw on science, experience, and research-based probability when we provide counselling and education...but...central to this is also balancing our intervention with realistic hope. If you get the balance of hope right, I think it builds a good foundation for walking beside the person with MS on their journey. Mary

The abundance of drug choices to treat RRMS was the source of much hope for MS Nurses in their work, leading to many discussions with patients about the role of hope in their future care. This correlates nicely with the hope that PwMS place in their medication choices and therapies, hope providing parallel experiences for both the patient and MS Nurse. For PwMS, this is thinking optimistically, desiring to stay ambulant and the hope afforded by being treated in a time where so much drug discovery and development is taking place (Burke, 2019). For those patients newly diagnosed, this was seen as an important adjunct to therapy to instill a sense of persistence and engagement with the MS Nurse. That there were still things “up their sleeve” if needed. Additionally, the continuing clinical trials and new drug developments inspired hope in the MS Nurse which made it easier to situate hope in patients.

I am glad to be working in this era of highly effective DMDs in comparison to years ago where treatments were sparse, and outcomes were worse. (Now) this gives us, and patients hope for the future, as well as all the new ongoing research. Sarah

My involvement in clinical trials also keeps me continually hopeful that we will find a remyelinating agent; a neuroprotective agent; something to fix the damage that's been done, to some extent at least. I'm not sure we'll find a cure per se, but I think that with our better understanding of the causes, the genetics, tailoring and timing of treatments for individuals may in time be almost as good. Olga

I'm overwhelmed with patients wanting to participate in research...not many say no...they want to be part of the solution. Not only hope for them, but also for their families with the genetic links there. Maggie

Charlotte felt that some people living with MS have too much hope (are sicker than they think they are) and others lack hope (are not as sick as they think they are). As the MS Nurse, she felt it was her job to instill hope by being there and reminding them that they are not alone and also bringing some honesty to the conversation. Finding that balance of the right amount of hope is a particular skill of MS Nurses.

The right amount of hope is that they go home and don't think about MS too much...to be able to do all the things they want in life...maybe slightly differently...they need to live their life as unencumbered by MS as possible...the flip side is that you don't want them to fall on their faces either, particularly with progressive patients...it's about getting the words right.

Liz

A now retired MS Nurse mentor told me very early on that the best thing that we can do is to pull the little positive bits from patients' lives and show that it isn't all bad. I try and instil hope within my patients that there is light out there and we need to work towards that rather than the negative things. Leroy

Hope is everything...to get patients to buy into our investment in their future...in their health and well-being now and there is a good chance their future will be better because of it.

Charlotte

It was also postulated by some MS Nurses that hope and optimism are closely intertwined, and perhaps one leads to the other or that each is part of the other? An area worthy of further research.

Subtheme 4: Leading teams for multidisciplinary care

MS Nurses reported the skill of managing teams, particularly in the area of multidisciplinary care. MS Nurses were early referrers, meaning they could quickly assess if something was outside the scope of their nursing practice and refer on to the appropriate specialty, and do this early in the process. This was performed in the best interests of the patient with a firm nod to holistic care. There was a lot variation here in what expertise the MS Nurse possessed in particular, some MS Nurses had special interests in continence or counselling for example and felt comfortable to continue care with patients. Others knew exactly the point of referral and sought outside help for the patient as soon as it was needed.

MS Nurses need the ability to manage patient expectations and the ability and knowledge to know when to refer for help because the patient needs are beyond their scope. Orion

The MS Nurses are leaders in the health care team...they advocate for the patient with their doctor, with their support team, other health team members and their family. Newera

Within teams, MS Nurses realised they did not have to be the only expert in the team. In fact, the MS Nurses did a lot of the co-ordination to ensure that patient needs were being met and that outstanding things were followed up within a team.

It's OK to ask for help, it is not an expectation that you have to be the only expert, because we are always, always learning. Grace

You are the co-ordinator, the go-to person when something goes wrong. Everybody rings me! I am the in-between person between the patient and the neurologist...we are specialised here and we have an interest and know the right questions to ask...we work well with teams, with field workers, GPs, physios, occupational therapists, I email them as well as referring, I get in touch when the patient needs it. Isobel

Teams are fundamental when looking at caring for anyone with a chronic condition...our key role is to link it all together, areas of need with a holistic approach. Nurses are the lynchpin, the main point of the spiral...the MS Nurse is the core to outreach to everything...the voice and the channel to maintain quality of life for that individual. Sue

Often, problems arising in patient care were sent through to the MS Nurse to liaise with other teams and find solutions.

I spend a lot of time on the phone arranging...I have a patient stuck in another state at the moment, so I am arranging for them to have their treatment there (and not miss their treatment) ...I am the go-to for everything that comes in the door. Dawn

As important as MS Nurses are to their teams, many MS Nurse reported that their teams were just as important to them. That sense of camaraderie and support when needed, and

especially on a bad day. Knowing that they were not alone and had sources of support within the team was grounding and valuable.

We have a multidisciplinary roundtable discussion...our team is educational, informative and inclusive and we discuss problems...supportive and brilliant. Olga

Reflection Points: Holistic Healers

Reflection points for each theme will identify important concepts arising from the theme and provide direction for future discussion and possibly areas for research. As Holistic Healers, these thoughts arose during data analysis:

- Where in the team is the MS Nurse? Can an MS Nurse be the Team Leader? Does current framework allow for an MS Nurse to lead the MS team, rather than a Doctor?
- How do MS Nurses maintain their high standard of holistic healing when there are so many demands on them in terms of time and resources? Will current frameworks of tasks and duties always allow time for MS Nurses to stay truly holistic in every sense or will something have to give?
- The concept of hope in MS has remained strong for decades, but perhaps now it is time to explore how MS Nurses view hope, the importance of hope to their toolkit and how they feel hope has changed over the years.

These concepts in Holistic Healing merge into the following theme which explores concepts of providing support in MS nursing. Theme 2 “Sources of Support” investigates the different forms of support that MS Nurses provide in their practice and how concepts such as rapport, connectedness and advocacy are pivotal to this role.

Theme 2: Sources of Support

The theme of “Sources of Support” embraces all the different areas of support to others which have become part of the daily work life of the MS Nurse. The things that happen, often seamlessly, in order to support patients and others on their journey. Being mindful that the MS Nurse is often setting the patient up to be independent and to be able to manage their own disease, of being a cheerleader, of being the voice of reassurance and also to actively advocate and champion the patients under their care. This theme also recognises the role of the MS Nurse in supporting the work of neurologists and how the team approach of MS Nurse/Neurologist works in clinical practice.

The ***central organising concept*** of this theme is the provision of support, providing back up to patients and neurologists and the various forms that this support takes. Some support is easily given and comes naturally to MS Nurses as part of core nursing ethos, other areas of support are more time consuming and challenging requiring refined skills, but both are equally important to patient care and improved quality of life on the MS journey.

The five subthemes to explore Sources of Support in more detail are:

- Setting up the long-haul partnership
- Being the balm of calmness
- Enabling self-management, independence and empowerment
- Advocacy Actions
- Supporting Neurologists

Subtheme 1: Setting up the long-haul partnership

All MS Nurses interviewed in the study viewed developing a long-term relationship with patients as fundamental to their role. Much time and effort were put into building these relationships, with the ultimate aim being the establishment of a true partnership, where the patient and the MS Nurse both placed value on each other. As people are often

diagnosed with MS early in their lives, it potentially represents many decades of living with the disease and of working together. Several MS Nurses in the study had been working in the field for over 20 years already. Some had seen patients diagnosed as teenagers and were now helping them through parenthood or seeing them as grandparents. As very few patients are ever discharged from MS clinics, services and organisations, this really is a long-haul partnership requiring special skills. The MS Nurses participating in the study viewed the following skills as crucial to developing this partnership and fundamental to the success of their role:

- The establishment of rapport
- The formation of trust
- The ability to have meaningful conversations
- Accessibility, flexibility, patience and commitment

An essential skill for the MS Nurse to possess for the partnership to move forward was that of being an excellent communicator. Having the ability to provide complicated information in a way that was understandable and contextual to the person. One MS Nurse referred to this as “gentle” communication. Time spent here was seen as valuable and important to develop the rapport that was essential for a successful partnership.

I think as an MS Nurse you need to be a good listener, be empathic, caring and have a genuine interest in people...and patience...to be a gentle communicator and conscious of building a relationship. Ruby

At the beginning of the journey, time put in is absolutely priceless, taking the time without rushing, letting them walk away knowing there's no stupid questions and they can ring me for support...that rapport...making them see they are not on this journey on their own. Mary

To build rapport is my real focus (for new patients) ...they are trusting someone they have just met...my role is to provide the information and say there's no silly questions ...I

encourage questions...I always say I'm not perfect. I may not have the answer, but I can guide you. Orion

Building trust and lifelong connections with patients is a coveted part of the MS Nurse role. Sometimes this meant sharing a part of themselves as well in a well-considered and patient sensitive way, in order to be seen as genuine and authentic. Sometimes the commitment shown by the MS Nurse encouraged trust and rapport.

Persistence...that capacity to persist with a long-term relationship...you have to have a willingness to share part of yourself in the role...not necessarily by disclosing your own situation, but by finding ways to relate by sharing. Sam

Our role is to equip people with confidence and we can do that in lots of different ways, but we need to be genuine in our caring...people need to trust us and we build relationships to be there with them...rather than just as boxes to be ticked off. Rosie

There is a commitment to what you are doing and the people you are working with...look at the person as a whole, you can't go into it with tunnel vision. Developing a rapport with the person...if someone doesn't trust you, you won't get the information you need to help them. Rapport is everything. Elizabeth

We are in this for the long haul...we develop a relationship with the patient and their family...they touch your life and make a personal growth moment for you, yourself. Flo

Part of developing the trust involved demonstrating commitment to the patients and actively responding when needed so patients could see the trust was well placed. Ensuring that the partnership was strong, enduring and comfortable.

We want people to feel comfortable with us so that when they need us, they feel confident to contact us...people need more nurturing at the start than later on...we have the ability to take things forward. Charlotte

We have an open-door policy...I get pulled into clinic whenever a patient needs help, even on non-clinic days...which is my role. Developing close relationships...the beauty of nursing a chronic disease is the relationship, it is a unique set-up. The relationship is even stronger because we don't just talk about MS, we talk about holistic care...MS is only one aspect of their health. Our education is focused on them contacting us early to work out if it is an MS related issue or not. Newera

The MS Nurse needs to be grounded in common-sense and be able to develop rapport easily...and to be reliable. This helps to build trust in you that you have committed to the longer-term picture here and that you will be there for them when they need you. Win

MS is just so chronic...you will see them for a long period of time, and you will see them change. It is an honour to see a lot on their journey from the start all the way through. Isobel

I've been accused by a doctor of getting too involved...but I think we need to get to know each other so they feel confident with me to tell me things. They can be tough cookies to crack sometimes and when they trust you, it feels awesome...to be easier going for the long relationship we have ahead. Dawn

We need the patients to do their part too, we need their help...there are things they can do such as stepping up to be healthier, letting us know when things go right or wrong...you are doing everything you can, what can they do to help in the process? This also creates trust. Sam

An MS Nurse shared her disappointment on the rare occasion that rapport was difficult to build with a patient.

In MS you meet someone and within two minutes you have to work out how to approach them...you want to build that trust...if people don't trust you, they will not tell you what's going on. However, you cannot develop a good rapport with every single patient...if that rapport didn't happen, I felt like I failed them when we could not engage together. Flo

Subtheme 2: Being the balm of calmness

This aspect of MS nursing involved providing the reassurance needed when working with a disease with unpredictability and uncertainty, as one MS Nurse referred to it, *being the balm of calmness*. To be able to detect when it is needed, sometimes ahead of time or before things happen. This also involved being the sounding board, the listener, the one person who would understand and provide the calmness that was needed.

Working with the newly diagnosed...with so many questions, you bring that balm of calmness and acceptance to give them correct information...to educate them on their family adjusting to their MS...it goes back to meeting them where they are at. Lillian

They may say I've got something silly to ask but when you take the time and really explain it properly they really appreciate it...I understand I need to be a sounding board for them, it's hard speaking to family and friends about another bad day...to the MS Nurse they can say whatever they like...to be there, even if it's to say one day at a time. Sarah

Sometimes there is nothing you can do and it is just very sad...sometimes it is the silence which is like a healing balm, sometimes it is just out of our control....a sense of coming toward someone when you are uncertain...but you don't have to say anything. Sometimes there's words of calm and sometimes there's not...people with MS, that's what you have to do when there's things you can't fix. Just be. Lillian

We maintain that connection...our ability to understand...that ability to say the glass is always half full, you will never run dry, you have so much help around you...changing tears into joy. Sue

(The neurologist was always so busy) but if patients needed more time, if they were struggling...then they got me for as long as they needed. Grace

An important aspect of the balm of calmness was a quiet lending of strength until patients could find their own. As will be discussed in the next subtheme, the goal is for patients to

become independent, so this role does not take over, it simply lends strength from the MS Nurse to the patient for a period of time.

You are involved with patients until they have the strength to move forward on their own...you lend them that strength to take charge and move forward... lending that strength is so important...later on they may be the one to climb the summit in Nepal to prove to themselves that this is not going to beat them. Sue

Subtheme 3: Enabling self-management, independence and empowerment

Patient care in MS nursing has a strong element of self-management involved, often from the very beginning with diagnosis. In chronic illness it is well recognised that self-management, in addition to medical management, is a priority, using a participative partnership to facilitate control (Koch, Jenkin & Kralik, 2004). Teaching self-management is recognised as a core activity of nurses in outpatient settings and works best if aimed at increasing patient motivation and self-efficacy (van Hooft et al; 2017). It has been reported that nurses are well placed to deliver preventative programs and promote health in primary care, with nurses improving the health status of chronic illness patients by leading self-management strategies (Massimi et al; 2017). Most MS Nurses participating in the study reported the importance of getting patients off to a good start at the beginning of their journey by investing time and effort in education, but of being mindful that there came a time when they had to pass the wheel over to the patient and take a back seat. In fact, this was seen as the ultimate aim of their intervention; that the patient would be able to self-manage in the community after an individualised period of time. Empowerment was a major goal to develop with patients.

I would teach patients my thinking processes out loud so they could see my process...“could this be an infection...is this new...OK...am I sick”? Patients would then call and say “I have a new symptom I haven’t had before, and I have already been to the GP to rule out a UTI”... to use that thinking muscle and give them tools to assess themselves. We speak the patient’s language but also teach them how to manage the disease themselves. Lillian

I like to be careful with my expertise properly...we can pamper them at the beginning but at some point, you need to start slightly moving aside...as part of empowering to direct them.
Newera

My role here is in empowering people with information, rather than making them dependent on me...to be non-essential because they already know the answer and they are calling me more for reassurance rather than true advice. Rosie

Patients need lots of touch points in the beginning...we don't discharge them and they always need to be able to jump back in later if they need us...we give them the diagnosis and then we build them up and we should have them managing their own disease independently and just coming back for a tune up. To self-manage from the beginning...and then have a plan in place...not hand holding all the way. Liz

I put a lot of time in the first 12 months to give patients the skills but then I don't need to be a hand holder. You build their capacity and then you let them go on their way, giving structure but not making the calls for them. There's the real skill in what we do. A patient once told me "you are the spare tyre in my boot". Lesley

As many people are diagnosed with MS in young adulthood, it may be the first time they have had to navigate the medical system and learn the intricacies of being a patient and how the health care system works. Teaching patients how to navigate their new world is an important aspect of the MS Nurse role.

We help people navigate the new world they are in. They need to know the landscape of their new world and where the help points are along the way. We want to be known as helpful, patients and families to say that we are on their side...part of my team. Lillian

We are the communication vessel to guide the patient to make informed decisions...we know where to go to get things sorted out...as we help patients navigate through their new world and the new systems. We have our fingers on the pulse of all areas. Sue

I try and get people to live their 10/10 life...the neurologist can't fix everything and sometimes you need a total shift to help people...getting them to understand expectations...I can identify areas for improvement in their life...I am here to talk to them if needed...to give control back to them and options. Charlotte

I teach patients to navigate the system, so I also need to know the lay of the land and what locations on the journey, so I can point patients in the right direction. This varies greatly between patients and their stage of life. Lillian

Subtheme 4: Advocacy Actions

Although the word advocacy came up in every interview as part of the role of the MS Nurse, it was in various formats and not always within the true nursing definition of advocacy as promoting and safeguarding the well-being and interests of patients, by ensuring they are aware of their rights and have access to information for informed decisions (McFerran, 2014). Mostly it was meant by the MS Nurses as being there for the patients, to be constantly on their side, of taking actions to protect them and to promote health. This is more in line with Vaartio et al's (2006) research which summarised nursing advocacy as voicing responsiveness; of a professional responsibility and active commitment to take part in the continuous expression and support of patients' needs and wishes.

Speaking on behalf of patients is probably the best candidate for a commonly held meaning for advocacy (Kalaitzidis & Jewell, 2015). Sometimes advocacy took the form of taking care of paperwork that was needed for NDIS even when there was no time to do this labour-intensive task in a consult, it was letters for employers, advocating for accommodation. Sometimes it was suggesting the right fit neurologist for patients or moving them to another doctor discreetly if requested. It was saying no to other health care professionals with unreasonable expectations of the patient, of making calls to try and get patients needing allied health treatment sooner, sometimes it was simply stepping in with families to make them aware of the invisible symptoms and difficulties a person may be challenged with. It truly was voicing responsiveness.

Advocacy is a big part of it no doubt...knowing the people, knowing the community and the history of what has gone before, what has worked and what hasn't...the willingness to go in to bat for people, not just in medications, but in funding support opportunities and for equipment and hunting around, heads together, which community group can we go to help fund a scooter? You do your best to get every service you can for them. Nim

MS Nurses really advocate for their patients, there are some quite achievers who are amazing. You want the patient to have a good experience, you don't want the patient scared and not knowing what to do or who to go to. You also need to be assertive with other health care providers, neurologists and other nurses...use all your peers and draw on everybody for the best outcome for the patient. Grace

Advocacy is a huge part of what I do...I see my role as really picking up what the patient needs...whether that's a referral or bringing them back to clinic. Sometimes it is as simple as getting the patient to recite back to me what the neurologist has told them so I can be sure they are going home with the correct information. It's so stressful for them and I want to advocate in this way for them. Maureen

If a referral doesn't look good, I get them in as early as I can. I also help choose the best fit for the patient with doctors...I get them onto the MS organisation as soon as possible to get home things and lifestyle sorted. Dawn

You want the patients to feel secure and for you to be authentic...it's not always easy for patients to come in and see me so there's lots of flexibility with my work times and quite often I'm in on my days off to suit a patient. I don't clock on and off as such. Maggie

I always tell the patients to let me know how they get on the neurologists in our clinic...I tell them to let me know if they do not bond, it's a long-term relationship and we need to set that up for them. Gerty

One story from Liz highlighted some of the extra work that some MS Nurses do to ensure their patients don't go through additional suffering on top of what they have already been

through and to make the system “work” for their best interests. Especially if they have had a difficult path.

Advocacy is part and parcel of the job, it is everyday...I drive around a bit for patients...I drop off medications regionally if the patient is going to be disadvantaged in any way. One time a new infusion was in jeopardy because they couldn't get stock for the patient. I couldn't let that happen as the patient had been through so much to get to the point of starting treatment...so I drove a long way to get the medication supply there. I've done that a few times to make things happen. It's nothing special. Liz

Advocacy can also often be demonstrated in completing the paperwork that has accumulated since the introduction of NDIS, often taking over a clinic appointment and taking so much time to complete correctly for the patient to have the services they require and the best outcome.

I advocate, advocate, advocate. I fill out most of the paperwork for NDIS and applications as needed to be on the patient's side and make them heard and seen. Liz

At times advocacy was knowing when to back off and not push too much when the patient was unsure. For one MS Nurse, this involved taking a back seat when a patient was not keen to start the drug therapy recommended. Advocacy actions can be shown by the MS Nurse informing the patient of all the possible outcomes, ensuring they have all the information, supporting their decision to not go on therapy but continuing to support them and see them as needed.

We treat aggressively with drug therapy for better outcomes...but if someone doesn't want to be treated, they don't want to deal, they just shut down...I just tap away, let them know I am accessible on the phone anytime they need me. I try to be there as much as I can, I refer them to other sources of support too, so they are not alone. Leroy

We try and understand the fear that people have and scratch beneath the surface to unload their fears...even if there's nothing you can do to help; I can listen, and you can be heard. I am there. Nim

Subtheme 5: Support for Neurologists

Throughout the study, support for neurologists from MS Nurses was evident in many different ways. From the more traditional doctor/nurse partnership where all patients were discussed in clinic and a team approach implemented, to community nurses responding to requests from neurologists for patient education and community support, to pharmaceutical company nurses being called in to train patients in drug administration or being available to answer queries on medication side effects. Many MS Nurses felt that the neurologist/MS Nurse relationship was one of the most important in the team and required careful nurturing and development on its own. The results were deemed to be well worth it - with open, seamless communication and mutual respect came improved patient outcomes. Many MS Nurses felt deep admiration for the neurologists they worked with and recognised in return that there was a great deal of mutual respect and understanding. This was not restricted to hospital or clinic nurses. Organisational, community and pharmaceutical nurses also reported enduring and respectful relationships with neurologists who trusted them in the role and relied on their support.

I am an extension of the neurologist's right hand...we had a whole team, but we worked particularly well together. I could communicate with him and achieve the best outcomes for the patient. Unfortunately, the neurologists have very limited time...we are there to be an extension of them, not only for communication backwards and forwards, but to highlight the areas we need to come back to. Sue

(We are a small team)...the neurologist I work for is very open minded and approachable...we work together very well. I send a lot of emails and messages. They are a good communicator and a great human being; I feel supported working with them. Ruby

I am always directed by the neurologist...I'm guided and aware of that, so I do always reiterate their instructions...sometimes the patients don't want to bother the neurologist with stuff...or they may be embarrassed...but they know I will always pass on the relevant information to the neurologist. I feel I communicate with him so openly and he knows I am not giving out my own advice. That helps build that relationship and we work very well together. Sarah

We (MS Nurses) have a close relationship with the neurologists...we do all of the initial referrals to clinic and we would discuss patients as a team before clinic and determine together who would take on the new patients. We stopped patients needing to go to ER, we streamlined relapses communicating with the neurologists, for the patient's sake and theirs. Nim

The neurologist I work with and I share the same vision...as I am so involved with medication decisions, he shows me the MRI, there is real respect that I need to have all the information to guide the best choices for the patient and make sound decisions. That has really evolved over the last five years and I really treasure it. It is mutual respect. Mary

There were also less traditional methods of support to neurologists, and these included the MS Nurse MRI tracking and organising follow-ups, collecting data for research, reporting serious adverse events, entering and managing research data and maintaining patients in research studies.

There is a lot of enthusiasm from the neurologist to do the studies, but not the hours to do all the work required...that's where I step in. Maggie

But working to support neurologists is not the only consideration here. It is the synergy of the roles that is important, taking over the role of the neurologist doesn't come into play for Sam, nursing has its own role.

With our extended roles we fill a gap between registrars and GPs, it gives confidence, but I still encourage patients to talk to their neurologists, I don't pretend to know it all. We relate

things between patients and their doctors, that relationship you build is the best part of the role. It doesn't matter the nurse setting; you do the same. Sam

There are lots of ways I support the neurologist, from logistics to collaborative consultations. I think the nurse has the advantage of developing a different relationship with the patient...we hold more knowledge about that particular person. We feed that back to the neurologist; the clinicians listen to us. Then they know the information, too. Maureen

An immense amount of support to the neurologist was evident in the area of drug therapy, this will be discussed in detail in Theme 5: Medication Managers. However, specifically relating to support for neurologists, it was suggested by an MS Nurse in the study that there is an increasing amount of role substitution happening as the medications have evolved, with MS Nurses becoming responsible for patient care in ways that they are not properly trained for and are not part of the nursing role, rather they fall into the domain of the medical role. Open discussion of this issue is crucial for the future of the MS Nurse.

There are a lot of boundaries and patriarchy issues...nurses have the opportunity to set boundaries, but when they start to role substitute, you set that expectation. This happened with Lemtrada when it first came out with many MS Nurses putting their hand up to receive after hours messages about abnormal pathology results...only a few nurses said they wouldn't take those calls. I'm all for safety, but it was a non-nursing role. They missed their opportunity to be clear about this and once that happens, it is hard to go back. It is expected then with each new drug to role substitute. That is definitely not my nursing role, but I feel many nurses missed that opportunity. Lesley

Reflection Points: Sources of Support

- Building the long-haul relationship provides an excellent foundation for the MS Nurse to have a lifelong strong partnership with the patient. But does this come at a price to the MS Nurse? How does the MS Nurse seek or receive support?

- Similarly, in the area of advocacy, are there avenues for MS Nurses to receive their own support and advocacy when needed?
- Are there boundaries which are too blurred in supporting neurologists in a team? Some teams have strong connections and meet each other regularly in a supportive environment. Others, including some in the community, rely on phone calls, emails and provide telephone advice to patients they will never meet. Is there a way to promote some unity between the roles to ensure open communication and meeting of common goals?

MS Nurses provide many sources of support as part of their nursing role, as demonstrated throughout this theme. This extends into education and disease management, often to the newly diagnosed, but also at many touch points along the MS journey. As an unpredictable disease, there is no certainty about the future for patients or MS Nurses, so there are always opportunities for learning and growth. The following theme “Disease and Symptom Educators and Managers” will discuss the many aspects of managing this complex disease in daily practice and the important aspects of the MS Nurse role in this journey.

Theme 3: Disease and Symptom Educators and Managers

The theme of “Disease and Symptom Educators and Managers” highlights the important role that MS Nurses play in educating people living with MS, their families and loved ones. This role is crucial, and several layers of the educational responsibility were revealed during the course of the study. The role of teaching and developing a teaching style to suit individual patients, the importance of setting the scene for later expectations, the role of storytelling and analogies in the MS Nurse toolkit. Also of importance in this theme were concepts of education in relapse management, of symptom management and the important role of home and community MS Nurses in easing the load for patients and of uncovering specific areas of need.

The ***central organising concept*** of this theme is the fundamental nursing role of providing patient education so that patients are able to gain independence and manage their

symptoms and disease in the best way possible. The MS Nurse is central to disease management and often the first port of call if new or concerning symptoms arise. The MS Nurse can also be a comfortable ear for symptoms which are embarrassing or not comfortable to be discussed with the neurologist, many of which can occur in MS. Stories of the impact of MS Nurses being involved in home and community care also underpin these concepts and offer a broader understanding of the MS Nurse role in adding value to the home situation.

The theme of Disease and Symptom Educators and Managers comprises four subthemes which will explore these concepts in greater detail:

- Education and setting the scene
- Relapse management
- Symptom management
- Adding value with home visits and community care

Subtheme 1: Education and setting the scene

MS Nurses revealed that one of their key responsibilities is the education of patients when they are newly diagnosed, as well as the many touch points of change throughout the journey of living with MS. These changes could occur at almost any time and were not always directly linked with times such as relapses or onset/progression of symptoms. They could be indirectly linked, for example during changes to employment, of pregnancy or of changes to infection status such as JC virus antibodies.

All MS Nurses interviewed reported that educating the newly diagnosed patient was one of their major responsibilities and one of great importance. Setting the scene for a lifetime of living with a chronic illness was viewed as possibly one of their most important roles. The expectation that MS Nurses put on themselves was that they needed to be excellent communicators, proficient with adapting different teaching styles for individual needs, they needed to be relatable and they needed to be astute with the level and length of education

so that patients would not get too overwhelmed. MS Nurses also recognised that educating the newly diagnosed patient involved setting them up to be independent and to self-manage, as discussed in the previous theme.

A special skill mentioned frequently was to respect the patient's knowledge before this educational process commenced, going at the patient's pace as outlined in theme 1. Assessing what the patient already knew or had researched was also a way to show regard to their own learning, without assuming that they knew nothing about MS. These discussions could also enlighten the MS Nurse to teaching methods and individual learning styles to ensure this was a success.

Patients have the same access to many sources of information that we have...accessing educational things, they have that capacity. Patients bring things in and sometimes they can surprise you. It's important not to dismiss them, asking them what is important for them to know? Let's respect their knowledge and then help them interpret and relate this information. We need them to be integral...they might talk through Facebook and we need not to dismiss the platforms they use, we need to respect their choices, it has to be putting the patient at the centre. Sam

Sometimes patients have unrealistic expectations and only look at the pros and not the cons...so I start education with what is good and then also what is not so good and what they already know. We do get challenged at times, but mostly we can get the best treatment options across. The newly diagnosed have not developed trust yet and they are learning us and we are learning them. Later on, I can be more confident with education, but we need much care in the early stages. Newera

Our education with every person is different, there is not a similar pattern like with other diseases and conditions, with MS there is no pattern, no nice, planned what will happen. Isobel

You get immediate feedback from patients, they certainly let you know. The satisfaction comes with working out the key to communication for that patient...the skill that I have

honed is being able to work out what each patient's communication needs are, the non-verbal clues...it's about listening to them. Do they want statistics, do they want information, do they want only a little bit and for me to go away? Providing the right amount and style of communication. Liz

Much of the information taught involved translating complex medical and scientific information and data into more easily understood concepts. To do this effectively, MS Nurses need to have an excellent understanding themselves. This also involved investing time into each patient to meet their individual needs.

You need to have very good translational skills; you need to be able to translate the research to bedside information and have good interpretation skills to compare all the drugs and in a way that is not too science based...into layman's terms. Orion

With the newly diagnosed you could take the load off them with education, simply explaining things and dispelling bad information early...turning their despair into hope with simple explanations. Flo

Generally, my first talk is not too in depth, I do only a little education early. I get them back when they have had a chance to settle into the information and then we talk about the life ahead. The teacher side of me only wants to do a short session when they are in shock but then a longer session where we put the pieces back together. Leroy

At the first consult, the patient doesn't hear much past the words Multiple Sclerosis, so we try and get involved then, to have that input and education early. Time here really pays off...that's when you need to invest the time. Olga

For the newly diagnosed patients I would get the ball rolling on education and I made such a difference. During education sessions you would also find out so much more about them. Let's make useful, meaningful things to use to educate our patients. Grace

Storytelling is a verbal recount of similar meaningful experiences that individuals share and allows an opportunity to discuss concerns (Curico, 2017). As an educational strategy, storytelling is well established and used on the healthcare frontline to promote healthy behaviours, focusing on educating and transmitting knowledge and skills (Haigh & Hardy, 2011). Additionally, stories are reflective, creative and value laden, and usually involves something important about the human condition (Haigh & Hardy, 2011). For nurses, storytelling is a special way of sharing, knowledge and creativity in a meaningful experience (Lindesmith & McWeeny, 1994) and uses intuition, empathy and emotion in the process of healing (Heinrich, 1992). Analogies have been used in medicine for a long time to describe various aspects of the disease process in a way that patients can understand (Troger, 2017). The use of storytelling and analogies in the toolkit of the MS Nurse deserves a special mention. Although used extensively in many educational and conversational interactions with patients in the MS journey, storytelling really came to the fore when calming an overwhelmed patient, trying to inject positivity into a situation or simplifying a complex concept.

I use storytelling a lot...just a different way to help patients see the light at the end of the tunnel. Patients like to hear stories of how others have overcome similar issues. Lesley

Answering people's questions with examples is so important...like with problems of proprioception I might liken this to being in the shower under the water with shampoo in your eyes and losing the sense of where you are at...it helps them understand how to be safer...I use examples of the electrical substation with an outage when explaining the disease process to patients. Lillian

I use analogies a lot... my favourite thing! When I compare treatments, I use an analogy of cars and trucks...of mini minors for some drugs and Mack trucks for others...I use telephone cords (electrical transmission concepts) and icebergs. It helps in order for them to retain the information and not feel so overwhelmed. It helps build rapport and lighten the mood...they can get intimidated with all the medical lingo and this makes it much less scary. Orion

I have learned to have several different explanations up my sleeve for what patients needed. In things MS, I have the totally lay version I could tell my partner without him getting bored, and also the version I would discuss with peers and colleagues...then I tailor those two explanations to what the patient in front of me needs. I use stories a lot...we tell them everyone's MS is completely different, but they need to hear about other patients. Elizabeth

The MS Nurse is an excellent translator...it is a good word to describe how we change the complex to simple. Translating information to make it more meaningful and to give context for people to tie it all together. Lesley

Subtheme 2: Relapse Management

A major part of the education journey about MS for patients is to learn about identifying and managing relapses. Certainly, this is one of the most common areas for concern when working with a newly diagnosed patient and requires intensive work from the MS Nurse. After a first or second relapse leading to a new diagnosis, patients are often anxious about what is and is not a neurological sign of a possible relapse and it takes considerable skill from the MS Nurse to communicate this information to patients in a way they can understand. Particularly considering that MS Nurses and neurologists do not know the site, timing or likelihood of the next relapse and what it may present as neurologically, the possibilities are endless. Many MS Nurses made themselves available to patients freely during this important time, believing it was important to be responsive and active with them in order to teach them the process of identifying a relapse early and the appropriate management. An important part of this education was to be easily accessible by phone or email so patients could contact the MS Nurse when needed.

Our education is focused on them contacting us early to work out if it is MS symptom or not...they learn...it is not that we will necessarily always do anything, but we help them work out what is MS and what is not. We teach them as they go along. Newera

Most relapses come through to me by phone, some through email...we demonstrate hospital avoidance with our service. Patients always know I will try and prevent them spending hours

in the ER, I get them seen and sorted and to miss ER, unless they are unsafe. I want the best outcome for the patients. Mary

I manage a lot of calls and emails triaging relapses and symptoms to keep patients out of ER, working out what's happening. I have headphones to help me as I am on the phone so much. Dawn

I am on the phone a lot, it is hard with relapse management as you are separated from the body, but I appreciate that patients know themselves better than me, so I rely on them and it usually goes fine. Win

Part of my work with patients (in relapse management) is for them to call in to me early to prevent an ER admission...we can use steroids and we can get them in straight away. I'm assessing if it's a sensory relapse, can it wait until Tuesday, or if it's more serious how soon we can get them in. Make them confident that they can ring and get an answer. Gerty

Subtheme 3: Symptom management

Symptom management of acute and chronic MS symptoms is undoubtedly one of the mainstays of MS Nurse clinical practice (Ben-Zacharia, 2011; Halper & Harris, 2016). Educating about and managing symptoms of MS for many MS Nurses was still seen as an important facet of the role if they could possibly help. Recognising the unique role of the MS Nurse in identifying issues and taking the time to do a proper assessment was key.

I'm the dogsbody of clinic...in my nurse clinic I deal with cognition issues, I do bladder and bowel assessments, remind about pap smears and skin tests and call the doctor if they need to be updated. I also talk to them about new symptoms, we address the things they really need help with. Liz

I make a lot of time for symptom management, especially with progressive patients. I make it my priority to do symptom management with them. Maureen

It is difficult explaining to people how disease progresses, even though everything is "fine"...when they feel like shit but the MRI is stable...we have the capacity to say, yes, that's good, but let's look at getting you functioning as well as you can be for your family. I talk it through, and I dig deep. Sam

Seeing patients in clinics or talking on the phone, it was a lot of joining the dots. Helping people to know that just because it might be a common symptom, they didn't have to put up with it...there's such a loss of control with MS...just have a chat about what we can do to give control options. At heart we are fixers. Charlotte

We bring different things as the nurse rather than the doctor to symptom management...I always give the person the time...we look at them in a more holistic way rather than putting the symptoms down as bits. We also go beyond medical...we facilitate with families and services that may not come to the mind of other health care professionals. We work well with allied health and refer when needed. Isobel

At times, part of the nursing skill required in symptom management was to recognise that the symptoms were there, even if there were no specific management strategies to assist, just to recognise and be an ear to a confused or weary patient.

It's very common for patients to blame MS for every symptom they have, on many occasions they forget that MS is only one aspect of their health. Our education focuses on contacting us early to work out if it is MS or not. Newera

There are things that the doctors can't fix...but as MS Nurses we explore those areas that cannot be fixed, it doesn't mean we can't talk about it and see how we can manage it better; we are in a good position to do that. Isobel

Even if the doctor might tell a patient that it is fine...EDSS is fine, MRI is fine...you are fine...but then the patient comes to me and tells me they are so tired, brain fog...they almost they wish something was on the MRI to relate to the symptoms they have. They come to me

to discuss what we can do and to have a whinge. They say they have no-one to talk to about these things, their families get sick of them. Dawn

An important rising area of symptom management is the promotion of wellness in patients and this is an area that MS Nurses have embraced.

I do a lot of holistic wellness, vitamin D, exercise and I try to instil general wellness...about diet, smoking and exercise, just being generally healthy. Sarah

We maintain a connection with the wellness approach...we are inventive and imaginative...we can help dive into it, trying to empower their ability to have strategies and resilience. Sue

I want to give them the practical things they can do...lifestyle...I talk on about exercise and there is sound research around the benefits...to stop smoking and all of those things. Zorro

Vital to the battle of MS was MS Nurses being actively involved in helping patients acquire and maintain mental health. Almost all MS Nurses interviewed felt strongly that this area was one of challenge for them with many feeling that although they already had strong skills here, there was always more to learn. And always that one patient they never felt sure or comfortable about.

We would see young and healthy patients being diagnosed with MS and spiralling with no psychological help...we knew we had to change that pathway for them. Sometimes suicide and depression would come into play. We had to upskill very quickly. We are so privileged to be in patient's lives at such a vulnerable point...we cannot change the diagnosis but we can enhance that path so that instead of a rocky path that looks dark, we can make it a smooth path with the lights on...to feel supported. We know how to swipe into different psychological services...to safeguard the patients mentally and stop the fear mongering. Sue

I always try and incorporate assessing for depression...and understanding more about suicide ideation. I put into my own words about negative thoughts and mood with patients

and then go in a bit deeper if needed. I refer them on as soon as possible once I identify a potential problem. Sarah

I sometimes feel I am lacking in mental health. I am not bad at it at all, I just need to learn more about it because our mental health service is under resourced and even if we refer on, we still have a period of time where we are all the patient has. For one young patient I was very worried about, I stayed in close touch until mental health were able to come on board, trying to avoid a crisis. Sadly, last year I lost a patient to suicide and I felt like I failed...I have accepted now there was nothing I could do, but I would like support in this area. Isobel

For MS Nurses working (often alone) in the community rather than in a clinic, there were special struggles with looking after mental health for patients.

I struggle with mental health crises and suicide ideation over the phone. It's heavy and tough and I feel like I have to carry them. They should have a network of care, me on the phone providing general advice should not be the fix...but sometimes it is their only option...that is so challenging. Charlotte

An interesting concept arose with one MS Nurse suggesting MS Nurses are “generalist specialists” in the role. It captures the essence of the breadth of MS nursing skills perfectly, especially in symptom management.

As MS encompasses so many symptoms...although we are specialists...we are generalist specialists ...some of the areas need more specialised care, such as continence, but for many other things we are generalist specialists, having the components of a specialist nurse but over so many generalist areas. Sarah

However, one of the problems in today's setting is that so many other demands (to be discussed further in Theme 5: Medication Managers) weigh in and compete with this most basic and traditional MS Nurse role. Several MS Nurses felt that symptom management now became a quick consult out of necessity to move onto other things, rather than the well-considered and planned MS Nurse skill of a decade ago.

I never really have had the time in recent years to spend too much time on symptom management, on many occasions I had to simply refer on to another health care professional. I know every MS Nurse would have a different perspective, but I wish I had more time for this, I really do. As the medications became available and there was so much care to take, by default they became the focus and symptom management I just could not fit in as well. I saw the risk management as more important. The symptoms still concerned me, so I referred on to others a lot. Lesley

I don't really have time for a lot of symptom management these days...I ask patients what are their biggest 1 or 2 issues and concentrate on them with the neurologist. I get them to ask the doctor what can be done and be tweaked. For symptom management, a lot is navigating where the concern needs to go...to a physio, to an OT, to a psychologist. They are the experts. It's that conductor thing. Gerty

Subtheme 4: Adding value with home visits and community care

Several MS Nurses participating in the study were able to do home visits as part of their nursing work. Some of the stories from MS Nurses about the value added to disease and symptom management if they were in a position to visit patients at their own home were extraordinary. Being able to provide education, training and assessment in a trusted, comfortable environment often enhanced the patient learning experience. Furthermore, MS Nurses visiting the home were able to gather additional information during these visits to be in a position to understand the patient situation more deeply or to arrange other areas of need identified with a home visit.

The home environment is usually more comfortable for patients, they can have more family there and I allow more time, and can do after hours if needed for work and family to fit in. A selfish benefit of these home visits is that I can see how they live, and it can guide me a little more on what may or may not work for them...whatever we are hoping to use in their battle plan to manage MS. Sam

During my time working with people with advanced MS, I saw how much effort went into preparing for medical visits, sometimes days preparing, avoiding activities to preserve energy and weeks of preparing questions as they were likely to be fatigued and forgetful by the time they got there...doing home visits these struggles are avoided and the person can have much more energy and concentration to discuss the issues they are facing at their clinic appointment. Elizabeth

Going into people's homes increased their comfort levels, they were more connected. In the home you got a bigger picture of what you couldn't see in clinic...an eye opener really. You could see if the home wasn't matching what you saw in clinic and if the patient was struggling. This was a huge plus for patients...then I could step in and arrange what was necessary. We also gave them all the time they needed. Nim

Mary recounted possibly the most poignant story of all the interviews. A story of assumptions based on the information you have and not knowing what you don't know. It is a long story, but the message is well worth it for MS Nurses. It encapsulates all that MS Nurses do, and what they want to do, to ensure that quality of life for the patient is the best it can possibly be. It expresses the heart of MS nursing.

I was doing an outreach visit about 4 hours away from the office, sometimes we made those visits if we were worried about someone. This young lady I had been helping over the phone had told me her walking was getting worse, so I decided to take a physiotherapist with me to also do an assessment. I didn't know if it was a relapse or background deterioration.

When we got there, she was already sitting on a bar stool at the table and waved us in the front door. After about a half hour of talking, she said she needed a bathroom break...(MS Nurse starts to cry during interview)...she slipped down to the floor hanging onto the chair and then proceeded to crawl to the bathroom on her hands and knees...I cannot tell you how shocked I was...in all the times I had been speaking to her on the phone, I had not realised how profoundly affected she was...when I thought back to our talks on fatigue, I had simply advised her to rest more...I couldn't believe what I was seeing...and the deep level of sorrow I

was feeling. When she came back from the toilet, I awkwardly helped her back onto her chair.

I told her then I didn't realise how much she was struggling, and I apologised if I looked upset, but she downplayed it a bit. She had been advised early on (when she was diagnosed) that MS was a progressive disease and she might have mobility issues later...so she just accepted what was happening and didn't question it. People, what they are willing to accept... if I had not seen that with my own eyes, I would have just kept offering reassurance on the phone. From that visit and what I learnt about her, I was able to organise steroid treatments and some equipment. It was the very first time I realised the inequity between city and regional patients...it changed my life forever. No-one has to live like this. I knew then I needed to upskill, and I needed to ask my questions differently over the phone. Seeing her on her belly on the floor...I cannot tell you the value of seeing someone in their own house, in clinic we see them how they want us to see them, but in homes you see it for exactly what it is. Mary

Reflection Points in Disease and Symptom Educator and Manager

- The argument was raised that with increasing roles in education and medications that MS Nurses are losing the time to help patients with symptom management. How can this important nursing function in MS care be protected, supported and maintained? Is there any capacity for it to be extended?
- As community and home visits have reduced over the years and most MS Nurses are now working in clinics and hospitals, how could the benefits of those home visits be reworked into clinic care? Is there a way to gain the depth of the information gained in home visits through different questioning or activities during a clinic visit?

Of course, becoming educated and confident in disease and symptom management with MS is only part of the journey for a person living with MS. A substantial part of the education and management process to look after the disease also involved discussions on the many and varied medication choices for people diagnosed with RRMS, and more recently, some

new drugs for progressive MS. The next theme will delve deeply into the role of the MS Nurse as a Medication Manager. This often goes hand in hand with the subthemes discussed here in Disease and Symptom Educators and Managers, especially for those newly diagnosed, but can occur at any stage of the journey and requiring specialist MS Nurse intervention.

Theme 4: Medication Managers

Early action, proactive monitoring and treatment with an appropriate medication to modify the disease course, incorporated with shared decision making in a holistic setting, is essential to treating and monitoring disease activity in MS (Giovannoni, 2016). The role of “Medication Manager” was seen by many participating in the study as the field of most expansion for MS Nurses in recent years. Several MS Nurses participating in the study were in the very first groups of nurses to become MS Nurses in the region with the advent of the first drug to treat RRMS, Betaferon®, becoming available in Australia in 1995. Initially known as injection nurses, these nurses quickly realised the potential of their role in safe and adherent administration; along with the many other areas they could upskill in to help patients manage the disease. It could be argued that MS Nurses started to be seen in practice more regularly as the result of this unmet need; the need for patients to receive training to self-administer the injectable medication. The medications used to treat MS became known as disease modifying drugs (DMDs). In 2005 there were four injectable medications approved for use in RRMS in Australia. In 2020 this has risen to include 13 injectable, oral and infusible drugs, all with different side effect, safety and efficacy profiles.

The ***central organising concept*** of “Medication Managers” is the role that MS Nurse play in organising the many different drug treatments available in MS, the DMDs. Critical roles in patient education, in shared decision making, in persistence and in adherence to medications and the safety programs that go along with some of the more recent approvals. The logistics of starting or switching drugs is also an important component of this role.

The theme of Medication Managers has four subthemes to explore the different components of this role:

- Initial decision making and treatment switches
- Drug safety monitoring and side effect management
- Adherence and persistence
- Logistical organisation

Subtheme 1: Initial decision making and treatment switches

Following a diagnosis of MS, the objective should be to initiate and continue treatment with the DMD which is most appropriated to the disease course and values of the individual (Giovannoni, 2016), considering the impact of employment, family planning, lifestyle, likely adherence and risk attitude (Giovannoni et al; 2016). It is also advised that these complex factors around DMD choice should be discussed collaboratively between the patient and the health care team (Costello et al; 2015), leading to shared decision making in an individualised setting. This was seen as the “bread and butter” of many MS Nurse roles, whether in the hospital, clinics, pharmaceutical training arena or in the community/organisational setting. There are two aspects to this subtheme – firstly, the initial treatment decision for those newly diagnosed with MS or starting on their medication, and secondly, those undergoing a treatment switch to another agent.

The initial decision-making role required excellent communication skills, being able to translate complex medical and scientific information to patients as discussed in the previous theme. Often the neurologist briefly introduced the drugs and left it up to the MS Nurse to further explain in depth about administration, side effects and safety management. Sometimes the neurologist recommended two to three options to discuss with the MS Nurse and left the final decision to them. Not as commonly, patients were told there were 13 drugs to choose from and to discuss them all with the MS Nurse. This was the least favoured option for the MS Nurses participating in the study. Patients could be left confused in this situation when faced with too much information, often at a time when they were overwhelmed with the diagnosis itself.

With new patients the doctor will often give a few options to discuss further with me...and others tell the patient there are 13 options and to see me! At that time, I won't do the 13, it is too overwhelming. I look at the patient, their lifestyle, who they are, and I get their own opinion and narrow it down to be manageable for them. Sometimes there are unrealistic expectations from the drugs and they only look at the pros, not the cons. So, I start the education. Newera

An important part of this task was acquiring as much information about the patient and their lifestyle as was possible. All MS Nurses in the study believed that time spent here was well worth it, setting the patient up for success when they selected the right medication for their situation and disease process. A drug that suited their individual lifestyle and invited adherence.

I like the opportunity to talk to patients about what their health beliefs are...I try and understand where the patient is coming from...it has given me more richness in the relationship and highlights sensitivities for them. I can then communicate this to the rest of the team to help make a sound medication choice for that person. One patient told me that they were forcibly held down for all their immunisations as a child and they couldn't get past that...so I started thinking about the drugs that might suit them better to ensure success for them, not failure. Mary

I find out about preferences for medications and I provide information on the drugs we are talking about. I discuss in depth side effects and efficacy, trying to get as much information as I can about the patient. It is a lot of information, I like to chat to them again in another week, or if more time is needed, that is OK too. Sarah

The fact that there is so much choice with MS medications can make it all very tricky. You need to have a level of patience...it is not black and white; it is so grey...sometimes the fact they have so many treatment options is not the model of medicine they are used to. They want a definitive plan of what to take and when...deciphering all of that is a unique part of our role in MS. You need to be all over the current information and side effect profiles and have a good scientific understanding and be able to translate all of that to the patient. Orion

I look at family planning, lifestyle in general, I gauge their risk/benefit feelings, their fears...often you will get a sense from the patient about where they are leaning. Their lifestyle, home situation, support systems, work. Olga

In MS there is a personal uniqueness which impacts treatment decisions. Here we have an A to Z of possibilities, and we don't know if P will be right for you...do we start at A and work all the way through methodically or do we go to M? We also need them to step up and be healthy and do their part too. Sam

We tend to talk about all the pros and cons of the drugs and I explain to patients we have to think about more than two weeks ahead in their life...we need to know their plans, who they are, we are thinking five or six years down the track. My first contact is brief, and I arm them with reputable information and arrange to meet them again soon to talk about the treatments in depth...I try to truly individualise care. Leroy

If there were side effects that were untenable, a change in infection status, approval of a new drug or breakthrough disease, treatment switches to another drug were considered by the neurologists and regularly forwarded to the MS Nurse for further discussion with the patient. Often the MS Nurses felt that this was more familiar territory as they had already developed a relationship with the patient, and it was a little easier to gauge how they would be feeling and where/how to direct their education.

Switching drugs can be much easier than the initial treatment choice, because you have a history with the patient. By this time, you can tell a lot about them, both verbal and non-verbal. Switching, I'm still being very careful, but I'm more confident with the patient and they are more confident with me to tell me if they are not comfortable. Newera

However, another MS Nurse felt that sometimes the treatment switches could be a more difficult proposition to counsel the patient on, as there had already been the experience of a problem or issue.

Switches can sometimes be more difficult because they have had a less than ideal experience for some reason...they may be a bit more reticent and have probably done their own research, forums etc...so it can be harder with them...they can be nervous about it and it can be a lot of work. Zorro

Subtheme 2: Drug safety monitoring and side effect management

Proactive monitoring of clinical and radiological indicators is key to therapy strategy in MS (Giovannoni, 2016). There are two primary reasons for monitoring; to evaluate treatment effect and to evaluate the drug safety (Giovannoni et al; 2016). Monitoring has also been shown to facilitate dialogue between the patients and their HCPs (Willis et al; 2014) and increases patient engagement and shared decision options. MS Nurses often took this opportunity to continue the education process and to make assessments on the progress of the patients and how they were managing their DMD.

Just the blood monitoring for drugs alone takes up so much of my time from when I first started ten years ago. I manage all of that...I do the education early on and prepare them...my aim is to equip people with confidence. Rosie

In my clinics I chase up the bloods and do the monitoring. I get messages about side effects and I manage those. Sarah

Because the drug treatment safety has become so demanding in screening and monitoring, we have spilt the workload at my clinic as we have such big numbers. Each nurse looks after different medications and manages those patients for side effects and monitoring. We are very involved. Newera

I do a lot of the drug monitoring after they start...I check the blood tests, I check the fluvax status, co-ordinating what is needed with each neurologist. Dawn

The MS Nurse also has an important role to play when patients feel more comfortable telling the nurse something important. Olga relayed a story that could have had a significant negative impact or side effects if not uncovered.

Recently a patient I was counselling told me she had genital herpes, a fact she had never disclosed to her neurologist, even though she had been seeing him privately for 10 years. This was extremely important as we were selecting drugs that may be suitable for her. She was happy to tell me and then for me to tell him...she just couldn't face doing that herself.
Olga

Subtheme 3: Adherence and persistence with DMDs

Adherence is defined by the World Health Organisation (2009) as “the extent to which a person’s behaviour – taking medication, following a diet and/or executing lifestyle changes – corresponds with agreed recommendations from a healthcare provider” and is a key issue in MS care (Burke et al; 2011). Medication persistence is defined as “the duration of time from initiation to discontinuation of therapy,” (Cramer & Burrell, 2008). Adherence to prescribed DMDs in MS is associated with fewer relapses requiring hospitalisation and lower medical costs (Bunz et al; 2013). MS Nurses have traditionally played a role in assisting patients in adhering and persisting with MS medications, from two decades ago with the introduction of the first injectable therapy and then increasing since that time with each new drug as it became available.

Strategies developed and employed by MS Nurses to enhance treatment adherence among their patients include establishing a trusting therapeutic relationship by ensuring effective communication and empathy (Burke et al; 2011). Developing a collaborative therapeutic relationship with the patient that is open and honest from diagnosis throughout the course of disease can contribute to the patient’s confidence in the health-care team and in their ability to manage the disease (Brandes et al; 2009) and is a core support of MS Nurse care. Additionally, it has been reported that an open, trusting relationship with HCPs improves adherence in MS (Remington et al; 2013).

Once the patient is diagnosed, I am brought in as the point of contact for everything...each patient requires different things in terms of direction... whenever I see a patient, I just check-in with them. Most neurologists now have too many patients to manage the MS medications...I also try and manage the other medications the patient is on, as well and assess adherence. Liz

I make sure I see everyone 6 weeks after starting new drugs to manage side effects and to get a sense of adherence issues, providing more education and encouragement at this point if it is needed. Mary

I see patients to start their drugs...(to help with adherence and persistence) I do a special phone clinic which works well, it's every week at a set time and gets documented in the notes. I use it especially for Tecfidera new starters for about 6 weeks to help them get through the side effects in the early days. To persevere. Isobel

That's a constant I think (in adherence and persistence), it was with the injections years ago and now also with the tablets. The infusions are probably easier because someone is calling to remind them to come in...but with the tablets...we just don't know if they are taking them. Sometimes I will call to check, and they tell me they have stopped. So, then we start at the beginning and I make sure they understand why they are needed and what they do. They sometimes stop because they feel worse...so I have to go back to the beginning and outline what our goals are and how the medications work. Zorro

Some patients just want you to tell them what to take, but I encourage ownership of the choice. If they feel comfortable with it and truly involved, they will persist over the longer term. Olga

With adherence and persistence, we should be open minded and not feed guilt. If there has been a relapse (after a period of non-adherence) we should keep engaging and be supportive...it is always close to me...where are the missing patients? Gerty

For those patients that choose not to persist with MS medications, or not to start on DMDs in the first place, there was a lot of worry on their behalf by the MS Nurse and a commitment to stay available and connected.

I educate them as much as I can, but it scares me when young girls go away and we don't see them...maybe permanent disability follows, and I find this hard to get over. To go on the "natural method" with no follow-up. You know how bad their brain looks with active disease. By all means try natural...but if anything changes, please contact me...don't go it alone and unsupervised. Dawn

I recently had a patient who had 6 kids who lived very remotely refuse to start a medication even though we were very worried about her and made recommendations. I always give my number so patients can always be in touch if things change. She just wanted to wait despite our advice. Now she has 4 new spinal cord lesions and you just think...bugger. But we will see her again and keep trying to get her sorted. Zorro

Subtheme 4: Logistical organisation

Multi-professional teams in healthcare consist of individuals with different functions working together for a common, specific goal (Gadolin & Wikstrom, 2016). In the field of DMDs in MS, the MS Nurse is often the conductor of this team in terms of the logistics of commencing treatment. With the introduction of each new drug therapy, there has been a whole new regime to learn and safety programs to get a handle on. Organising the logistics of how each drug would be administered and by whom, how to access supplies, how to monitor when patients needed to have specialised tests and follow-up, all became the role of the MS Nurse. Some felt that there was not any formal discussion about this in teams, the workplace or professionally, it just all happened. But another MS Nurse noted that although there was not a clear-cut directive, most MS Nurses, no matter what their setting, came to be doing very similar work in this field. The logistics also involved developing close relationships with the infusion units for the monthly, six monthly or annual infusion regimes, creating contacts with pharmacy, arranging paperwork and prescriptions and ensuring that GPs were also aware of the safety requirements for the medications.

I go through all the drugs with patients, make sure bloods are sent, approvals have gone...vaccination guide given. I have many lists waiting...tests all done, vaccinations all done, referral to day infusion ward...getting drug charts done, pharmacy...trying to manage it all. I have cheat sheets for all of the drugs, checklists to organise tests like ECGs and OCTs. I give the patients their own responsibilities though. This is half my load. Isobel

I organise everything...clinics, the whole team. I audit all of the clinics, the scans and pathology for the medications to make sure they are done or scheduled. I make the referrals if they haven't been done for the required tests. Liz

You need to have very good organisational skills to do this job. In the context of all of the drugs requiring vigilance you have to be organised to ensure the patients are monitored correctly, bloods, scans, when to see the doctor. Orion

Reflection Points from Medication Managers:

- The points already raised around role substitution in Medical Managers need to be considered; what is a nursing role and what is the domain of the medical staff? Is there crossover, and if there is, is crossover satisfactory if all members of the team are informed, aware and agreeable to the role? Are we pushing the boundaries of the scope of nursing practice here? Is our role here clearly defined as a nursing role, or as a support for the neurologist?
- With the newer medications, oral and infusible, are there new methods of ensuring adherence and persistence with medications that could be utilised in the MS field?
- Could help be sought from other areas in logistical organisation around Medication Managers to free up more time for more direct nursing responsibilities? Potentially this could be accessed from administration assistants or from other team members (if they exist within a team).

Although the role of Medication Manager takes up a lot of time in MS nursing care, MS Nurses still made time for professional development and their own learning, often essential because of the complicated medications and the vigilance required. With the increasing complexity of the role of Medication Manager firmly at the forefront, the following theme will explore the different ways that MS Nurses acquired their learning and professional development so that they could be more effective supporters, educators and managers of care.

Theme 5: Professional Development Advancers

The theme of “Professional Development Advancers” incorporates all of the activities MS Nurses do to build up MS Nurse networks, facilitate their own learning and development and the advancement of their own career, as well as the profession of MS Nursing as a whole. Since MS Nurses became an organisation in Australasia (MSNA Inc) with just a few members almost 20 years ago, there has been a gradual increase in MS Nurse numbers. Along with this there has also been an increase in educational opportunities, research collaborations and professional and personal development.

The ***central organising concept*** of this theme is building and maintaining networks and collaborations, continuing to learn, identifying areas of learning need, advancing the MS Nurse role and demonstrating leadership in the field.

There are four subthemes to explore this part of the MS Nurse role more deeply:

- Building networks with other MS Nurses
- Dynamic consumers of self-development and learning
- The rise of MS Nurse clinics
- Commitment to research

Subtheme 1: Building networks with other MS Nurses

The value of building mentoring networks for nurses has been well established (McBride, Campbell, Woods & Manson, 2017). Building a network is one of the most powerful opportunities that membership in a professional association can provide to an early career nurse, making it possible to gain access to and act on new information faster (Sherman, 2017). It takes experience, reading, talking, contemplation, education and mentoring to identify strengths in practice and develop them further (McBride, 2020). For almost all of the MS Nurses participating in the study, building networks early was a highlight and put them on the road to a more confident career. The enrichment to their own education from reaching out to other MS Nurses and receiving support and learning, to visits to other centres and clinics to see different practices first-hand, to the support of organisations such as MSNA Inc and IOMSN, the importance of networks was frequently emphasised.

When starting in the field, many MS Nurses reported feeling alone and unsupported, knowing they were on a very steep learning curve, feeling very unsure of their skills and lacking in confidence. Many reported having excellent support from the neurologist or organisation they were working with, but it was *nursing* support and an opportunity to talk about *nursing issues* in MS that was the issue. Finding out about MSNA Inc and the inherent learning and networking opportunities often changed the trajectory for MS Nurses, especially if they were working as the sole MS Nurse in their practice, clinic or organisation. They now had people, their people, to support them. There did not appear to be any differences in this concept between more experienced MS Nurses recalling their early feelings in this area and those newer to the specialty.

I don't know of any other area which has national and international support like we do...it is infinite and boundless. Working together to get that sense of achievement with a patient. You definitely get what you give here and the more you put into it, the more professional development and networking you do, the more you get out of it. Flo

At the beginning, I had wonderful support from other MS Nurses when I didn't have confidence or belief in myself. I had a mentor who really believed in me, sharing tools and

knowledge which was such a great help. I continue to do that to other new nurses now when they come along. Grace

My first MSNA conference was amazing, I met a whole bunch of MS Nurses which opened my eyes for the first time (I was working solo and regionally) ...I didn't realise at that point that there were that many MS Nurses in Australasia! And nurses in my home state too...I got introduced to many nurses who I stayed in touch with, one becoming a mentor to me and is still who I reach out to. Sarah

We have an amazing network and support system in MS Nurses, we have regular catchups and educational meetings and conferences. We look after each other and we are privileged to have this support. Nim

It was a very fast learning curve, I had experience in research, but not in MS. getting that whole jigsaw puzzle of MS together, I feel like there is still so much to learn. What supported my launch into the MS world was meeting other MS Nurses and researchers and the MS Nurse conferences. Maggie

I am so humbled to know so many beautiful MS Nurses which gives me aspiration and inspiration to do better...we all try so hard and work with many different groups...all my questions go out to them for help. We have a kindred spirit, when we all work together there is nothing missing from the puzzle. I watch other MS Nurses sharing quality care with respect and communicating across all domains. Sue

(After recently starting in the position) I have gone and spent time with another MS Nurse with many years of experience. She was so generous with her time and her information and very inclusive. I can email her anytime. There are other MS Nurses I wish to spend time with as well to learn about the areas I am lacking. Ruby

Several MS Nurses were able to attain a level of support from their own organisation or team.

There was a lot to learn. I knew elements but not a full understanding. I was so lucky I had a mentor nurse at the organisation I worked at who encouraged my own research but was always there if I needed. Not everything about MS nursing is in the book! I said to people "I'm sorry I don't have the answer right now, but I will get back to you". And I did. Elizabeth

(The organisation I worked for), the nurses would always consult with each other and debrief, it was very supportive. The debriefing was so important to work our problems and patients. Some of the neurologists gave us huge hurdles but we worked together to let them know we were there for the patients and worked ethically. We worked well as a team. Huge learning curve but the MS Nurse support made them very good days. Flo

However, one MS Nurse did have experiences that were less than ideal when she first started where more support would have been welcomed. Another MS Nurse felt that she had not been able to engage with the sharing aspect of nursing in a worthwhile way.

When I started I felt so afraid. My first conference I was so scared...seeing "those people" there were groups I was afraid to speak to and worried about being judged as nurses sometimes "eat their young"...I did feel intimidated by the senior nurses. I felt anxious and unsupported I would say. It would have been great to have a crew of rookies and be mentored and then move up to be a mentor yourself. Some people were lovely and helped me and answered questions, but others were unapproachable. Charlotte

It has been my experience that MS Nurses don't do that well at making professional relationships work. I feel like mentorship is not well done. The MS Nurse conferences can be very cliquy. I often support other MS Nurses with information, but I have found that often you don't get that back...very few nurses get in there...you have to do the work yourself and I have found they aren't keen to help each other. I have seen firsthand how some other nursing groups support each other in ways that we don't. Lesley

The value of learning and development provided by pharmaceutical companies working in the MS arena was appreciated by many MS Nurses, who were often surprised at the scope

of the learning that was offered, not just in medications as would be expected, but in many aspects of MS care.

We receive so much education from the pharmaceutical companies with our learning, we are so privileged to have that. Nim

As MS Nurses we are so very privileged compared to other nurses. We have regular conferences and meetings and the educational content from the pharmaceutical companies is so great- it is more than prescribing, they realise when it comes to MS, every individual suits a different drug and there is a place for everything. They also provide a lot of general information and symptom management education too. Sarah

As I worked on my own and came in with no experience in MS, I was lucky with the educational support I received from the pharmaceutical companies, you don't get that in other areas. They wanted to get in and help me. Leroy

Subtheme 2: Dynamic consumers of self-development and education

Many MS Nurses participating in the study viewed themselves as lifelong learners, of never being satisfied with the status quo and of always seeking out further opportunities to learn more about MS. Several MS Nurses had visited other clinics to enhance their learning, participated in preceptorship programs with other MS Nurses, completed online courses or gained certification in neurology or MS nursing. There was a tendency to gather as much information about MS as possible in order to be able to answer the myriad of patient questions and provide quality care, a tangible eagerness to learn and to be a nurse leader for the future. Conference attendance, and in particular the MSNA Inc annual conference, was a popular way of keeping up to date with the many changes to the MS landscape and keeping learning contemporary.

The role of nurse leader, that sense of passing on knowledge to others coming through...an avenue that the wisdom of the years can be given to those who are eager to learn. Lillian

We all have something to learn...sometimes the most experienced nurses are the ones saying that there's still so much that they don't know...there's always so much more to learn here. I enjoy the diversity and the people with MS are fascinating. Isobel

It was a very fast learning curve; the MS component was steep. What supported me was meeting other MS Nurses and going to conferences. Maggie

I recognised early on that in MS I will never learn it all, but to keep on learning. As soon as you think you are on top of it...things change. You have to continually work on confidence and education and networks to gain confidence and ensure you are always up to date. You need to do the job properly. I think there has to be striving for excellence in our skillset, in delivery and in the knowledge base, to learn within the context of multidisciplinary health we have...to strive for excellence. Lillian

Back in the beginning I went to two experienced community MS Nurses and saw newly diagnosed patients with them I then went to every educational and dinner meeting I could get my hands on really. Dawn

My favourite days are having some education for me, even after all these years. A speaker or a journal club. I also really loved family educational sessions, seeing the dynamics and you talk about what they really want to know. You also help their families adjust to MS. I am fortunate that I have been respected by my team neurologist as an intelligent nurse and brought into conversations outside my skillset, but that help me learn, this was a great gift to me. Lillian

Learning is always ongoing and (even after 20 years) I would never class myself as an expert in MS...that is why I have been in it for so long...you are constantly learning. Sue

With the MSCN exam I was grateful for it...because when I passed, it meant something. I was grateful to get that credential, it's like having your training wheels taken off. It shows excellence in the field, a defining moment for me. Charlotte

The MSNA conference I love. I am shy, but in that group, I am never scared to ask questions.

Zorro

Learning off patients in particular proved to be a popular learning tool for MS Nurses, recognising that often patients are experts in the field. Many MS Nurses took up the opportunity to learn as much as they could from their own patients. This, of course, also helped form the basis for the narratives that MS Nurses would tell other patients in their journey whenever they needed that extra help.

Working face to face with patients...I learn a lot from these patients, I really cemented my learning even more. Grace

There was a lot to learn. Doing the professional development, reading learning...but people with MS are the greatest sources of information, they are the expert in their condition.

Elizabeth

(I am still very new at MS) but there is so much value in just sitting still and learning off the patients, and I am making that my priority...I spend a lot of time just listening and learning off them. Win

I had patients in my early days that guided me with learning...I told them I had no concept of what MS is, I told them they had to give me all of the information...and they did. This helped me more than any book or article could teach me. Leroy

Subtheme 3: The rise of MS Nurse clinics

The rise of specialist nursing led clinics has had a positive effect on managing patients with chronic illness, such as MS (Ayer, 2018). Nurse led clinics also fit efficiently into the personalised assessment and patient centric management style often recommended by experts in MS (Rieckmann et al; 2015). Over the years MS Nurses in Australasia have commenced their own independent clinics; some clinics are completely nurse run; others have a neurologist working independently elsewhere in the hospital or available on call if

needed, others are outreach clinics servicing patients in isolated areas. As patient numbers have risen, some clinics are now for a specific purpose; such as those for the newly diagnosed, relapse clinics, DMD screening clinics and high-risk DMD education clinics, in line with other international MS Nurse colleagues in countries such as the UK (Ayer, 2018).

I do a very full day in my MS Nurse clinic, up to 16 patients in a day. For patients, it has taken some time to adjust to a nursing clinic rather than seeing a neurologist. I am doing consistent assessments which guide care rather than talking lesion numbers or walking distance. When people are not feeling great, we discuss that. There isn't a typical day, but there is structure. They can be doing great for 3 years and then something changes...what is it? We need to work out what is happening, and I get them back when they need to be seen, not waiting like they sometimes do for medical clinics. Sam

Many MS Nurses are already doing MS Nurse led clinics but don't even realise it...it is happening, just not conceptualised as such with a name and clinic space. In my nurse led clinics I counsel; I provide education and also discuss the drugs. The main skillset is in helping patients decide the best drug for them after we work out what will suit them...I also have the opportunity to talk to people about their health beliefs...and taking the time without rushing. I feel like every time I go to work that I make a difference. Mary

Our nurse clinics are an extension of trust with mutual decision making with the neurologists. I review the patient and their symptoms and make my own recommendations...sometimes I pick up things such as other conditions and it is appreciated. I take a very in-depth history and it builds up trust. Newera

I loved my MS Nurse clinics, they were exhausting with only a small number of patients, but I was so focused...keeping time focused in a nursing consult is hard because you want to give them everything, especially the newly diagnosed. I made such a difference and they reported that they were so much better off, only seeing the neurologist again at 6 months. You would find out so much more about them and once I did a big save with a comorbidity. I taught them wellness and they turned around. Grace

We have recently started doing nurse led clinics here with more nurses. These have evolved and are now held regularly, I do all the medication assessments, the EDSS evaluations and a complete review of what has happened to them since they were last seen. I wanted to change the factory atmosphere of just seeing and doing paperwork...chronic disorders like MS need a proper complete review, not just tick boxes. I have had some really positive feedback. Isobel

Time in a nurse led clinic really pays off...you invest the time when patients are struggling the most. If you don't have that investment of time early, they may fall apart later. We encourage the patients to call us as much as they need early on as mental wellbeing is paramount at that point. Olga

Subtheme 4: Commitment to research

In the inaugural International Year of the Nurse and Midwife, nurses are being urged to unite and progress nursing research agendas, in order to recognise the essential work they do in diverse settings (Peters & McDermid, 2020). There are many challenges in performing nursing research, especially for clinical nurses who are already under pressure trying to balance teaching and clinical care workloads (Resnick, 2019). Substantial time and skill are required for ethics submissions, grant writing, performing the research and then the writing up and reporting; as well as a lack of mentors in the field (Resnick, 2019). Research is challenging, but in MS nursing, there were clear attempts to raise the profile and output of research by MS Nurses.

There were two distinct areas of research demonstrated throughout the study interviews. The first was a more active role in research, where the MS Nurse was either employed specifically as a research nurse in the area or was actively conducting their own research or collaborating with others in research. The second area was a more passive role, but still one of great importance. This involved the MS Nurses being involved in research almost by default, as part of their support to neurologists. Some enjoyed this unexpected part of their role, but some preferred to be more patient focused in clinical care.

The role of active researcher in MS was taken on by several of the MS Nurses interviewed. Firstly, the role of research nurse in MS care involved mainly involvement in clinical research studies and trials, often as the study co-ordinator. But this also could extend to assisting with investigated Initiated clinical research at times, often by the neurologist they were affiliated with.

A lot of my time is spent trying to find suitable patients for studies. I love the face to face part with patients the best. A lot of my time is spent organising visits for people and the things I enjoy the least, the ethics and the governance. Even though my role is research, I usually start taking notes and asking patients if they need follow-up, as a duty of care even though it is not formally required in the research. Maggie

I am mostly clinical, but I do have a small part of my role in research. I am mostly working on observational studies in MS and newer ones later in the year, there is no one dedicated time for research, the work is spread right through my week. Dawn

I like the research work, it gives you an insight into what things actually mean, collecting the data is important. It is a huge advantage to then be able to relay things back to the patients. Maureen

I help the neurologists with research, and I would love to do my own research one day...but...being a small centre it is really hard, there is no back up and no team to assist me. I have approached a few avenues about getting help to do research, but I've been knocked back as we are not a big hospital with a name. I also find that some centres want to keep to their own and are worried about others taking their research ideas. Leroy

Several nurses interviewed during the study had a more direct role to play in nursing research. In addition to their normal clinical care roles, they participated in nursing research to generate new knowledge, promote innovation and service development. However, this could be challenging on top of the regular workload and getting research to publication was often difficult. The unavailability of nursing mentors was also seen as a problem in addition to the time to actually physically complete the research.

In the nursing research I have done, I was lucky enough to have a mentor...someone who pushed me and was willing to read the embarrassing first draft. Someone who said "well, where is it?" I have an idea now and my neurologist is pushing me to write it up, but without mentors it is hard to get it out there. We need more research mentors. Gerty

Research fits into my role, doing research is something I feel strongly about. My own research is a few years old now, so it is time to start something new...but where to find the time? There are simply not enough hours, but I would love to get back there...developing models of care that improve access and patient experience is what motivates me. Liz

The more passive role of researcher was actually demonstrated by many more MS Nurses than expected during the course of the study. Many MS Nurses contributed to research by collecting and entering data for the MS Base international registry (Butzkueven et al; 2006) as their workplace was a contributor to the registry. Although not officially part of their role, it was seen as important to the overall mission of MS care in Australasia and internationally. Serious adverse event reporting in both a trial format and as part of the post registration of drugs was also a role often taken on by the MS Nurses. Assessing relapses for clinical drug trial notification and advising of medication and clinical changes also came into play. Most MS Nurses accepted this passive research role as part of their work, but others MS Nurses were not as happy with this aspect of their role.

I try and avoid the research! It doesn't feel patient centred to me and doesn't sit well with me. I help with clinical things...at first, I was more involved with the research but someone else has stepped in now. I would, however, be interested in doing qualitative research to help us know how we can be better nurses for patients, rather than just dealing in figures. Rosie.

I am still involved with research, but I want to slow down here, it is time consuming...I would prefer to concentrate more on direct patient care as there is such a need. Newera

Reflection Points: Professional Development and Advancement

- How can collaboration and learning be supported and encouraged in a time of unprecedented busyness in the field of MS care? In what innovative ways could learning be enhanced?
- There is likely to be an increase in need for MS Nurse positions with drug and science advancements, growing clinic and community numbers and the rise of MS Nurse clinics. How can this be organised to ensure that there is a succession plan in place for trained and experienced MS Nurses in the future? How can new nurses to MS be recruited, educated and encouraged?
- How can MS Nurses be mentored and supported in their research endeavours? Is there a role in MSNA Inc/IOMSN for research focused activities and support? Are there possibilities for collaborative research through the MSNA Inc network? How can we secure willing and appropriate research mentors?

The themes of Holistic Healers, Sources of Support, Disease and Symptom Educators and Managers, Medication Managers and Professional Development Advancers seek to define the many varied and challenging aspects of the role of the MS Nurse in Australasia. The next section of this report will outline other factors which come into play along with these themes to fully explore the role of the MS Nurse, not just what they do as part of the role, but of who they are in the role, how they feel, the obstacles that prevent work satisfaction and the joys of the position. Additionally, the next chapter will also explore education and support needs for MS Nurses, discuss current skillsets and provide a definition of the role.

Chapter 6: Phase 2 additional findings to themes and role definition

This study aimed to explore the role of the MS Nurse in Australasia by exploring the education and support needs, identifying the skillset and defining the role of the MS Nurse. The themes in the previous chapters contribute towards defining the role and clarify what MS Nurses do in their daily clinical practice with patients. This chapter will discuss the findings of education and support needs as well as the MS Nurse skillset. However, unexpectedly, several other factors came up in the course of the study interviews which require identification and discussion. In some ways they also help shape the role of the MS Nurse, and help in our understanding of the overall role in contemporary times. At the end of this chapter, after considering all of the themes and other findings, a formal discussion of the skillset and role definition will be addressed.

The areas of additional findings expected in the study aims include:

- Educational and learning needs of the MS Nurse
- Support needs of the MS Nurse

The unexpected findings from the study, but integral to exploring the role of the MS Nurse comprehensively include:

- Characteristics of the MS Nurse
- Distinctive features of MS Nursing
- Obstacles to the MS Nurse role
- Joy in the MS Nurse role

Together with themes in the preceding chapter, this chapter will conclude with a discussion of:

- The skillset of the MS Nurse
- Definition of the MS Nurse role

Educational needs of MS Nurses: future learning

There was an overwhelming learning need appearing consistently throughout the interviews which had no relationship to years of practice, MS Nurse experience or seniority in the field. MS Nurses consistently voiced a desire to strengthen skills in the area of mental health management, specifically in counselling, crisis management, mental health first aid and in managing suicide ideation. Over half of all study participants in phase 2 interviews expressed a need for further learning in this area, where they sometimes felt out of their depth and uncomfortable.

In mental health you come across suicide ideation, and while, yes, I can talk to patients about it...I am sometimes not sure how I am really doing with it. It crops up often...you can only manage so far and that's when the feeling of inadequacy comes in. Maureen

We recently had an aggressive build up with a volatile situation in clinic...it was confronting...to have the skills to de-escalate and other information would be good to have to deal with those difficult situations. Orion

I would like more on counselling skills...I find that is a huge deficit for me...I have worked towards it...but...I can do only so much and then I need to refer on. I know what I don't know...and always looking to improve yourself so that you are half a step ahead of the patient walking it. Leroy

The topics which came up most frequently as learning needs are shown in Table 7. Mental health and immunology were by far the most popular topics amongst MS Nurses for future learning.

Area of care	Topics within this category
Mental health	Suicide ideation, crisis management, mental health first aid, general counselling, managing volatile situations, managing mental health whilst waiting for services, managing adaptive disorders after diagnosis
Immunology	Understanding the immune system, understanding immunosuppression, linking the effects of drugs on the immune system
Radiology	Understanding basic MRIs, advanced lesion identification
General MS introduction	Course to start when new to MS in Australasia, covering symptoms and management, more support packages at the start of MS Nurse career, a one-week course on site learning course
Specific symptoms- a deeper understanding of management strategies	Fatigue, sexual health and sexual dysfunction, neuropathic pain, continence, swallowing and speech
Research	Getting started, troubleshooting the obstacles, how to collaborate with others, how to publish
Social support	Helping patients with employment issues and disclosing diagnosis, cultural diversity
Improving patient care	Motivational interviewing, reflective listening, multicultural issues
Neuroanatomy	Linking lesions to symptoms, anatomical pathways
Assessment skills	Learning EDSS and neurological assessments

Table 7: *Most common areas identified by MS Nurses in study interviews as learning needs*

Support needs of MS Nurses: tools and support to maintain mental and physical wellness and job satisfaction

For the purpose of this study, support needs were defined as areas where the MS Nurse needed support to successfully perform their MS Nurse role in whatever setting that was in; hospital, clinic, organisation, company or community. This included their own needs as well

as the needs of their patients and could be expressed as mental, social, spiritual and physical support needs. Interestingly, but perhaps not surprisingly, most support needs were linked to helping the MS Nurses assist their patients, rather than purely for their own benefit.

By far, the intense and heavy workload on MS Nurses called for more physical help on the ground to perform the role. Help with administration and research tasks to allow MS Nurses to spend more time on patient care and to give patients and their families the time they needed instead of always rushing, was a popular wish. For many, their jobs were already funded by insecure or temporary means and so the opportunity to have more staff to help them was always only ever an aspiration.

We are grossly understaffed...we have over 1,000 patients in our service and it grows every week. And one full time nurse! I plug up holes where it leaks rather than doing anything in the big picture. I lay awake at night trying to think of ways to make it run more smoothly and processes that might help. Liz

From the management side, my job is not secure. We need security. We know it is an important role and the patients do, but in commercial medicine we are not important.

Newera

Many MS Nurse told of their feelings of inadequacy at the commencement of the role and felt that welcome packages and mentorship programs may have improved their initial steps into MS nursing. Having that special someone they could call up on the difficult days or just to ask questions in a safe environment.

We need to immediately connect new nurses to a more senior mentor when they first start in MS nursing - their "go to" person to provide resources and extra tuition and someone to oversee wellness for MS Nurses in Australasia. A national register of all MS Nurses would also be helpful. Lillian

I was thinking of how I felt when I first started in MS nursing and “inadequate” pretty much covers it. Maureen

I was very scared to start work as an MS Nurse...I didn't have the confidence or belief in myself. Grace

As mentioned in the themes, the area of nursing research requires dedicated support avenues to ensure that MS Nurses have the capability to commence and successfully complete projects. They don't have to be intense and consuming studies, just starting with a small study with the right mentoring and support could make a big difference. This suggestion was for a virtual platform to share contemporary topics and research.

We need support in the area of research, this is our platform, we are passionate...we need to share more about what we are doing, but MS Nurses don't do that in real time, we wait for a conference. Support to share our knowledge base in real time would be good. No one seems to have to time to do anything...so research collaboration and time need to be supported.

Sue

A topic which came to light repeatedly in the phase 1 surveys was also noted in the study interviews. Participants reported the need to debrief appropriately and have someone to go to on the challenging days, so their work did not go home with them and cause issues.

When people are in tough situations and they take it out on me...I get that they are frustrated but it still hurts. I debrief with my direct manager...but I am mindful to show vulnerability...I don't always want to disclose what is happening with my own mental health in the workplace. Charlotte

We don't have any clinical supervision...we just do an informal rant and debrief...we really need to have more help here and perhaps a clinical supervisor. Isobel

Characteristics of the MS Nurse

Defining the MS nursing role is essentially exploring and describing what MS Nurses do in their clinical practice with patients. However, it became apparent early on in the study interviews that there was another aspect which had not been previously considered by the study investigators but was integral to a full understanding of the MS Nurse role. This was the concept of what MS Nurses *are* alongside what they *do*; the intrapersonal characteristics MS Nurses possess in order to fulfil the many demands of the role. The concept of characteristics of MS Nurses was interesting for several reasons. Firstly, characteristics help tell a more complete story of the MS Nurse, the nursing ethos of the role. In all likelihood, many of the characteristics reported herein are indeed common to nurses around the world, in any region and in any setting. Several of the characteristics are likely common to nurses working in chronic illness, some in neurological nursing, some in nursing young adults and some in nursing an unpredictable disease. However, they all came together to tell a story of the unique role which is that of the modern-day MS Nurse. Secondly, the characteristics provide a window into the nature of nurses who may be better suited to the role, for nurses to have an understanding of what may be required of them as an MS Nurse.

These individual characteristics were consistently brought up in the discussion of the role of the MS Nurse (in order of acknowledgement during the interviews, most commonly reported from empathic to least commonly reported, dependable):

- Empathic
- Caring
- Compassionate
- Kind
- Patient
- Wanting to make a difference
- Effective communicator
- Flexibility
- Adaptability

- Strong sense of professional development
- Sense of humour
- Resilience
- Genuine interest
- Curious
- Eager to learn
- Maturity and life experience
- Professionalism
- Hard working
- String work ethic
- Modesty (knowing there is always so much more to learn)
- Non-judgemental
- Agility
- Confident
- Grounded
- Common sense
- Reliable
- Responsible
- Realistic
- Inquisitive
- Sharing
- Dependable

Having an empathic nature was seen as an intrapersonal characteristic essential to the role by MS Nurses participating in the study. Empathy in nursing is recognising and appreciating another's perspective and being able to put ourselves in the situation of others, and thinking beyond one's own concerns (Clark, 2018). However, it has also been recognised that empathy is hard to teach and hard to measure (Donnelly, 2016) making it an elusive, yet expected caring behaviour in nursing (Idvall et al; 2012). It has been suggested that HCPs who exhibit empathy improve the quality of their care (Marcysiak, Dabrowska & Marcysiak, 2014) and improve the nurse-patient relationship (Brackenbury, 2016). Empathy is a

personal investment by the nurse in the patient. Empathy goes beyond merely acknowledging suffering, the nurse shares the struggle and ensures the whole patient is seen, not just the illness (Davies, 2014). Empathy as the most prevalent intrapersonal characteristic in MS Nurses participating in this study, fits in perfectly with the concept of being Holistic Healers, which was discussed as the first theme of the preceding chapter.

I think empathy, care, compassion and patience all go together to make the MS Nurse. Orion

MS Nurses have something that is deeper than caring...this is hard to articulate. You identify problems before they even present themselves. There's science behind it with your knowledge of the disease and pathways but you need to anticipate it before it happens and put things in place to minimise this for patients. Intuition isn't a science word, but it comes from experience and a desire to do the best you can for patients. Mary

I have the same characteristics as all nurses I think, compassion and empathy... you have to have a good tolerance for sadness and be prepared to sit back if needed. Nim

Possessing characteristics such as resilience, modesty and an eagerness to learn were also seen as valuable in the role.

You need to be a little ambitious...you are in a role which is always challenging, you have to be up for that challenge, you cannot sit still. You have to be on your game always or you cannot help the patients. Maureen

We have to be smart and savvy, organised and good at co-ordinating care...you have to not be "cocky" or afraid if you don't know the answers. Olga

This is definitely an area worthy of further exploration, of finding the essence of an MS Nurse. Added to this list by the Investigators is pride, all of the MS Nurses who were interviewed during the course of the study demonstrated an immense amount of pride in their work and the way they are able to help patients, of their desire to help patients live their best life possible.

Distinctive features of MS Nursing

Early on in the study interviews it also became clear that there were areas of MS nursing which were possibly niche to the role, aspects which may be distinctive to MS. This aspect was explored with study participants to find those key things about MS nursing which set it aside from other specialties of nursing. Those aspects which made it special, different and helped define the role. Some of the key features which emerged as being distinctive to MS nursing included the following:

- Managing unpredictability and uncertainty

We are dealing with a disease with no predictability about what is going to happen next...but also no guarantees as a clinician that what we are going to do is going to do them good...we put them on drugs which can cause significant harm. Sam

What strikes me most is the unpredictability of the pathway in MS and that is what people living with MS struggle with the most...other diseases can be clear cut and the likely disease pathway and drug pathway are known. This is not so with MS. Olga

Every patient is so different...in MS there is often no pattern and that is unique...no pattern. No nice planned line of what will happen...which leads to both positive and negatives. It could be good for them...or it might not be. There is so much diversity between patients. Isobel

- Inviting rapport and connectedness for a long partnership

We as nurses are deserving of privileged information and patients regards us with trust. There is an inherent warmth, a softness, compassion and immediacy of rapport that gives that instant connection. We give our patients permission to show their vulnerability...we invite it in with our rapport. Olga

The way we work in MS, we work more in partnership with the patients. Rosie

- Dealing with complex and complicated symptoms

MS Nurses are not common, and MS is so complex...often no-one outside of MS health care professionals knows that much about MS...so patients may see their GP for something, but they get referred back to us anyway. We are so focused on holistic care; we cover so much.
Newera

MS Nurses are agile...they are ready for anything, any question, any family...they look at the person holistically and work out what is best for them. Yes, it is a chronic disease, but MS Nurses are agile and help patients adapt. The questions are usually not textbook, and you have to think outside the box. Elizabeth

Our patient cohort...some people come to work in our team, and some enjoy it, but some don't...they say our patients are very challenging. Dawn

Obstacles to the MS Nurse role

These were the things that came up in MS nursing practice which could hinder the MS Nurse from performing their role to the best of their ability. The obstacles which could get in the way of doing the work needed to help patients or be the cause of much worry for the MS Nurse.

- Jobs in jeopardy

Insecurity in the MS Nurse role has always a concern. Some MS Nurses have job security and are funded permanently by their employer, but others are employed using temporary funding from research grants, infusion units or other sponsorship. There is no universal federal or state-wide funded position description or designated salary scale/level for MS Nurses, it all depends on individual hospitals, clinics and organisations as to how the position is created and funded. Several MS Nurses suggested that long term this could lead to burnout and exhaustion, constantly worrying about where the funding was going to come

from for them to continue in their role. In the setting of the long-term partnerships already discussed as essential to the role, this seems a contradictory issue.

We looked at jobs in jeopardy a few years ago but it died out...we need support when we are starting in MS. Sam

The role is not supported by my local area health department. I have been told that an enrolled nurse could do my job and why would we pay for a Ferrari service (high quality of care) when a beat up old Holden will get you from A to B...with an attitude like that, I think I have hit the ceiling for what I can achieve here. Liz

My nurse led clinic role is under threat from funding...I have lost some of my patient load even through the need is high. It is deflating to me and to the patients. There is just not the budget to do it. Sam

- Heavy workloads

Several MS Nurses reported such intense and heavy workloads that acquiring any sort of joy or satisfaction from their role was almost impossible. There was constant worry about missing things, cutting corners and feeling inadequate.

I don't have many good days at work...it is hard work and I often wonder if my expectations are too high and if I am good enough to do this job (after more than a decade in the role). I have my days where I just...call a nurse friend who understands...which has been a lifesaver to stop me falling apart. Rosie

I would love to see MS Nurses supported to do their roles without the constant pressure of significant time constraints. It would be great if we were staffed appropriately. The MS Nurse role has accumulated many new tasks over time, services grow but staffing numbers do not follow the same growth. It leaves me feeling rushed and with less time for patients. I often feel forced to cut corners, leaving me with the feeling of not finishing things properly, just getting through the bare minimum. Mary

The government could support MS Nurses more with funding positions, there is not enough time to do all the tasks generated by clinic and these patients need to be supported. Nim

Our biggest block at the moment is not enough resources...not enough clinic space, not enough time to see people in the way they need to be seen. You are restricted in delivering the care you want to deliver. Mary

- Stress, burnout and compassion fatigue

Stress, burnout and compassion fatigue has been touched on in MS nursing from time to time in Australasia at conferences and seminars, but it seems the possibility of occurrence is always there in the background and needs to be openly discussed and serious management plans developed professionally in order to take this matter seriously. An MS Nurse felt so overwhelmed by burnout and compassion fatigue that they requested ahead of time not to discuss those concepts in the interview because it was too raw and real.

We are losing nurses to burnout...not to boredom or wanting to do something glitzier...it is burnout. We are losing them, and it has to stop. Mary

We need to be able to manage patient expectations so we can avoid MS Nurse burnout.

Orion

I have a few key people in my team that really get "it". They also have the patient focus...I get support from being understood by MS Nurse colleagues, whom I see only rarely. I don't realise how stressed I am until I go to a meeting with colleagues. It's like a valve opens and it surprises me the truth of what I am feeling. Like I am bottling it all up. Liz

We see some terribly sad stuff...especially around PPMS, you know how tough life is going to be for them. Nim

How can I help improve things? MS Nurses have no vanity...we are all selfless and we make a rod for our own back...if you are always saying yes, yes, yes...you aren't able to reach your own full potential. Sue

- Acceptance for pharmaceutical company nurses

MS Nurses working for pharmaceutical companies were traditionally involved in training patients in self-injection techniques for earlier DMDs in the patient's own home. Over the years as new drug treatment routes have been established and oral and infusible medications have been approved, the self-injection training aspect has reduced.

Pharmaceutical company MS Nurses now primarily provide advice and support for patients on a variety of DMDs, providing phone and email access and occasionally home visits.

Pharmaceutical company MS Nurses specialising in MS can be particularly helpful in regional areas with no formal clinic or organisational MS Nurses, for patients seeing private or general neurologists with no MS Nurse support, or even for those patients who already have an MS Nurse but cannot access them for a variety of reasons such as the MS Nurse being too busy or on leave. For some reason, which is not clearly understood, acceptance of pharmaceutical company MS Nurses has not been universal and it was reported by a study participant they felt overlooked by some other MS Nurses in the course of their work as a pharmaceutical MS Nurse, even obstructed in their role.

PQ: A few clinical MS Nurses told me they would never use my service...I think we are better at it now, including pharmaceutical MS Nurses in meetings and conferences, years ago they were not even allowed to attend general MS Nurse meetings. By having pharmaceutical company nurses interact directly with MS Nurses and neurologists, it helps the patient's MS team understand the role better, as well as building trust and confidence to work together.

PQ: It saddens me that some MS Nurses think they are all for their patients and they won't accept any help in looking after them...they don't see the value of what we as pharma nurses can add...we could help so much, especially if they only work part time...we can be there for patients at any time and there are so many options of how we can do this. But some refuse

to refer their patients to us. Some also decide not to refer on to MS organisations in their state.

- Feelings of being territorial and “martyrdom” in practice

Several nurses voiced concerns that they detected some form of territorialism in their own work, however they were not prepared to do anything to combat the feeling. Others presented it slightly differently, noting that they had feelings of hanging on and not allowing others in, a bit of “martyrdom”. This is an informal sense of the word martyrdom; meaning in this case exaggerating their suffering to attain praise or recognition (Collins dictionary, 2020) by not accepting help from others in order to keep control. No information around this concept could be found in the literature to capture these feelings presented by the nurses. The theme was not strong enough to become a final theme, but it was mentioned enough to be an area of concern to be on the lookout for in practice. Perhaps it could be a trigger or co-symptom to burnout or compassion fatigue.

I think this is possibly a characteristic of many nurses really...and chronic health gives you the platform to be needed. That burden of co-dependency and the need to be everybody's hero...taking over medical substitution a bit is like that too...tying your role to your sense of self is a classic road to burnout. Lesley

Support wise I would love another nurse...but...I feel I might be a bit territorial with my patients...I don't really want another nurse coming in...it's a character flaw of mine. I just want to be everything to everybody...but you know that you really don't want that. Liz

PQ: I have had patients contact me whose MS Nurse had declined to give them a specific card which is ideal for a certain type of treatment. They wanted no help with patient care. Surely something that helps your patient and frees up your time and creates less anxiety for the patient has to be a really good thing...doesn't it?

Joy in the MS Nurse role

Despite all of the obstacles described above, there was much pride and joy expressed by all of the MS Nurses participating in the study in their role. There were things that constantly brought a smile to their faces and made them feel great as they walked out of the door at the end of a long day. These are the aspects of MS nursing that kept them coming back to work day after day, even if they were far apart in time and occurrence, the feelings gave sustenance and value to the role.

The many mums that we see in MS, we have supported them before and through the pregnancy...then to go and see them and the new baby...that's a wonderful feeling. One of my favourite things. Maureen

Being able to be useful...if someone is unwell and I can work out what is going on and organise help and provide total patient care...then that is a really great day. Rosie

It sounds corny but I get so much happiness when I manage to get patients over the line to help them get comfortable with treatment choices to suit their lifestyle...and helping my colleagues. Making a difference and helping people, when they are so vulnerable and scared, to be able to make a difference can be lifesaving. Orion

I love the diversity of the patients you meet. You can learn so much from them, so many obstacles in front of them and they handle it with so much grace. That's a great day for me. Maggie

(Even with all the obstacles)...every day is kind of great for me...I feel like every day I go to work I am making a difference. Mary

I love the days I am really busy talking to people...someone may have told me that something was difficult for them and they were scared or worried and they tell me now they feel better after talking to me...knowing you are making a difference to the lives of others...inspiring in them hope, we help them fight MS, we put them in control. Elizabeth

I just love being in the hospital for my clinics and the fact I can also move it to the home. I love group education when you see the lights go on...just one person to say I now understand...if just one person says that is exactly what I needed...that is so good. Sam

I have great days. I love the working relationship I have with the neurologist I work with and a lot of respect. That patient who calls you in a crisis and you can make a difference...that's really great. Zorro

I value patients in my current role...patients looking after themselves and giving them permission to ask questions. Our neurologist leader is exceptional...we have a great team. Gerty

I love coming to work...every day...I love working with patients and their families...the IOMSN and MSNA are also highlights for me...it is just wonderful. Lillian

I enjoy the diversity and the people living with MS are fascinating. If I have made a real difference in someone's life that day, I feel really good...I think most days we do. I enjoy my job because I do feel like I make a difference and that gives me purpose in the world. Isobel

Reflection Points for additional findings:

- Compassion fatigue and burnout are extremely serious and casual contemplation regarding its meaning and occurrence is not enough in the modern-day MS world. There needs to be a dedicated research study and management plan put in place to increase awareness of the phenomenon and strategies developed to recognise and treat MS Nurses should burnout or compassion fatigue occur. This could possibly be co-ordinated by MSNA Inc members.
- The jobs in jeopardy phenomenon in Australasia needs to be revisited and updated with current information as to which MS nursing positions in Australasia are permanently funded and which are not. Perhaps a register of all MS Nurses in

Australasia could address this and have the information on hand as part of MSNA Inc annual registrations.

- The continuing heavy workloads are also an area of deep concern. In the setting of poor funding for MS Nurses, there does not seem to be a likelihood that extra help could be sought in the current situation. However, as patient numbers continue to grow, this obstacle will only grow in tandem and needs addressing to retain the experienced MS Nurse workforce and to prevent compassion fatigue and burnout.
- Having the knowledge of the areas MS Nurses need for future learning and support ensures that MS Nurse can continue to achieve and practice holistic healing, be providers of support, manage and educate in the disease process, manage medications safely and effectively and continue to strive for professional excellence in their work. Providing this knowledge is the next task to ensure this support.
- The immense pride that MS Nurses have in their role and their specialty is an outstanding feature of this research. Continuing to support them in the role by recognising the obstacles in their practice and discussing solutions to be implemented, is an important way of supporting and nurturing this pride.
- Focusing on the advantage of using mixed methods and the benefit that triangulation of the study methods provided, the researchers noted a slight difference in tone between the anonymous surveys returned in phase 1 and the one-on-one interviews in phase 2. There was a much more open discussion of negative themes in phase 1, such as workplace pressure, lack of clinical management, lack of appreciation in the role, impossible workloads and isolation when compared to the interviews in phase 2. This could potentially be because of the anonymity of the surveys and no possibility of perceived personal judgements or it could be due to other reasons. An interesting consideration. However, many of the support, educational and job responsibility themes were echoed uniformly throughout both phases of the study, enhancing confidence in the findings.

- **Skillset of the MS Nurse**

Drawing on the findings from the phase 1 surveys, the themes in the preceding chapter and the additional findings in the current chapter, an overview of skills has been established to reflect the role of the MS Nurse in Australasia. This skillset can provide the foundation for new nurses to aspire to and to direct their career milestones, learning and development. The skillset can also be used to inform employers, colleagues, other health care professionals and the community of the role of the MS Nurse. The setting of the MS Nurse; whether in a hospital, clinic, organisation, company or community, will influence the drawing down of the skillset appropriate to individual circumstances and patient needs. It would be an objective of professional development to continue to grow this skillset and further develop areas as they are needed. Acquiring the skillset will take time and experience in the specialty. This skillset also highlights the importance of experience in areas of nursing outside of MS, and indeed of nursing in general and values each nurse's unique path to the field of MS. This skillset reflects a nurse functioning at a highly sophisticated level within a defined patient population.

- Excellent communication and partnership building skills (developing rapport and connectedness, listening and observing, storytelling and analogies)
- Skills in managing vulnerable patients (empathy, compassion, kindness, direction)
- Skills in managing family and work dynamics
- Skills in critical thinking and clinical reasoning
- Skills in responsive, flexible and consistent care in dynamic situations
- Skills in acquiring and presenting resources appropriate to individual needs
- Creation of realistic and personalised expectations

- Education and teaching strategies appropriate to individual needs
- Identification of own areas for further learning and development
- Skills to utilise and promote current nurse support systems (collaborative, seeking answers)
- “Generalist Specialist” experience in some or all of the following symptom management areas: balance issues, bladder and bowel dysfunction, issues in cognition, fatigue management, mental health and mood disturbances, sensory and motor issues, pain management, sexuality and sexual dysfunction, sleep hygiene, spasticity, speech and swallowing dysfunction and visual disturbances
- Skills to identify relapses and pseudo-relapses
- Skills to identify disease progression
- Significant medication management skills from initiating and switching DMDs, managing side effects, monitoring for efficacy and safety, promoting adherence and persistence, and logistical organisation of DMDs.
- Skills in situating realistic hope appropriate to individual circumstances
- Skills in enabling self-management and independence
- Avenues for advocacy led by self or referring to others
- Leading teams in multidisciplinary care settings or in smaller groups
- Understanding basic research and applying to clinical practice

- Self-awareness of areas of lack of knowledge or skill and ambition to seek this when identified
- Skills in accurately assessing entirety of a complicated situation
- Promoting improvements in pathways for patients

Defining the role of the MS Nurse in Australasia

Defining the role of the MS Nurse is challenging. The sheer breadth of the themes and subthemes in the preceding and current chapters demonstrate the considerable knowledge and skill required to successfully perform in the role. This is further complicated by the diverse titles given to MS Nurses in Australasia and the variety of MS settings that MS Nurses work in. However, common to all MS Nurses are some basic skills and responsibilities that assist in defining the role.

A definition of the MS Nurse role

An MS Nurse practices holistic, empathic and patient centred care supporting advocacy, self-management, independence, empowerment and confidence, valuing long term partnerships which promote wellness in people living with MS. Understanding the importance of the DMDs and other medications in MS care and an ability to conceptualise appropriate medications for the lifestyle and beliefs of each individual is vital. MS Nurses recognise that the course of MS is unpredictable, and that flexibility, accessibility, responsiveness and constant learning are necessary to assist people living with MS to achieve their best life possible. Possessing highly developed skills in relapse and symptom management, acting as Conductors of Care in the healthcare team and humanising the medical world for people living with MS are all integral to the role of the MS Nurse.

The final chapter will provide a summary of the overall study, link the study findings to current literature, discuss study limitations, demonstrate typical days in practice reflecting the study themes and provide recommendations for MS Nurse practice and for future research.

Chapter 7: Conclusions and recommendations

The final chapter of this report will reconsider the aims and purpose of the study and explore how the findings of the research provide deep insights into the role of the MS Nurse and enable a contemporary definition of the MS Nurse role to be formulated. This chapter will also link the study findings to recommendations to support and provide professional development for MS Nurses in the future. Additionally, areas of MS nursing practice identified in the study that need to be addressed in the future will be discussed in order to maintain a nursing specialty who have mental and physical wellness, job satisfaction and value.

Introduction

This research study asked the question “What is the experience of MS Nurses in Australasia?” The aims of the research study were to explore the MS Nurse role in Australasia in order to understand current skillsets, identify areas of support and education need and to define the MS Nurse role. The purpose of the research was to achieve a greater understanding of the role of the MS Nurse for key stakeholders in MS care, to facilitate learning and support by suggesting approaches to address unmet needs and to assist MS Nurses to develop professionally by having a clear and defined role. By providing this knowledge and understanding it is hoped this will assist in improving the quality of life, job satisfaction and career fulfilment for MS Nurses, thereby improving the quality of life for patients under their care.

This mixed methods study had an overarching qualitative focus in exploring the lived experience of the MS Nurse. The study was underpinned by ontological perspectives of constructivism and realism and epistemological perspectives of constructivism as the researcher and participants co-created knowledge. The first phase of the study employed a cross-sectional survey to provide a snapshot of MS nursing in Australasia and identified some basic demographics of the current MS Nurse workforce. The anonymous, electronic survey reflected the views of 60 MS Nurses in regard to current levels of support, support needs, current job responsibilities, areas of nursing strength and topics for future learning.

Free text opportunities also enabled the MS Nurses to talk about issues that were causing concern such as job insecurity, lack of respect in the role and rising stress levels as workloads increase. Findings from the surveys helped to establish the beginnings of the role definition and opened up areas to explore more deeply in the phase 2 interviews; notably job responsibilities, the role of MS Nurses in medications, MS Nurses as co-ordinators and providers of support to patients.

The second phase of the study used life history methodology to reveal the spirit of 25 MS Nurses as they went about their daily work, uncovering the meaning of their role and adding clarity to a complex profession. This phase of the study brought deep understanding to the MS Nurse role and developed five key themes as MS Nurses demonstrated the essence of their role as Conductors of Care. The study participants revealed thought provoking, well prepared, honest and generous insights into their working lives at a very deep level which was unexpected, but highly valued.

This deep level of understanding was able to reflect new meaning as the study participants highlighted aspects of the role which were not anticipated prior to study commencement. These new meanings were developed into additional findings to the themes and consisted of characteristics of the MS Nurse, distinctive features of the role, obstacles to the role and joy in the role. Prior to the study commencing, these aspects were not considered to be elements of the MS Nurse role, but as the study interviews progressed, the pathways to these findings were so universal and organic that they demanded clarification. Defining the role was not just going to be about skillsets and a formal set of definitions, fully exploring the role meant that what MS Nurses **are** (their characteristics) also greatly influenced what they **do** in the role and **how** they do it (skillset and definition). Exploring and grasping the essence of the MS Nurse was an important part of achieving immersion in the role. Once this was revealed, a new level of understanding to the role was uncovered, leading to recognition that distinctive features of MS nursing were also important to consider, in addition to obstacles getting in the way of safe and effective practice and the sources of joy that kept MS Nurses working in the role. All of these expected and unexpected study findings came together to inform the eventual definition of the role of the MS Nurse. MS

Nurses consistently demonstrated being Conductors of Care, no matter what their work setting, job description or job title. In the end, it all came down to one phrase.

Summarising the key study themes

The study theme of Holistic Healers focuses on an aspect of MS nursing care which study participants took immense pride in, being at the forefront of patient centred care and often reminding others in the health care team of the importance of this. Often informally leading the health care team, the MS Nurse was the lynchpin in expressing and welcoming holistic care and being the vehicle to effect change in pathways for patients. Sources of Support explored the various ways that MS Nurses provide patient support, recognising the importance of establishing a long-term partnership with patients and the value of communicating well and developing rapport. Often being the balm of calm to an overwhelmed and vulnerable patient, the MS Nurse was also always conscious of enabling self-management and independence. Actioning advocacy on many fronts, MS Nurses championed their patients. Almost innately known but not formally acknowledged, the support that MS Nurses provide for neurologists is often discreet but always valued.

Disease and Symptom Educators and Managers would perhaps be the most obvious part of the role of MS Nurse in a speciality disease, however exploration of these concepts revealed the importance of the MS Nurse as a teacher and confidante for patients, setting the scene for future MS care and expectations by encouraging realistic expectations. To teach using the “thinking muscle” in relapse and symptom management so patients could gain confidence in themselves and in their bodies. MS Nurses were instrumental in relapse and symptom management, by being flexible, adaptable and accessible when patients needed help and advice. For those MS Nurses fortunate to incorporate home visits in their nursing practice, an extra dimension to care was identified which provided additional support to patients in the community.

The theme of Medication Manger highlights the important role that MS Nurses have in all aspects of DMD management. This role in particular has a substantial responsibility and recognises how the holistic focus of care greatly benefits patients as MS Nurses consider all

aspects of lifestyle and patient need when assisting patients to make treatment decisions that are truly personalised. The depth of understanding MS Nurses wish to achieve in DMD selection is profound and reflective of the time and effort they value in building rapport and relationships with patients.

The final theme of Professional Develop Advancers encompassed the dynamic way in which MS Nurses approach their professional lives. As a relatively small specialty group, the outreach shown in building networks and collaborations is extremely important to them and the source of great professional support and understanding. As career-long learners, MS Nurses take every opportunity to learn more and discover answers for patients under their care. The rise of MS Nurse led clinics showcases the unique offerings that MS Nurses bring to patient care and is reflective of the professional status they have acquired through professional determination and acquisition of knowledge. An active or passive commitment to research ensures that the future of MS nursing is in good hands with a commitment to a cause bigger than current care, an investment in the next scientific or medical development which may be a step closer to a cure for PwMS.

Relating the key themes to typical workdays

All features of the themes work together with MS Nurses often moving from aspects of one theme to another during a single intervention or consultation. For example, working as a Holistic Healer, concepts of whole patient care mean the MS Nurse working in a hospital clinic is already thinking about a patient's mental health as they call to report worrying new symptoms indicative of a serious spinal cord relapse. As the MS Nurse is being the balm of calm to the patient on the phone providing instructions of what to do next, they have already called ahead to plan the steroid treatment possibly needed so that the patient can be in and out of the clinic as quickly and fuss-free as possible. They have booked the wheelchair from the front door to the infusion unit and contacted the registrar to come and review the patient as soon as they arrive. They have organised the chair in the infusion suite for the probability of immediate steroids and neurological examination. They have prearranged a sick leave certificate for work, phoned pharmacy for the outpatient scripts needed and looked up the JC virus status of the patient to start thinking about a possible

treatment switch on the way to the MRI suite to see when the patient can be squeezed in for an urgent scan. They have already worked on a plan of how to greet the patient wearing a face that says, "It's all OK, we can do this together, we have got this" instead of a face full of the worry, disappointment and concern they are actually feeling. They have organised a follow-up appointment for next week before they leave the clinic, just so the patient doesn't have to wonder what will happen next for another month. Possibly there is a call in to the Physiotherapist or the Occupational Therapist too, if that looks like a potential need here with motor function deficits. Only after all this is over will the MS Nurse then call a trusted MS Nurse colleague to say, "it's been a really rough day, do you think I did OK here?". Almost all of the themes and subthemes in the findings are covered here in a typical workday as a Conductor of Care.

An MS Nurse working in the community setting might have the situation unfolding on the phone of a patient they provided a single session of MS disease education to 3 months ago calling to say are they feeling very low and they worry about what will happen to their family in the future; they can't see how their wife and two children are going to survive the loss of income and quality of life as they battle primary progressive MS at 35 years of age. This MS Nurse as the Holistic Healer is talking through all the avenues of support they have identified, meanwhile emailing the general neurologist the patient sees in a regional centre to let them know what is unfolding, instructing the administration assistant with a handwritten note to please phone the local mental health team immediately to see if there is any emergency care available today and already thinking ahead to the name of that wonderful psychologist someone else mentioned with a long wait, but who is a perfect match for a young male patient living with MS. Putting these needs at the forefront, the MS Nurse will change the pathway for this young patient and his family by listening, actioning advocacy by referring to others with expertise in the needed areas and phoning them all personally to explain the situation further and plead for an earlier appointment. They will focus on the rapport they have developed in a quick amount of time to calm the situation and provide hope in the form of the support services that can step in when needed and the potential for new drug developments they read only last week were closer to fruition. They will call on every favour they can gather in order to get the help that is needed for this patient as soon as humanly possible. What was that community group who helped Mr Smith

get a walker? That's who we need on the case. They will ensure a phone call to the patient later in the day and again tomorrow to demonstrate commitment and support and they will follow through on this no matter how busy they are. The MS Nurse will keep calling and checking in on the patient until the mental health care team has caught up with the resources to help. Therein lies another typical workday and a reflection of all of the themes and subthemes in a different work setting and situation with the MS Nurse again as the Conductor of Care.

Recommendations for practice

Many of the study themes and subthemes have some elements of previous work exploring the work of the MS Nurse (Ward-Abel et al; 2014; Mynors et al; 2016; MS Australia, 2017; Abel & Embrey, 2018) such as the importance of advocacy, holism, relapse and symptom management. The current study also highlights new findings such as professional development advancement, adding value with home visits, the rise of MS nurse-led clinics and commitment to research. Recent research from Meehan and Doody (2020) used an integrative review to explore the role of the MS Nurse from the perspective of patients, families and carers, and several of the themes developed in that study parallel the findings from the current study. The MS Nurse as a longitudinal care provider was a common thread from previous work in Meehan & Doody's (2020) review, which is reflected in the current study strongly, as is being a bespoke care provider practicing holistic, individualised care and an expert resource possessing knowledge about the disease. The current study extends these findings and delves more deeply into these themes, as one would expect from the MS Nurses performing the role. It is satisfying that many of the perspectives of patients, families and carers reflect the perspectives of the role from the MS Nurses themselves. This indicates a synergy of expectations.

From the descriptive statistics and thematic analysis in phase 1 of the study and the thematic findings and additional findings from phase 2 of the study, there are numerous recommendations that have been developed for MS Nurse practice. Some of the recommendations can be organised by MS Nurses individually if desired, some fall under the banner of responsibility for workplaces and some represent opportunities for MS Nurse

organisations such as MSNA Inc and IOMSN to provide support and learning. However, some of the recommendations are sadly more of a wish list for the time when MS Nurse funding and support reaches real unmet needs, a time in modern healthcare we have yet to see.

Areas of support recommendations

- The intense and heavy workload currently on MS Nurses calls for more physical help on the ground to perform the role. Help with administration and research tasks would also allow MS Nurses to spend more time on patient care and to give patients and their families the time they needed instead of rushing through critical times of patient engagement.
- Feelings of inadequacy at the commencement of the MS Nurse role were common. Providing welcome packages and mentorship programs to new or novice MS Nurses could provide much needed personal and professional support and an avenue for collegial advice from an experienced MS Nurse.
- Nursing research requires dedicated support avenues to ensure that MS Nurses have the capability to commence and successfully complete projects, large and small. Mentors in this field may also provide support and guidance at all stages of the research process and be willing to review draft papers and reports.
- Participants reported the need to debrief appropriately and have someone to go to on the challenging days so that their work did not go home with them and cause issues in their personal lives. The possibility of clinical supervision or a professional debriefing avenue for MS Nurses needs to be explored.
- Secure and permanent funding for MS Nurse positions would ensure that MS Nurses felt supported in their roles and valued. With many positions funded on research,

infusion units, pharmaceutical company grants or other insecure and nonrecurrent funding, there was a feeling of uncertainty about futures and a feeling of lack of insight by others into the value of the role. As building long haul partnerships is fundamental to the role, this is a major concern and contradictory in nature.

- Many MS Nurses felt poorly physically supported in their roles. This included a lack of resources such as laptops, ergonomic chairs, clean and clear desk space to work and private rooms for consults and sensitive phone calls.
- Spiritual support was also important to several MS Nurses and this was also expressed as a desire for debriefing and mentoring to allow their spiritual side to feel less weighed down by the role, and for others it was looking for ways to get together with colleagues to share the load. Finding time in the workday for self-care and spiritual refuelling also proved a challenge.

Areas of learning recommendations

Opportunities for learning were always welcomed by MS Nurses keen to continue their own education and mastery of as many components of disease management as possible, this was irrespective of seniority or years of experience, it was a career long ambition. Areas of learning were identified by MS Nurses in the following areas which may be of interest to MSNA Inc, IOMSN and individual workplaces for educational workshops, conferences, seminars or webinars:

- Mental health management: mental health first aid, counselling, crisis management, suicide ideation, post-traumatic stress disorder, adaptive disorders
- Immunology concepts: understanding basic immunology, immunosuppression, linking DMDs and the immune system
- Neuroanatomy: linking lesions to symptoms, understanding neurological pathways
- Diagnostics: basic and advanced MRI concepts

- Assessment: performing an EDSS or neurological exam
- Symptoms: a deeper understanding of, and strategies for: fatigue, sexual dysfunction, bladder and bowel issues, spasticity, neuropathic pain, swallowing and speech, rehabilitation aspects, tremor, spasticity, menopause management, palliative care, complementary therapies
- Research: getting started, troubleshooting obstacles, collaborating with others, developing research ideas, getting published, research terminology, research ethics
- Social support: cultural diversity, employment, diagnosis disclosure, end of life planning, ethnocultural issues
- Improving patient care: Motivational interviewing, reflective listening
- New treatments: stem cell therapies, emerging and new therapies, remyelination therapies
- Professional development: leadership, time management, wellness coaching, understanding basic statistics and critiquing of articles

Removing obstacles from best practice

These were the hindrances that came up in MS nursing practice which could obstruct the MS Nurse from performing their role to the best of their ability and cause frustration and lack of job satisfaction. Open discussion of these issues in MS nursing forums would likely foster a nurturing and understanding environment and support possible solutions.

- Jobs in jeopardy

Insecurity in the MS Nurse role has always been a concern. As mentioned above in the support section, this issue needs addressing and constant revisiting. Not just for current jobs which are disappearing but to grow the MS Nurse numbers that will be needed for the future and retain as much of the experienced workforce as possible. Sustained pressure can lead to low job morale and feelings of isolation.

- Heavy workload

Several MS Nurses reported such heavy workloads that acquiring joy or satisfaction from their role was seen as impossible. There was constant worry about feeling inadequate and the constant threat of a mistake being made which could cost a patient their life. A lack of respect for the role of the MS Nurse was an issue for several participants, receiving little support or appreciation from management. In some cases, the tasks were so overwhelming there was often a sense of waiting for something bad to happen. There was too much work, too many patients, too many tasks, too much paperwork and not enough time, resources, appreciation, connection, support or recognition of the highly functioning role. Of course, these issues need to be addressed in the individual workplaces as they do not apply to everyone, but perhaps support could be given to those MS Nurses affected from MSNA Inc in some capacity to be able to manage the issues and seek help from appropriate sources. The possibility of a wellness co-ordinator for MS Nurses at MSNA Inc was raised, an interesting idea to consider.

- Stress, burnout and compassion fatigue

For all of the reasons mentioned above, stress, burnout and compassion fatigue need to be openly discussed and management plans developed professionally in order to take this matter seriously. On top of jobs in jeopardy and heavier workloads, the stress on MS Nurses can be overwhelming and can lead to burnout and compassion fatigue. Finding ways to combat this is critical to retain the workforce and position MS nursing as a viable and supported career choice. Several nurses also voiced concerns that they detected some form of territorialism in their own work, however they were not prepared to do anything to combat the feeling; perhaps it could be a trigger or co-symptom to burnout or compassion fatigue. Further exploration would be helpful to understand this phenomenon.

- Acceptance for pharmaceutical company nurses

For some reason, which is not clearly understood, acceptance of pharmaceutical company MS Nurses has not been universal, and it was reported in the study that pharmaceutical nurses had been treated unfairly by other MS Nurses in the course of their work and at

times, obstructed in their role. Acceptance of organisational nurses in the wider MS Nurse community could be supported by improved inclusivity and highlighting their roles and functions as areas where MS Nurses can receive extra support themselves at meetings and conferences. Perhaps a workshop addressing the added value of these nurses and the best ways to engage them as a resource could also be helpful.

- Setting up positive teams

Many MS Nurses expressed a desire for productive, effective, nurturing and energetic teams so they could feel better supported in the role and feel less isolated. This includes facilities for clinical supervision and debriefing as mentioned in the support areas previously. This is a potential area of well-being that could also be explored by MSNA Inc in the future and best practice guidelines in this field investigated.

Promoting fulfilment in the role

Despite all of the obstacles discussed previously, there was much pride and joy expressed by all of the MS Nurses participating in the study about their role. These were the things that constantly brought a smile to their face, made them feel worthwhile and gave sustenance and value to the role.

For many MS Nurses these were the feelings of great connectedness with their patients, the times they broke through in a difficult or challenging situation, the things that made them punch the air as they ran to their next case. It was rarely about the “easier” patients; it was often the complex, more difficult situations that brought the greatest joy. Seeing patients do well in extraordinarily difficult situations was always guaranteed a special mention by MS Nurses as a highlight and the resilience and grace shown by many PwMS never failed to shine.

Limitations of the study

There are some limitations to this research study. As a cross sectional study, the research focuses on a snapshot in time, it is possible that participant feelings and opinions may change over time and be different in the future to what was reflected at the time of the survey or interview. As qualitative research, the study draws on a relatively small number of participants and may not be reflective of all members of the peer group of MS Nurses. The study was situated geographically in Australia and New Zealand and may not be transferable to other regions internationally.

As one of the study researchers (TB) identifies as an MS Nurse, there may be influences on the interpretation of the data. Reflexivity practices were outlined and followed in order to secure trustworthiness of the findings; nevertheless, it is possible that this clinical experience may have been influential in the findings in some way. However, this could also be a positive influence on the study, bringing a greater depth to the research through rapport, shared understanding and connection with the study participants.

Directions for future research

This mixed methods study has used a primarily qualitative lens to explore the experiences of MS Nurses in Australasia in 2020 and provide information on current skillsets and a definition of the MS Nurse role. Further research is required to explore the roles of MS Nurses in other countries as part of understanding the role internationally and providing opportunities for collaborative research projects across regions and sharing expertise.

As MS is an area of rapid change and development, further research will be required at designated time points in the future to assess the relevancy of current support and educational programs and to amend the skillsets and definitions of the role to fit contemporary models of care. The reflection points from each phase 2 study theme also provide a focus for future possible areas of research.

The role of Medication Manager emerged as a strong evolving theme which warrants close monitoring as new DMDs are brought into the resources of treatment options for PwMS in the future. Consideration needs to be given to the needs of the MS Nurse in this area in terms of education and support to continue to be effective and safe in this role.

The consistent hints of stress, burnout and compassion fatigue throughout the study need to be addressed with deeper, focused research in this area and the development of strategies for MS Nurses to be aware of and able to seek help in the event that it is needed.

Other specialty areas of nursing practice, particularly new specialties, may also benefit from a similar deep exploration of the role of their particular specialist nurse.

A final word

As nursing researchers, there can be nothing more special than having a research idea develop into a plan, which then develops into a consuming need to understand the participants and the situation more deeply...and then becomes a story which helps others understand something which is complex and captivating, created by generous and enthusiastic participants. The journey of this incredible story from MS Nurses is only possible because of the honesty, time commitment, effort and grace that they all individually put into the study, either by participating in a very long survey asking some tough questions, or by laying their hearts on the line in a long face-to-face interview telling their life story as an MS Nurse, as one participant referred to it *“the good the bad and the ugly”*.

The fact that most of the study took place during the COVID-19 lockdown in Australasia added another dimension to the study. During this time many of the MS Nurses were trialling new ways of connecting with their patients using telehealth and virtual platforms and were trying to ensure their roles of Holistic Healer, Sources of Support, Disease and Symptom Educator and Manager, Medication Manager and Professional Development Advancer survived the threats they were under and in fact, would perhaps come out ahead of times before the crisis. Looking for opportunities to extend their skillset and knowledge

and be in a position to provide sound, timely and accurate advice to patients feeling vulnerable in the COVID-19 world. The Conductors of Care demonstrated their flexibility, empathy and compassion time and time again as they added this research study to their already growing piles of work in the hope of contributing to the greater good. Thank you to every one of you for your gifts, you made the research study an absolute privilege.

It is hoped that the outcomes of this research study, and particularly the definition of the role, will assist MS Nurses to develop professionally; to support strategies to meet unmet support and educational needs, to plan workloads, to support adequate staffing and to support the development of a skilled and recognised career with respect and acknowledgement of the MS Nurse role. We appreciate that the definition provided is much longer than we would have liked or envisioned at the beginning of the study. However, the breadth and complexity of contemporary MS Nurse work required such a deep introspection of the role. Additionally, the definition is not absolute nor exclusive; it is open to change and interpretation by others and ideally will be the subject for future research and exploration. Furthermore, replicating the research in other countries advances an international profile of the MS Nurse role and allows the definition to evolve.

In the International Year of the Nurse and Midwife, this study acknowledges the skills of MS Nurses and the unique contribution they make to patient care and quality of life. If the professional development and quality of life for MS Nurses can be understood and improved, there follows improvements to the nursing care and quality of life for people living with MS.

In the words of the Dali Lama (undated) *“Many illnesses can be cured by the one medicine of love and compassion”*. In MS care it is never truer. The illness of MS as such may not yet be curable, but many of the resulting illnesses from MS can be cured by love and compassion, initiated and demonstrated by the Conductors of Care.

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Appendices

Appendix 1: Approved flyer text for study survey phase 1

Appendix 3: Approved flyer text for interviews phase 2

Appendix 3: Reflection questions prior to interviews



Calling for volunteers: **A survey** exploring skillsets, role, education and support in MS Nursing in Australasia

Dr Therese Burke and Associate Professor Joanna Patching from the School of Nursing at The University of Notre Dame in Sydney are calling for your help in completing a survey exploring the role of the MS Nurse.

- The survey will take about 30 minutes to complete. All responses are anonymous.
- A Participant Information Sheet is attached to give more information on the purpose of the study, or you can contact Therese Burke directly on therese.burke2@my.nd.edu.au
- Please feel free to suggest the survey to other nurses working in the field of MS

The link to the survey is www.surveymonkey.com/r/TBJPND

*This study has been approved by the UNDA HREC: approval number 019162S.
Version 2 dated 1st December 2019*



Calling for volunteers: **One-on-One interviews** exploring skillsets, role, education and support in MS Nursing in Australasia

- Dr Therese Burke and Associate Professor Joanna Patching from the School of Nursing at The University of Notre Dame in Sydney are calling for MS Nurses to talk about their roles in MS care in one-on-one interviews which will last about an hour.
- Confidential interviews will be performed in person or by Skype and will take place at a mutually convenient time and location. Interviews will be audio recorded.
- A Participant Information Sheet is attached to give more information on the purpose of the study, or you can contact Therese Burke if you are interested in taking part on therese.burke2@my.nd.edu.au

*This study has been approved by the UNDA HREC: approval number 019162S
Version 2 dated 1st December 2019*

Reflection Questions (version 2; dated 27th October 2019):

STUDY TITLE: Exploring skillsets, support and education of Multiple Sclerosis Nurses and defining the role in Australasia

You will be asked to tell your life history as a reflection of your lived experience, with a special emphasis on your life as an MS Nurse. You may tell your story in any way you wish and starting at any point you wish. These notes are designed to help develop your thinking about your life as an MS Nurse ahead of our interview. You can use all of them, use some of them, or choose not to think about them at all, they are just a tool to possibly help you on your way.

- How long have you been working in/how long did you work in the field of MS?
- Can you remember what first brought you into MS nursing? If yes, what was that?
- When you first started, how did you feel?
- How do you feel about being an MS Nurse now?
- Are there any areas of MS Nursing that you feel particularly knowledgeable in?
- What areas do you perform to your best in or excel at?
- Are there any areas of MS nursing you feel you lack in confidence or education?
- Do you feel secure in your role in terms of role longevity?
- What sources of support do you have in your role?
- Are there any areas where you feel support is lacking?
- Career highlights/ career lows
- What do you enjoy most about your role?
- Is there anything you do not enjoy about your role?
- Describe typical days and weeks in your role
- Do you remember any poignant moments in your career as an MS Nurse that you would like to share with me?