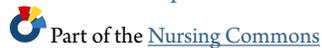

Theses

2019

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

Therese Burke
The University of Notre Dame Australia

Follow this and additional works at: <https://researchonline.nd.edu.au/theses>



COMMONWEALTH OF AUSTRALIA
Copyright Regulations 1969

WARNING

The material in this communication may be subject to copyright under the Act. Any further copying or communication of this material by you may be the subject of copyright protection under the Act.

Do not remove this notice.

Publication Details

Burke, T. (2019). "Taming the beast": Exploring the lived experience of relapsing remitting multiple sclerosis using a life history approach (Doctor of Philosophy (College of Nursing)). University of Notre Dame Australia. <https://researchonline.nd.edu.au/theses/207>

This dissertation/thesis is brought to you by ResearchOnline@ND. It has been accepted for inclusion in Theses by an authorized administrator of ResearchOnline@ND. For more information, please contact researchonline@nd.edu.au.



CHAPTER 1: INTRODUCTION

Introduction

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

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

Background

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

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

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

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

Aims of the study

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

The research question

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

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

Methodology

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

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

Significance of the study

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

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

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

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

Nuances of the thesis writing style and terminology

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

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

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

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

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

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

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

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

Overview of the thesis

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

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

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

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

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

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

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

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

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

Conclusion

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