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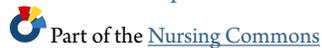
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2019

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

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

Therese Burke

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

School of Nursing  
The University of Notre Dame Australia

2019

## **DECLARATION OF AUTHORSHIP**

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

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

Therese Burke  
Candidate's name

18<sup>th</sup> February 2019  
Date

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## **LIST OF ABBREVIATIONS**

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

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

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

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## **ABSTRACT**

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

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

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

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

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