

# Management of 'surplus suffering' in relapsing remitting multiple sclerosis to improve patient quality of life

Therese Burke, Steve Vucic and Joanna Patching

**M**ultiple sclerosis (MS) is one of the world's most common neurologic disorders, with 2.3 million people diagnosed with the disease and the rate steadily increasing (Browne et al, 2014). The most common form of MS is relapsing remitting MS (RRMS), affecting 85% of people living with the disease, with a peak age of onset between the ages of 20 and 40 years, and showing a female preponderance of 3:1 (Compston and Coles, 2008). RRMS is characterised by short relapses followed by a return to usual function over a period of weeks; but recovery can be uncertain, variable and incomplete (Sorensen, 2014). RRMS can present with a complicated array of symptoms, that may affect function in many ways, including sensory function, motor function, vision, gait, cognition, mood, bladder, bowel and sexual function (Ben-Zacharia, 2011). Although disease-modifying therapies (DMTs) can alter the course of the disease, RRMS currently has no cure. MS nurses, neurology nurses and other healthcare professionals (HCPs) may come into contact with people living with RRMS (PwRRMS) in many areas—in direct MS care or during the period of another illness, maternity care or in community health settings.

## Aims of the study

The purpose of this research study was to gain insights and understanding into the lived experience of RRMS, aiming to produce a rich account of how it feels to live with RRMS. It is anticipated that these insights may provide nurses and other HCPs with a deeper understanding of the patient experience to enable more holistic and empathic nursing care.

## Literature review

In a seminal paper on the lived experience of RRMS, Miller (1997) reported a theme of conflict arising as a result of RRMS in two ways. The first was conflict of patients with HCPs, particularly physicians, regarding the diagnosis of RRMS or explaining the disease. The second area of conflict involved patients' own families. However, there is a paucity of recent research exploring the lived experience of PwRRMS, and very

## ABSTRACT

**Background:** A study exploring the lived experience of relapsing remitting multiple sclerosis (RRMS) identified the potential for 'surplus suffering' in this group of patients. This article explores the concept of surplus suffering and the role nurses can play in identifying and managing it. **Methods:** Qualitative inquiry, using a form of focused ethnography called life history, explored the experiences of 13 people living with RRMS. Semi-structured interviews were analysed using thematic analysis to reveal key themes from the data. **Findings:** A total of eight key themes explained the journey of living with RRMS. This article explores one particular theme, surplus suffering, as it is novel to the area of multiple sclerosis and neurology, and may severely impact upon quality of life. Surplus suffering is suffering over and above suffering caused by the disease itself, and may be inflicted by healthcare professionals, friends, family and community. **Conclusion:** Awareness by MS and neurology nurses of the potential for surplus suffering, and subsequent management, may enhance clinical nursing care and quality of life for people living with this chronic neurological disease.

**Key Words** relapsing remitting multiple sclerosis; lived experience; life history; surplus suffering

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little literature describing concepts of suffering, and particularly the concept of 'surplus suffering' in MS.

## Suffering in illness

Suffering has been defined as 'the distress that is brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person' (Cassell, 1991:4). It has been argued by Cassell (2004) that little attention or discussion has been given to the problem of suffering and patient emotions in medical education, research or practice, despite relief of suffering being considered one of the primary ends

**Table 1. Demographics for study participants experiencing surplus suffering**

Study number	Pseudonym	M/F	Age at interview (years)	Marital status	Years since RRMS diagnosis
01	Piper	F	38	m	2
03	Kate	F	46	m	24
05	Joy	F	57	d	12
07	Paul	M	38	m	2
11	Susan	F	40	m	14
12	Davina	F	54	m	32

F, female; M, male; m, married; d, divorced; RRMS, relapsing remitting multiple sclerosis

of medicine by both patients and the general public. Medical models of suffering tend to concentrate on fixing, curing and eliminating illness, compared to the nursing perspective, which tends to look at the broader paradigm of the quality of a life lived. As nurses play a fundamental role in caring for those who suffer, and are present for people as they struggle through illness, the relief of suffering is at the core of a nurse's work (Ferrell and Coyle, 2008).

### Surplus suffering as a concept

Surplus suffering as a concept was first described by James and Clarke (2001) as they explored the experience of immigrant women adjusting to life in a new country and the extra suffering inflicted on them as a result of seeking healing in a western healthcare system. Surplus suffering was defined as the women suffering over and above the signs and symptoms that brought them to medical care in the first place. Further work in surplus suffering by Clarke and Fletcher (2005) explored experiences of parents when their child was living with cancer, and conceptualised surplus suffering as the extra, unnecessary suffering that can result from HCPs and the healthcare system, in addition to the inherent physical suffering already resulting from cancer and its treatment. Clarke went on to explore further themes of surplus suffering as a key component in studies of people living with Asperger's syndrome (Clarke and van Amerom, 2007), parenting a child with mental health issues (Clarke, 2012) and childhood mental health issues (Clarke, 2013).

### Methodology

The qualitative research paradigm, and specifically ethnography methodology, was chosen to gain a greater understanding of the lived experience of RRMS. This methodology involved key informants representing a culture under study, discussing their lives so that others can better understand the culture (de Chesnay, 2014), the culture in this study being a

person living with RRMS. This study used a particular form of focused ethnography, life history, to explore a retrospective account of each participant's life. Although there was an emphasis on living with RRMS, participants were encouraged to tell their life histories in any way they wished.

### Methods

#### Participants

Study participants were purposively recruited using a flyer provided to the local, New South Wales branch of the national MS patient organisation, MS Australia. The inclusion criteria required participants to be over the age of 18 years, diagnosed by a physician with RRMS, to be ambulant, and to speak and understand English. A total of 13 people were enrolled into the study; nearly half of the participants reported experiencing surplus suffering. Study demographics are shown in *Table 1*.

#### Ethical considerations

Ethical approval for the study was granted by the Notre Dame University, Australia, Human Research Ethics Committee under a full ethical review process. All procedures were performed within guidelines and informed consent was obtained prior to study-related activities. Pseudonyms were used to protect participant confidentiality. Counselling options, although not needed, were put in place in case the life history interviews induced distress in participants recalling their past experiences.

#### Data collection

Semi-structured, one-on-one, audio-recorded interviews took place in a venue chosen by the participant. Recorded interviews were transcribed verbatim by the principal investigator (PI), the first author (TB), and field notes recorded observations from the interviews. Participants were not asked specific questions about surplus suffering; all stories were told organically and developed as a theme later in data analysis.

#### Data analysis

The Braun and Clarke (2006; 2013) method of thematic analysis was used to identify patterns within the dataset. This systematic and robust method of data analysis allowed inductive, and both semantic and latent interpretations of the study dataset. This analytic method involved familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes. It was followed directly as recommended by Braun and Clarke (2006; 2013).

#### Study rigour

Study rigour was enhanced by the use of a reflexive diary, systematic data analysis, peer debriefing of themes, thick and rich descriptions of the phenomena,

and the addition of direct quotes from study participants to support the study findings.

**Findings: surplus suffering in RRMS**

While listening to the stories of the study participants during the interviews, the realisation struck that the health system had induced further suffering in addition to the burden of already living with RRMS. There were many stories of outstanding support from HCPs, and of support and love from family and friends in the life stories. However, very sadly, there were stories of additional suffering experienced by the participants, and this sometimes involved compromised care from their HCPs, or emotional pain inflicted by family or friends, or sometimes by their community.

**Surplus suffering inflicted by HCPs in clinical care**

Surplus suffering was experienced by several study participants, feeling ‘brushed-off’ in their dealings with HCPs during their life journey with RRMS. This was conceptualised as feeling ignored or dismissed by HCPs, the emotional pain induced by the refusal of HCPs to take symptoms seriously, to trivialise symptoms or to investigate symptoms further. One of the most moving stories was the surplus suffering experienced by Joy. Growing up in a rural community, Joy suffered various neurological complaints over the years, presenting frequently with her symptoms, but often ignored.

*I was sick ... and they just treated Mum like she was a Munchausen's mother ... they thought she was crazy, so when I went to the doctor's and said "I'm sick" they just believed that this is the child of the Munchausen's mother, well of course she's going to be a hypochondriac ...*

*I went deaf and my right leg dropped and right arm ... but again he [doctor] wouldn't send me for tests to see if I'd had a stroke ... and I thought you're frigging joking! My right side had dropped and you're not willing to do any tests on me? I just ... despair ... it nearly broke me. Joy*

Almost half of all participants in this study described feeling ‘brushed off’ in their encounters with HCPs in the lead-up to a diagnosis of RRMS, meaning that they presented with symptoms, but weren’t taken seriously or investigated further. Piper struggled with her unexplained and undiagnosed symptoms for many years.

*The doctor said "there's nothing wrong ... you know, go away" ... I went to a few doctors actually ... I feel like a fraud because I can feel these things ... I was told "it's cold, because this is winter go home and put some gloves on" ... it actually makes me cranky because I'm not making it up ...*

*I got to a point that I remember laying in bed one night ... I was becoming more and more anxious with it, knowing there was something wrong ... and I said "I*

*really think I'm going crazy ... like the doctors think I am" ... in the end I gave up almost ... they can't find anything wrong. Piper*

Susan’s general practitioner (GP) would not refer her to see a specialist, despite her neurological symptoms and repeated requests. Although since her diagnosis he has apologised to Susan, the impact of the surplus suffering from his initial rejection of her symptoms has remained with her.

*To acknowledge what I was feeling, that's all I wanted ... and I was angry when it all started with my GP not listening to me ... I accept his apology but he needs to listen to his patients, people know their own body. Susan*

Kate, highly educated and working in the medical and scientific field, sought neurological medical attention after sudden episodes of blindness. Over 25 years prior to the study interview, Kate recalled her first visit with the neurologist when she was told her likely diagnosis was MS. Kate had no knowledge of the disease and struggled with the abrupt delivery of the diagnosis and the lack of follow-up education.

*He says "you probably have MS" ... he turns around and goes to me "and you may end up in a wheelchair and you will probably be blind in 5 years' time" ... I looked at him and thought, 5 years ... I said I'm only going to be 27 and I'm going to be blind? And I was a mess ... he gave me antidepressants to get over it and I thought ... Oh, this can't be happening to me. Kate*

Davina’s experience of surplus suffering was also the result of the news of her diagnosis, at the foot of her bed in a hospital room shared by others. Davina was left devastated, with no offer of follow-up care. Davina also tells how she felt secluded and isolated by the ward nurses at this time of intense vulnerability.

*He stood at the end of the bed and said it's probably 99 percent definitely MS because you fit the age, your sex and your symptoms are very textbook ... so I suggest to you that you think of your future and perhaps if children was something you were looking forward to, it might be something you think about now, because better to be a disabled younger mother than a disabled older mother ... I was distraught ...*

*They put me in the end room and the nursing staff on the neurology ward avoided me because I don't think they wanted to face me, that was very, very obvious ... how do you treat someone who has just been given the worst news of their life ... of which they didn't understand either. Davina*

Paul’s story has significant implications for poor clinical research conduct, but also highlights the continued physical impact of surplus suffering. Paul

had not told anyone about his experience of surplus suffering until the study interview, and carried the burden of surplus suffering for many years. Paul was already under the care of a neurologist who had recently diagnosed him with RRMS. In the wait time before his next appointment, he suffered a further relapse and was admitted to a local hospital. He then saw a different neurologist, who provided emergency treatment and advised a follow-up appointment to check Paul's progress. As Paul had very little experience with the hospital system, he was unsure of the correct etiquette in this situation, and agreed to attend the appointment. Upon arrival to his consultation with the new neurologist, Paul did not know what to expect. He was ushered through to a room, where he felt pressured into signing trial consent forms and assumed that he would be given better explanations later. This did not happen.

*I said "what's going to, what's this all about?" and he says "Oh well, we can go over all of this later on but what I want to know is to see if you would like to start treatment today or in the near future?" ... and I said "well, you know, obviously I want to get onto something, but what does that mean?" And he says "Oh well, OK, I'll take you out to the nurse out the back and we'll get you enrolled in this trial" ... and I'm thinking ... what is this? what is this? ... And so, ten-minute consult without anything ... what the hell is going on?" ... He went and stood at the door ... it was quite horrific in hindsight. Paul*

### Surplus suffering inflicted by family, friends and community

Another area of surplus suffering experienced by study participants involved considerable conflict within their own family. Joy continued to suffer emotionally after a neurological episode, but this time from the people she loved.

*No-one believed me, my teachers didn't believe me, my parents didn't believe me, I wasn't taken to the doctor, no-one believed me, no-one cared, no-one did anything about it, nothing ... you are lazy, stupid, ridiculous. Joy*

Further on in her MS journey, Joy's husband forced her to continue to work as she battled a severe relapse, not allowing her to take sick leave (which would have been unpaid) and pushing her to breaking point.

*I'm so sick and I can't work and he was ... "absolutely not, you have to go to work" ... I was just heartbroken, I kept going but my legs went on me and I started walking with a cane because I was really struggling to walk ... and then I lost my job because I wasn't doing my job, so while my husband was screaming at me "you have to go to work", I lost my job, so I couldn't go to work. Joy*

The impact of surplus suffering from Davina's family

was from the unkindness inflicted by her family over many years. Davina's (now ex) husband treated Davina and her RRMS symptoms with contempt, and also encouraged their young children to do the same.

*The problem is...because my husband didn't want to know, he never shared it with them (our children) ... he never was supportive of me ... so then it became them against me ... so if I lost it or I got really tired, I've got MS or whatever, don't stress me so much, they'd turn around and say "Oh, don't pull that MS card again" ... he would never defend me, he'd never say "don't you speak like that to your mother, she's got a condition" ... and that went on for years. Davina*

### Discussion

For several participants in the study the delivery of the diagnosis of RRMS caused additional suffering to them. It has been suggested that proper disclosure of an MS diagnosis with effective communication requires discernment, tact, timing, flexibility, responsibility and sustained attention to the particular needs of the patient as a person in their own, unique context (Krahn, 2014). As the physician–patient relationship has an effect on long-term adherence to therapies and lifestyle prescriptions (Koudriavtseva et al, 2012), the impact of this time cannot be underestimated. The consultation where a diagnosis of MS is revealed should be planned thoughtfully, with adequate time for preparation, a discussion of the likely diagnosis and planned treatment options, sources of support for afterwards, time for questions from the patient and a planned date for a follow-up appointment.

### Nurses managing surplus suffering

Empathic nursing and 'going the extra mile' may be the key to setting up better outcomes for people with MS in the future (Davies, 2014). When a nurse truly practises empathy with a patient, they share the patient's struggle and feel their pain (Davies, 2014), allowing the nurse to interact on the same emotional level as the patient and helping to establish trust (Ward et al, 2012). As MS and neurology nurses, part of nursing is to lend strength until the patient finds their own. The MS or neurology nurse is perfectly positioned to assess for, recognise and discuss previous surplus suffering with patients and to help them heal.

### Towards a definition of surplus suffering in RRMS

Based on the stories from the study participants in this study, and the literature on the phenomena of suffering discussed above, a definition of surplus suffering has been developed to fit a conceptual model of living with RRMS:

*Surplus suffering is suffering caused to PwRRMS over and above suffering from the existing physical,*

**CPD reflective questions**

- Think about a time when you may have felt surplus suffering yourself in your personal healthcare experience. How did it make you feel?
- What are some methods the nurse could use to assess for and discuss previous experiences of surplus suffering with a patient?
- Think about ways of managing surplus suffering in those patients affected. How could the nurse help to resolve these feelings and assist the patient to move on in a positive way?

*emotional and mental burdens of the disease. Surplus suffering in RRMS is caused by the actions of others, including HCPs, the healthcare system, family, friends or community.*

**Study limitations**

As a qualitative study these data draw on a relatively small number of participants living in one state of Australia. The role of the first author (TB) as an MS nurse in clinical practice invariably influenced data interpretations during the study. A constant assessment of reflexivity throughout the study aimed to recognise these influences; however, despite these safeguards, it is possible they influenced the research findings.

**Conclusion**

When nurses ask questions and act as confidants for patients, they can have a significant positive impact on future medical and nursing care. The incidence of surplus suffering reported by participants in this study was surprising; the release of the emotional pain came with acknowledging and talking about the experiences. Even if surplus suffering was not inflicted under their own nursing care, the nurse could possibly be dealing with the impact of previous surplus suffering. Asking the right questions about prior care and experiences can greatly improve future care, by opening doors for communication and healing. MS and neurology nurses cannot always alleviate suffering, but can listen, practise kindness and compassion, and create a safe, empathic environment in which patients can heal and gain strength. Surplus suffering in RRMS care emerged as a key, novel finding for this particular population and could form the basis of further research work on this phenomenon, not just in RRMS, but also in other neurological diseases. **BJNN**

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**KEY POINTS**

- Surplus suffering is a concept which explores suffering over and above that caused by a disease state itself, and can be inflicted by HCPs, the medical system, family, friends and the community
- Allowing the voice of the patient to be heard and acknowledged can induce a more positive experience for the patient to move forward with confidence and optimism
- Nurses are in an ideal situation to assess for the presence of surplus suffering in patients and to take steps to discuss and manage surplus suffering. Nurses are also in an ideal position to lead the healthcare team by example: practising compassion, kindness and empathy
- Asking the right questions about prior medical and nursing care and experiences can greatly improve current care, by opening doors for communication and healing and managing expectations for the future.

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