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“It feels like someone is hammering my feet”: Understanding pain and its management from the perspective of people with Multiple Sclerosis.

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Keywords:	Pain, Multiple sclerosis, Experiences, Qualitative, Management, Thematic Analysis
Abstract:	<p>Background: Pain affects around 63% of people with Multiple Sclerosis (pwMS). Biomedical treatments demonstrate limited efficacy. More research is needed to understand pain from the individual's perspective in order to better inform a patient-centred approach that improves engagement, self-management and outcome.</p> <p>Objective: To explore pwMS' experience and responses to pain, and their perspectives on pain management.</p> <p>Methods: Twenty-five, in-depth, semi-structured, telephone interviews were conducted. Interviews were audiotaped, transcribed and analysed using an inductive thematic analysis approach with elements of grounded theory.</p> <p>Results: Key themes included vivid descriptions of pain and beliefs that pain is unpredictable, a sign of damage and may worsen. Anger was a common emotional response. Two dominant pain management themes</p>

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	<p>emerged: one related to pain reduction and another to acceptance. Those focussing on pain reduction appeared to engage in cycles in which they struggled with symptoms and experienced continued distress.</p> <p>Conclusion: Findings identify pain-related beliefs, emotional reactions and disparate pain-management attitudes. All may influence pwMS' responses to pain and what they ask of their clinicians. Uncovering pwMS' personal beliefs about pain, and introducing a broader biopsychosocial understanding of pain in the clinical context, may provide opportunities to rectify potentially unhelpful management choices and enhance pain acceptance.</p>

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8 management from the perspective of people with Multiple Sclerosis.
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14 **Authors:**

15
16 Anthony M Harrison¹, Angeliki Bogosian¹, Eli Silber², Lance M McCracken¹ and Rona Moss-
17
18 Morris¹

19
20
21 (Health Psychology Section), Institute of Psychiatry, Kings College London, UK

22
23
24 (MS Specialist Outpatient Neurology Service), King’s College Hospital London, UK
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Corresponding author:

Rona Moss-Morris, Health Psychology Section, Institute of Psychiatry, 5th Floor Bermondsey

Wing, Guy’s Campus, King’s College London, SE1 9RT, UK

Email: rona.moss-morris@kcl.ac.uk

Tel.: +4420 7188 0180 Fax: +442071880184

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Table 1: Characteristics of the sample (total N=25)

Table 2: Interview schedule

Table 3: Key Themes additional examples

Figure 1: Thematic diagram of key themes and subthemes

Figure 2: Catch-22 example (60 year-old Female, RRMS)

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13 **Authors:**

14 Anthony M Harrison¹, Angeliki Bogosian¹, Eli Silber², Lance M McCracken¹ and Rona
15 Moss-Morris¹
16

17
18
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47

48 **Corresponding author:**

49 Rona Moss-Morris, Health Psychology Section, Institute of Psychiatry, 5th Floor

50
51 Bermondsey Wing, Guy’s Campus, King’s College London, SE1 9RT, UK

52
53 Email: rona.moss-morris@kcl.ac.uk

54
55
56 Tel.: +4420 7188 0180 Fax: +442071880184
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Abstract

Background: Pain affects around 63% of people with Multiple Sclerosis (pwMS). Biomedical treatments demonstrate limited efficacy. More research is needed to understand pain from the individual's perspective in order to better inform a patient-centred approach that improves engagement, self-management and outcome.

Objective: To explore pwMS' experience and responses to pain, and their perspectives on pain management.

Methods: Twenty-five, in-depth, semi-structured, telephone interviews were conducted. Interviews were audiotaped, transcribed and analysed using an inductive thematic analysis approach with elements of grounded theory.

Results: Key themes ~~reflected included idiosyncratic beliefs that~~ vivid descriptions of pain and beliefs that pain is unpredictable, a sign of damage and may worsen. Anger was a common emotional response. ~~Two dominant Attitudes about~~ themes emerged: one related to ~~ranged from a focus on~~ pain reduction and another to ~~acceptingance and living with pain. Those focussing on pain~~ A pain-reduction agenda appeared to ~~be associated with~~ engage in unhelpful ~~cycles in which they of struggling~~ struggled with symptoms and ~~experiencing~~ experienced continued distress.

Conclusion: Findings ~~provide novel insight into~~ identify ~~-~~ pain-related beliefs, emotional reactions and disparate pain-management attitudes. ~~All have the potential~~ to ~~All may~~ - influence pwMS' responses to pain and what they ask of their clinicians.

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3 Undcovering pwMS' ~~idiosyncratic~~ personal beliefs about pain ~~causal beliefs~~, and
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5 ~~enhancing their knowledge of a~~ introducing a broader biopsychosocial understanding
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7 of pain in the clinical context, may provide opportunities to rectify potentially
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9 unhelpful management choices and enhance pain acceptance.
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Introduction

A recent meta-analytic review estimates pain affects around 63% of people with Multiple Sclerosis (pwMS).¹ MS pain can be broadly classified as either neuropathic, directly caused by a primary lesion or disease of the somatosensory nervous system (including Lhermitte's sign and trigeminal neuralgia), or non-neuropathic, arising from actual or threatened damage to non-neuronal tissue including activation of nociceptors (musculoskeletal).^{2, 3} Pain can be indirectly related to MS, coincident, or caused by other MS symptoms and treatments.⁴ A third of pwMS describe pain as one of the worst MS symptoms.⁵ Many experience uncontrollable pain⁶ and current biomedical treatments demonstrate limited efficacy.⁷

MS pain is yet to be carefully understood or extensively studied within a broader biopsychosocial framework.⁸ Whilst there is a growing body of evidence for psychosocial factors associated with MS pain⁹⁻¹¹, few studies have engaged patients in direct discussion about their experience. Two qualitative studies offer useful insights into pwMS' descriptions of pain and its impact.^{8, 12} However, little is known about pwMS pain-related beliefs, which may be important since the way individuals conceptualise their MS symptoms¹³⁻¹⁵ and treatments¹⁶ can determine self-management behaviour and outcome. Therefore, using qualitative methods to better understand how individuals perceive pain may guide the development of patient-centred clinical approaches that improve engagement in specific treatments.

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3 The aim of the current study was to explore pwMS' experiences of pain and their
4 beliefs about pain and its management.
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9 10 **Participants and methods**

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14 The project was approved by the Berkshire Research Ethics Committee.
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19 Participants were included if (a) they were over eighteen years of age, b) diagnosed
20 with MS, and c) experience of pain in the context of MS~~experienced any type of MS-~~
21 ~~related pain.~~ PwMS were excluded if they were non-English speakers.
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28 Recruitment was via national advertising and through ~~hospital MS clinics. Fifty~~
29 ~~pwMS responded to advertisements placed through~~ National Health Service (NHS) MS
30 ~~clinics and the National MS Society. Thirty four patients were approached by health~~
31 ~~care professionals (HCPs) at three NHS MS neurology outpatient clinics.~~ Potential
32 participants were invited to complete a screening questionnaire, ~~completed either in~~
33 ~~clinic or sent to them via post with a pre-paid return envelope.~~ The screening
34 ~~questionnaire was used to purposefully sample participants with a range of~~
35 ~~demographic and illness characteristics and to capture a diversity of perspectives.~~ The
36 ~~screen included including~~ demographics, Self-report Leeds Assessment of Neuropathic
37 Signs and Symptoms (S-LANSS)¹⁷, MS subtype pictorials¹⁸ and Self-administered
38 Expanded Disability Status Scale.¹⁹ Once returned, purposive sampling was used to
39 select a diverse range of participants. ~~decisions about who to select for interview were~~
40 ~~made based on this information.~~ Thirty-two responders to study advertisements
41 returned the screening questionnaire. ~~(64%),~~ and 26 ~~(52%)~~ from ~~those approached in~~
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MS clinics. Twenty-five participants were interviewed (Table 1): 12 from the MS Society and 13 from NHS specialist clinics. Interviewing ceased once data saturation was reached, defined as the point at which no new information or themes are observed in the data.²¹

[Table 1 Here]

Participants included six men and nineteen women, with a mixture of ethnic backgrounds, ages and occupational status ~~(see table 1 for further demographic details)~~. PwMS reported an average pain severity rating of 6.5 on the S-LANSS 11-point scale suggesting pain in the moderate to severe range (see Table 1 for further demographic and disease information).

Design

Non-directive, semi-structured telephone interviews were conducted by A.H. to elicit accounts of participant's experience. The interview schedule (Table 2) , piloted and edited by three patient and public involvement members with MS, included seven open-ended questions, encouraging individuals to share issues that were important to them. Questions were provisional and modified if more clarification was required. Telephone interviews were used to improve access to pwMS who might otherwise be excluded due to severe disability. Interviews ranged from 30-60 minutes in duration, and were digital-audio recorded and transcribed verbatim. ~~Interviewing ceased once data saturation was reached, defined as the point at which no new information or themes are observed in the data.²¹~~ Once data saturation was reached, At this stage

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3 those who consented but were not interviewed were thanked for their time, and given
4
5 the opportunity to participate in future studies in this research programme.
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8 9 10 **Data analysis**

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14 Data were analysed following established guidelines for inductive thematic
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16 analysis²² and procedures from Grounded Theory,²³ used specifically to gain
17
18 psychological insights to guide the next stages of the MS pain treatment research
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20 programme.
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26 A.H. listened to interviews, and repeatedly read transcripts to become immersed in
27
28 their content. Coding was undertaken with regular discussion with authors A.B. and
29
30 R.M.M., who read and coded excerpts from four transcripts to ensure AH's coding was
31
32 grounded in the data. Each unit of coding was assigned a descriptive name on Nvivo 10
33
34 software, and wherever possible, reflected participant's vocabulary.²³ Codes were
35
36 redefined and combined, and new and alternative codes were generated.²³ Broader
37
38 themes were identified and organized into a preliminary framework. A.H.'s written
39
40 accounts and diagrams of themes and their interrelationships were repeatedly
41
42 checked against transcripts to ensure they accurately represented the data.²⁴ An audit
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44 trail of coding and thematic developments was maintained.
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51 **[Table 2 Here]**

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55 **[Figure 1 Here]**
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Results

Figure 1 summarises five key identified themes and their subthemes: 1) Pain in the context of MS, 2) Vivid & paradoxical descriptions, 3) Pain beliefs, 4) Dealing with frustration and anger, and 5) Attitudes & beliefs about pain management.¹ Each of these is described in turn and a summary provided in table 3 with additional examples of coded quotes.

[Table 3 Here]

1. Pain in the wider MS context

This first theme explains that many participants viewed pain as the worst symptom of MS. PwMS described pain as inherent to other MS symptoms, including optic neuritis, spasms and sensory dysfunction. The co-occurrence and interaction between pains, fatigue and sleep disruption were also highlighted. A few pwMS suggested that pain had become a common label to identify or describe other MS symptom experience.

I think it's all just swirled into one... MS pain is wrapped up with a lot of other MS symptoms. All symptoms around my legs seem to have some sort of pain attached to them... I think a lot of my symptoms have now become about pain. (Female, 46 RRMS)

¹ More detailed information of all the themes can be obtained from the authors.

2. Vivid and Paradoxical Descriptions

Although many patients said pain was hard to describe, most in fact provided clear descriptions. Many of these descriptions also included strong imagery.

In my feet, you know, I could say that um it feels as though somebody is um hammering my feet with a claw hammer, a metal hammer... but how do I know that because that has never happened to me? (Male, 62, PPMS)

3. Pain beliefs

Three types of pain-related beliefs were prominent.

Pain is unpredictable. Many participants suggested their pain had no discernible pattern, arising randomly from day-to-day and changing unpredictably across the disease course.

It changes quite a lot with MS. I get these feelings in my toes... it feels like there are pins sticking in... and the pains change as well, and all the feelings in the feet change. It's become more painful over the last year than it was before. (Female, 58, RRMS)

Personal/Idiosyncratic causal beliefs. PwMS expressed a variety of **personal** ~~idiosyncratic~~ causal beliefs about pain, ranging from the use of cholesterol medication to having a stressful lifestyle.

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3 *I would definitely say... the main thing is stress... stress really flares it up. (Male, 35,*
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5 RRMS)
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10 Pain was sometimes assumed to be a direct result of damage to nerves and viewed
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12 as a sign or omen of worsening pain, further damage, relapse and disease
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14 progression. Some pwMS felt this explanation came from HCPs.
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18 *I have been told by neurologists it's to do with the scarring on the right-hand side of my brain*
19
20 *[headaches]. I've had quite a few MRI scans that have shown up where the areas of the...*
21
22 *damage, the myelin sheath are, and I experience quite serious headaches... I don't know*
23
24 *whether I believe if it's a pain more telling me to calm things down a bit or whether it's*
25
26 *something going wrong with my nerves. (Female, 42, SPMS)*
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31 PwMS sometimes referred to vivid causal descriptions of the central nervous
32
33 system being confused or faulty.
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38 *I know that a lot of it is caused by... the electrical cable of your nerves, the myelin has holes in*
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40 *the plastic sheath around a cable and so it isn't working properly, some of the signals are not*
41
42 *getting through... that's when it ends up causing pain. (Female, 55, RRMS)*
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47 ***Pain will get worse.*** Most pwMS' felt that pain would worsen over time.
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51 *Well, I'm expecting... it does, it has got worse... over the past say five or six years, walking*
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53 *distances is more and more difficult. So I'm imagining that it will get worse, hopefully not too*
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55 *quickly because my progress has been quite steady over the years. (Male, 52, RRMS)*
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4. Dealing with frustration & anger

The fourth subtheme reflects the idea that pain is an unwanted companion for pwMS, often resulting in frustration and anger. Many described these difficult feelings were due to pain's intrusive and unrelenting nature, becoming a central focus in their awareness.

The discomfort causes frustration. The best way to describe it is... when... something is just... like a dripping tap or something, it's just like, 'Oh god why is this...? Just go away!' kind of thing.

(Male, 35, RRMS)

Most reflected on pain's ability to prevent spontaneous or planned engagement in enjoyable activities. This aroused frustration and anger, and some highlighted a tendency to dwell on pain and an inability to disengage from angry feelings.

If I go for a walk with my friend... after half an hour, I know I can feel pain increasing... I can feel myself getting upset and cross and then I have to sit down and wait... that makes me really angry ... if I go home and dwell on that... and if it doesn't recede, then I get more angry and upset.

(Female, 46, RRMS)

Some described becoming short-tempered towards others, which resulted in socially isolating behaviour to manage pain and preserve relationships.

I get really grumpy... to the point where nobody can talk to me because I'm so 'ahhhhhh, leave me alone!' and let them know everything is painful. I feel guilty about it afterwards (Female, 38,

RRMS)

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5 Other causes of anger and upset arose from disappointment with recurrent,
6 unsuccessful attempts to reduce pain with medications. A few felt treatments
7 specifically addressing anger may be helpful.
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11 12 13 14 **5. Attitudes & beliefs about pain management** 15

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19 The fifth subtheme illustrates how pwMS shared mixed successes in attempts to
20 reduce pain.
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26 ***I've tried most things and it's a case of hit and miss.*** PwMS used a variety of
27 treatments and management strategies, ranging from medications and self-
28 administered physical strategies (e.g. bathing or stretching) to mental
29 visualization or distraction techniques.
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37 *With my headaches, it's been quite hard to control because there is... something that will work*
38 *on me, and then there are some things that don't, and they will work for a certain amount of*
39 *time, and then it won't work.* (Female, 18, RRMS)
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46 ***Common ways to self-manage.*** While a minority of pwMS used exercise to reduce
47 pain arising from standing or sitting still, the majority PwMS identified two
48 common ways to self-manage, including taking pain medications (even if
49 ineffective) and being careful not to over-exert themselves by stopping and resting
50 regularly.
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5 ***Pain reduction agenda.*** When asked about expectations of future treatments,
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7 many professed adherence to a pain reduction agenda, reflecting an eagerness to
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9 try new ‘wonder drugs’ and learn new ‘mental tricks’.
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14 *Just relief from the pain... so I don't have it anymore, or if I do, that it's less than what I have*
15
16 *been experiencing that has to be the ultimate goal, I can't think of anything else... I would*
17
18 *want the pain to be less or non-existent - it has to be!* (Female, 38, RRMS)
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22 ***Catch-22.*** Consistent with the reduction agenda, pwMS often described unique
23
24 ‘Catch-22’ situations or unhelpful ‘cycles’ that undermined common ways to self-
25
26 manage. Figure 2 shows how one lady’s attempts to manage or reduce pain
27
28 (avoiding movement), in combination with other debilitating symptoms (fatigue),
29
30 tended to result in worsening pain and symptoms, and additional problems
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32 (weight gain). This often equated to pwMS feeling increasingly stuck.
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39 **[Figure 2 Here]**
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43 ***Fighting talk.*** The same pwMS often described themselves as ‘fighters’,
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45 suggesting they needed to think positively or be a ‘positive person’. For some,
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47 motivation for their struggle reflected the desire to remain independent and
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49 overcome the inclination to avoid everyday activities.
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3 *I don't like that idea at all [loss of independence], that is to me the worse consequence and*
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5 *... I mustn't think about it because... I'm a fighter and I will fight as much as I can... Now,*
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7 *once I can't... that doesn't bear thinking about. (Female, 62, PPMS)*
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11 For others fighting was about problem-solving their pain and MS, or an internal
12 battle focussing on the pushing away of thoughts related to their disease
13 progression, sometimes rejecting advice offered by HCPs and family members
14 (e.g. over-exerting when resting has been prescribed). One participant with long-
15 standing pain explained that improved pain management was about
16 understanding when to fight and when not to.
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27 *You can't fight it; you just go with it. When I talk to a friend of mine about her problems, I*
28 *say to her well... today is one of the days you can't work through it, you have just got to go*
29 *with it. We're not these kind of defeatist people, we like to... hold our own... but you can't.*
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33 (Male, 45, SPMS)
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38 ***Managing and accepting agenda***

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40 In contrast others felt adapting or planning a lifestyle to fit with pain was more
41 realistic. This reflected the view that curing pain and MS was unlikely. Accepting
42 pain as part of life, being in touch with the body and knowing one's limits were
43 viewed as integral to improved management.
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51 *The thing is you can't cure it can you, so it is all about management... managing yourself and*
52 *knowing what medications to take at what time... a lot of it is pain management rather than*
53 *pain curing. (Male, 35, RRMS)*
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Discussion

This study provides a unique insight into the experience of pain in the context of MS. PwMS identified pain as part of a conglomerate of interacting symptoms where it was often hard to separate pain from sensations such as numbness, stiffness and fatigue.

Most pwMS interviewed for this study provided vivid and sometimes dramatic descriptions of their pain to convey the intensity of the pain experienced. PwMS viewed pain as unpredictable, uncontrollable and attributed a variety of potential causes. Detailed descriptions of damage to nerves or 'wiring' were often recounted, sometimes in conjunction with ominous beliefs about worsening pain, other MS symptoms and disease progression. Beliefs about worsening and uncontrollability of pain are reflected in the construct of pain catastrophizing measured in the MS quantitative literature.¹¹ Pain catastrophizing Similar pain perceptions or beliefs have ~~been is~~ associated with poorer outcome in patients with chronic low back pain.²⁵ ~~While a~~ recent study has shown patient's MS illness perceptions are associated with pain severity and interference.²⁶ However, pain-specific illness perceptions have not been explored in relation to MS pain.

Consistent with the primary chronic pain literature²⁷, pwMS frequently reported frustration and anger, which worsened when faced with limitations preventing planned and spontaneous activity. Anger was expressed in conjunction with themes of unpredictability, dissatisfaction with pain medications and HCP interactions. Some described an inability to disengage from difficult feelings, expressing a desire to manage anger more effectively.

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5 PwMS employed a range of management strategies to reduce pain or associated
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7 distress, often with mixed results. This is consistent with the finding that medications
8
9 for neuropathic pain may benefit some, but not all individuals, with other chronic pain
10 conditions.²⁸ ~~Our findings are in line with and~~ a study²⁹ showing that pwMS ranked
11
12 pain medication as the most *effective* and *ineffective* coping strategy, and exercise, rest
13
14 and sleep were identified as common ways to self-manage. More importantly, our
15
16 findings revealed pwMS' attempts to manage pain using these common strategies
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18 often resulted worsening of others and unhelpful 'catch-22' vicious cycles.
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26 Attitudes towards management were split between those who focused on reduction
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28 of pain, where pain was viewed as something to be fought, and those who felt
29
30 management was about acceptance and adapting to a life with pain. Acceptance is a
31
32 key predictor of adjustment in MS.³⁰ *Pain acceptance*, defined as willing engagement in
33
34 activities, in a way that includes contact with pain, without attempts to struggle with
35
36 or control it, is also a predictor of better functional outcome in primary chronic pain
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38 conditions.^{31, 32} PwMS who talked more about acceptance expressed a preference for a
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40 more holistic biopsychosocial approach to pain management. In contrast, the majority
41
42 held a more mechanistic biological account of cause (e.g. 'bad nerves', lack of
43
44 medication, external stressors) and talked more about the need for 'wonder drugs'.
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46 This split in attitudes might also reflect a recent study showing that chronic pain
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48 subgroups held distinct models of causal interpretation of pain that were consistent
49
50 with views of how it should be treated.¹⁶ It therefore seems important to examine the
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52 role of pain acceptance and broader causal schemas of pain and management in MS.
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Implications for treatment

Some pwMS explained their biomedical interpretations of pain were provided by HCPs (particularly related to causes and control beliefs). Such interpretations may influence patient's to rely on medications which to date show limited efficacy. While health professionals are unlikely to have the time to replicate an in-depth interview exploring pain, it may be beneficial to provide a broader biopsychosocial understanding by asking a few targeted questions centring on pain and management beliefs. It may be beneficial to provide broader biopsychosocial understanding of pain and its management. For example, a patient with recurrent (perhaps vivid) thoughts that pain is associated with increased damage to nerves (e.g. 'if I push myself I'm going to damage myself even more') may begin to avoid everyday activities. While such thoughts may be protective in certain contexts (e.g. not over-exerting during an exacerbation), they are likely to be unhelpful if followed as generalised rules. Therefore, orienting patients to a biopsychosocial perspective of pain via psychological interventions that actively target pain beliefs and distress by exploring their validity (an aim of traditional Cognitive-Behavioural Therapy³³), or changing the person's relationship to their mental and bodily experience (Acceptance-based approaches³⁴), may lessen their influence on behaviour, by interrupting catch-22 cycles. Since pwMS describe pain as interacting with other MS symptoms within vicious cycles (with some possessing their own psychosocial consequences³⁵), it may be that a broader symptom management strategy, rather than a pain-specific one, is necessary.

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3 There were several limitations with this study. A single data-gathering period
4 cannot elucidate the variable and every changing presentation of MS pain. Therefore,
5 future research may benefit from an ongoing assessment across the course of illness
6 by conducting a series of interviews tracking the individual's beliefs across time,
7 identifying factors pertinent to functioning. Because recruitment focused specifically
8 on participants with pain participants may have experienced higher than average pain
9 severity. Pain ratings in this study were in the moderate to severe pain on average.
10 Other MS studies using similar measures commonly report average pain ratings of
11 'mild to moderate.'²⁰ As with all qualitative research interviewer demographic
12 characteristic could have influenced the interview process. However, use of telephone
13 interviews, carefully constructed open questions and the fact that the interviewer was
14 independent of patients' health care will have reduced this bias. It is also possible that
15 prior knowledge of psychological models of pain may have influenced the salience of
16 certain themes reported potentially resulting in less emphasis being placed on
17 alternative explanations for the data collected. It is possible the interviewer could have
18 affected accounts offered by pwMS, and bias interpretation of the analysis. All authors
19 had prior knowledge of psychological models applied to numerous health conditions.
20 The exclusion of non-English speakers may mean findings do not extend to pwMS
21 from different cultural backgrounds.
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48 Overall, our data indicate there may be benefits to talking through pain- and
49 treatment-related beliefs with pwMS. This process may uncover pain-related anger,
50 and provide the opportunity to rectify idiosyncratic pain-beliefs, which influence
51 ineffective management strategies and perpetuate vicious cycles of distress and
52 reduced functioning. Future quantitative research would enhance our understanding
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3 of these key issues within a representative sample, observing changes using a
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5 longitudinal design.
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Table 1 Characteristics of the sample (total N=25)

Characteristics	Number (%)
Sex:	
Male	6 (24)
Female	19 (76)
Age (years):	
18-30	4 (16)
31-40	5 (20)
41-50	5 (20)
51-60	5 (20)
61-70	6 (24)
Ethnicity:	
White-British	17 (68)
Black African-British	2 (8)
Black Caribbean-British	2 (8)
Asian-British	2 (8)
Mixed (White-Asian)	2 (8)
Years of education:	
1-11	3 (12)
>12	22 (88)
Employment Status:	
Full-Time	2 (8)
Part-Time	9 (36)
Full-Time Education	1 (4)
Unemployed	7 (28)
Retired	6 (24)
MS Subtype Pictorials:	
Primary progressive	3 (12)
Secondary progressive	6 (24)
Relapsing remitting	16 (64)
Experiencing current relapse:	
Yes	1 (4)
No	22 (88)
Not Sure	2 (8)
Neurological Disability Self-Report EDSS:	Mean (SD) (Range)
	5.68 (.98) (4-7)
Current MS Symptoms:	
Fatigue	23 (92)
Bowel or bladder dysfunction	4 (16)
Balance disruption	23 (92)
Cognitive impairment	19 (76)
Blurred or double vision	12 (48)
Difficulties with Speech	17 (68)
Difficulties with swallowing	16 (64)
Stiffness and spasms in muscles	20 (80)
Tremor	10 (40)
Sexual dysfunction	10 (40)
Time Since Diagnosis (years):	
1-10	13 (52)
11-20	7 (28)
21-30	5 (20)
Pain Severity 11-point Numerical Rating Scale (0 'no pain' and 10 'pain as severe as it could be')	Mean (SD) (Range)
	6.58 (Moderate) (1.98) (3-10)
Pain Type (S-LANSS) ¹	
Non-neuropathic (≤ 11)	8 (32)
Neuropathic (≥ 12)	17 (68)
Recruitment Source:	
NHS Specialist Clinics	13 (52)
MS Society UK	12 (48)

¹This is an approximation based on a self-report measure not yet validated in the MS population

Table 2 Interview Schedule

Questions	Prompts
Can you tell me about the pain you experience?	How would you compare these different kinds of pain?
How would you view your pain in relation to other MS symptoms?	Where does pain fit in? How do you rate you pain compared to other symptoms? How does pain affect your day-to-day life compared to other symptoms?
Health care professionals have certain views and beliefs about pain. I am interested to hear about your personal beliefs or views about your pain?	Things that make pain worse or better, causes curing or controlling, consequences, how long do you think you will have MS-related pain?
Tell me what you usually do when you experience pain?	How would you usually react, similar reactions for different types of pain?
Can you describe how you deal with your pain?	Concrete example / a typical day, most helpful things, least helpful, how effective, similar for all kinds of pain?
How do others (i.e. family or friends) react to your pain?	Concrete example?
What do you think could be done to help you with your pain?	Do you think anything else should be offered to you? What should be addressed in treatment? How might services assist you? What might a treatment look like / target? How might you expect to feel after a fictitious pain management treatment? How would know the outcome was successful?

Table 3 Key Themes: additional Examples

Themes and Subthemes	Example Quotations
1. Pain in the wider MS context	<p><i>"I think it is all just swirled into one... MS pain is wrapped up with a lot of other things."</i></p> <p><i>"Everything comes together. They [symptoms] all happen around the same time, and that normally starts to occur the more tired I get."</i></p>
2. Vivid and Paradoxical Descriptions	<p><i>"Like pins sticking into my toes."</i></p> <p><i>"Feels like somebody has just stood on my hands."</i></p> <p><i>"Imagine a hundred times worse than you could squeeze in a bear hug."</i></p> <p><i>"It's really hard to describe these things!"</i></p> <p><i>"I am not too sure how it feels or how to describe it... I think that I have only recently understood how it feels."</i></p>
3. Pain beliefs	<p>Personal causal beliefs</p> <p><i>"The lesions on the brain... they are putting pressure on certain parts of the brain, I think that causes a bit more pain in that certain area."</i></p> <p><i>"When I have the lower back pain, it's obviously got something to do with the nerves in that area, it can't be anything else."</i></p> <p><i>"Pain is like the brain or my nerves are saying, okay you need to do something different."</i></p> <p><i>"So I'm taking it [Simvastatin], not for pain but for high cholesterol, and it and it may have affected my pain."</i></p> <p>Pain is unpredictable</p> <p><i>"It's so unpredictable and you have no idea when and where, if and how."</i></p> <p><i>"There is no way I could point to a diary and say it is going to happen then it's just decides "okay, we are going to do this today."</i></p> <p>Pain will get worse</p> <p><i>"I envisage it getting worse."</i></p> <p><i>"I think I see it every day, you know what that path is, I am not getting any better, and the intensity is a bit more as time passed."</i></p>
4. Dealing with frustration & anger	<p><i>"When I get my everyday pain, as I call it, it's just like – it's an annoyance, it's just there and it's like, oh, okay then!"</i></p> <p><i>"Oh, I just find it frustrating because I can't do the things that I want to do."</i></p> <p><i>"I went to the pictures the other day to see a film and you get involved in it for a certain time and then your mind wanders because you think, will this F-ing pain ever go away?!"</i></p>
5. Attitudes & beliefs about pain management	<p>I've tried most things and it's a case of hit and miss</p> <p><i>"It's been hard to control because there is... something that will work on me, and then there are some things that don't, and they will work for a certain amount of time, and then it won't work."</i></p> <p>Common ways to self-manage</p> <p><i>"Well if it is really bad, I just stay in bed and I rest."</i></p> <p>Pain reduction agenda</p> <p><i>"Find me a wonder drug for pain."</i></p> <p>Fighting talk</p> <p><i>"I'm not very good at giving in to things and... I'm not very sensible sometimes."</i></p> <p>Catch-22</p> <p><i>"The actual painkillers and medication you take can end up debilitating you just as much as the pain."</i></p> <p>Management and acceptance agenda</p> <p><i>"I will have to adapt to leading my life with it there".</i></p>

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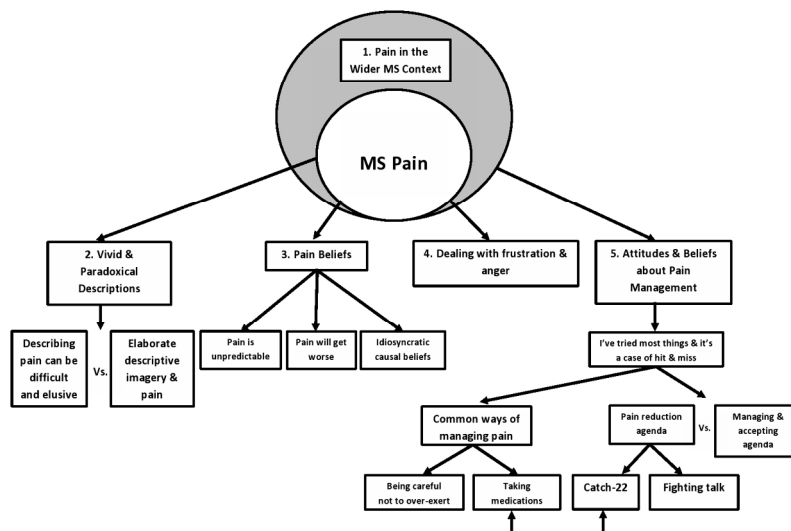


Figure 1: Thematic diagram of key themes and subthemes
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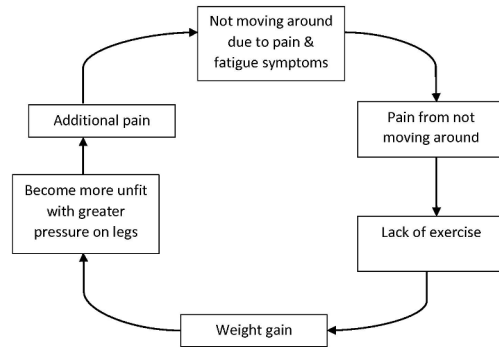


Figure 2: Catch-22 example (60 year-old Female, RRMS)
210x297mm (300 x 300 DPI)