Article type: Original Article

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

Authors:

Anthony M Harrison[1], Angeliki Bogosian[1], Eli Silber[2], Lance M McCracken[1] and Rona Moss-Morris[1]

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

(MS Specialist Outpatient Neurology Service), King's College Hospital London, UK

Conflict of Interest Statement: The authors report no conflicts of interest. This research project is supported by the Multiple Sclerosis Society UK (Grant number: 967/12).

Keywords: Multiple sclerosis, pain, experiences, management, qualitative, thematic analysis

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

Article type: Original Article

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

Authors:

Anthony M Harrison[1], Angeliki Bogosian[1], Eli Silber[2], Lance M McCracken[1] and Rona Moss-Morris[1]

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

(MS Specialist Outpatient Neurology Service), King's College Hospital London, UK

Conflict of Interest Statement: The authors report no conflicts of interest. This research project is supported by the Multiple Sclerosis Society UK (Grant number: 967/12).

Keywords: Multiple sclerosis, pain, experiences, management, qualitative, thematic analysis

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

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~~ pain management themes emerged: one related to ~~ranged from a focus on~~ pain reduction and another to accept~~ingance 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.

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

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 pain[6] 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 pain[9-11], 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 symptoms[13-15] and treatments[16] 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.

The aim of the current study was to explore pwMS' experiences of pain and their beliefs about pain and its management.

Participants and methods

The project was approved by the Berkshire Research Ethics Committee.

Participants were included if (a) they were over eighteen years of age, b) diagnosed with MS, and c) experience of pain in the context of MS~~experienced any type of MS-related pain~~. PwMS were excluded if they were non-English speakers.

Recruitment was via national advertising and through ~~hospital MS clinics. Fifty pwMS responded to advertisements placed through~~ National Health Service (NHS) MS clinics ~~and the National MS Society~~. ~~Thirty-four patients were approached by health care professionals (HCPs) at three NHS MS neurology outpatient clinics.~~ Potential participants were invited to complete a screening questionnaire, ~~completed either in clinic or sent to them via post with a pre-paid return envelope. The screening questionnaire was used to purposefully sample participants with a range of demographic and illness characteristics and to capture a diversity of perspectives. The screen included~~ including demographics, Self-report Leeds Assessment of Neuropathic Signs and Symptoms (S-LANSS)[17], MS subtype pictorials[18] and Self-administered Expanded Disability Status Scale.[19] Once returned, purposive sampling was used to select a diverse range of participants. ~~decisions about who to select for interview were made based on this information.~~ Thirty-two responders to study advertisements returned the screening questionnaire ~~(64%),~~ and 26 ~~(52%)~~ from ~~those approached in~~

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~~

those who consented but were not interviewed were thanked for their time, and given the opportunity to participate in future studies in this research programme.

Data analysis

Data were analysed following established guidelines for inductive thematic analysis[22] and procedures from Grounded Theory.[23], used specifically to gain psychological insights to guide the next stages of the MS pain treatment research programme.

A.H. listened to interviews, and repeatedly read transcripts to become immersed in their content. Coding was undertaken with regular discussion with authors A.B. and R.M.M., who read and coded excerpts from four transcripts to ensure AH's coding was grounded in the data. Each unit of coding was assigned a descriptive name on Nvivo 10 software, and wherever possible, reflected participant's vocabulary.[23] Codes were redefined and combined, and new and alternative codes were generated..[23] Broader themes were identified and organized into a preliminary framework. A.H.'s written accounts and diagrams of themes and their interrelationships were repeatedly checked against transcripts to ensure they accurately represented the data.[24] An audit trail of coding and thematic developments was maintained.

[Table 2 Here]

[Figure 1 Here]

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.

I would definitely say… the main thing is stress… stress really flares it up. (Male, 35, RRMS)

Pain was sometimes assumed to be a direct result of damage to nerves and viewed as a sign or omen of worsening pain, further damage, relapse and disease progression. Some pwMS felt this explanation came from HCPs.

I have been told by neurologists it's to do with the scarring on the right-hand side of my brain [headaches]. *I've had quite a few MRI scans that have shown up where the areas of the… damage, the myelin sheath are, and I experience quite serious headaches… I don't know whether I believe if it's a pain more telling me to calm things down a bit or whether it's something going wrong with my nerves.* (Female, 42, SPMS)

PwMS sometimes referred to vivid causal descriptions of the central nervous system being confused or faulty.

I know that a lot of it is caused by… the electrical cable of your nerves, the myelin has holes in the plastic sheath around a cable and so it isn't working properly, some of the signals are not getting through… that's when it ends up causing pain. (Female, 55, RRMS)

Pain will get worse. Most pwMS' felt that pain would worsen over time.

Well, I'm expecting… it does, it has got worse… over the past say five or six years, walking distances is more and more difficult. So I'm imagining that it will get worse, hopefully not too quickly because my progress has been quite steady over the years. (Male, 52, RRMS)

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 'ahhhhhhh, leave me alone!' and let them know everything is painful. I feel guilty about it afterwards (Female, 38, RRMS)

Other causes of anger and upset arose from disappointment with recurrent, unsuccessful attempts to reduce pain with medications. A few felt treatments specifically addressing anger may be helpful.

5. Attitudes & beliefs about pain management

The fifth subtheme illustrates how pwMS shared mixed successes in attempts to reduce pain.

I've tried most things and it's a case of hit and miss. PwMS used a variety of treatments and management strategies, ranging from medications and self-administered physical strategies (e.g. bathing or stretching) to mental visualization or distraction techniques.

With my headaches, it's been quite 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. (Female, 18, RRMS)

Common ways to self-manage. While a minority of pwMS used exercise to reduce pain arising from standing or sitting still, the majority ~~PwMS~~ identified two common ways to self-manage, including taking pain medications (even if ineffective) and being careful not to over-exert themselves by stopping and resting regularly.

Pain reduction agenda. When asked about expectations of future treatments, many professed adherence to a pain reduction agenda, reflecting an eagerness to try new 'wonder drugs' and learn new 'mental tricks'.

Just relief from the pain… so I don't have it anymore, or if I do, that it's less than what I have been experiencing that has to be the ultimate goal, I can't think of anything else… I would want the pain to be less or non-existent - it has to be! (Female, 38, RRMS)

Catch-22. Consistent with the reduction agenda, pwMS often described unique 'Catch-22' situations or unhelpful 'cycles' that undermined common ways to self-manage**.** Figure 2 shows how one lady's attempts to manage or reduce pain (avoiding movement), in combination with other debilitating symptoms (fatigue), tended to result in worsening pain and symptoms, and additional problems (weight gain). This often equated to pwMS feeling increasingly stuck.

[Figure 2 Here]

Fighting talk. The same pwMS often described themselves as 'fighters', suggesting they needed to think positively or be a 'positive person'. For some, motivation for their struggle reflected the desire to remain independent and overcome the inclination to avoid everyday activities.

I don't like that idea at all [loss of independence], *that is to me the worse consequence and … I mustn't think about it because… I'm a fighter and I will fight as much as I can… Now, once I can't… that doesn't bear thinking about.* (Female, 62, PPMS)

For others fighting was about problem-solving their pain and MS, or an internal battle focussing on the pushing away of thoughts related to their disease progression, sometimes rejecting advice offered by HCPs and family members (e.g. over-exerting when resting has been prescribed). One participant with long-standing pain explained that improved pain management was about understanding when to fight and when not to.

You can't fight it; you just go with it. When I talk to a friend of mine about her problems, I say to her well… today is one of the days you can't work through it, you have just got to go with it. We're not these kind of defeatist people, we like to… hold our own… but you can't. (Male, 45, SPMS)

Managing and accepting agenda

In contrast others felt adapting or planning a lifestyle to fit with pain was more realistic. This reflected the view that curing pain and MS was unlikely. Accepting pain as part of life, being in touch with the body and knowing one's limits were viewed as integral to improved management.

The thing is you can't cure it can you, so it is all about management… managing yourself and knowing what medications to take at what time… a lot of it is pain management rather than pain curing. (Male, 35, RRMS)

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~~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 literature[27], 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.

PwMS employed a range of management strategies to reduce pain or associated distress, often with mixed results. This is consistent with the finding that medications for neuropathic pain may benefit some, but not all individuals, with other chronic pain conditions,[28] ~~Our findings are in line with~~ and a study[29] showing that pwMS ranked pain medication as the most *effective* and *ineffective* coping strategy, and exercise, rest and sleep were identified as common ways to self-manage. More importantly, our findings revealed pwMS' attempts to manage pain using these common strategies often resulted worsening of others and unhelpful 'catch-22' vicious cycles.

Attitudes towards management were split between those who focused on reduction of pain, where pain was viewed as something to be fought, and those who felt management was about acceptance and adapting to a life with pain. Acceptance is a key predictor of adjustment in MS.[30] *Pain acceptance*, defined as willing engagement in activities, in a way that includes contact with pain, without attempts to struggle with or control it, is also a predictor of better functional outcome in primary chronic pain conditions.[31, 32] PwMS who talked more about acceptance expressed a preference for a more holistic biopsychosocial approach to pain management. In contrast, the majority held a more mechanistic biological account of cause (e.g. 'bad nerves', lack of medication, external stressors) and talked more about the need for 'wonder drugs'. This split in attitudes might also reflect a recent study showing that chronic pain subgroups held distinct models of causal interpretation of pain that were consistent with views of how it should be treated.[16] It therefore seems important to examine the role of pain acceptance and broader causal schemas of pain and management in MS.

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 Therapy[33]), or changing the person's relationship to their mental and bodily experience (Acceptance-based approaches[34]), 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 consequences[35]), it may be that a broader symptom management strategy, rather than a pain-specific one, is necessary.

There were several limitations with this study. A single data-gathering period cannot elucidate the variable and every changing presentation of MS pain. Therefore, future research may benefit from an ongoing assessment across the course of illness by conducting a series of interviews tracking the individual's beliefs across time, identifying factors pertinent to functioning. Because recruitment focused specifically on participants with pain participants may have experienced higher than average pain ~~severity. Pain ratings in this study were in the moderate to severe pain on average.~~ Other MS studies using similar measures commonly report average pain ratings of 'mild to moderate.[20] As with all qualitative research interviewer demographic characteristic could have influenced the interview process. However, use of telephone ~~interviews, carefully constructed~~ open questions and the fact that the interviewer was independent of patients' health care will have reduced this bias. It is also possible that prior knowledge of psychological models of pain may have influenced the salience of certain themes reported potentially resulting is less emphasis being placed on ~~alternative explanations for the data collected. It is possible the interviewer could have affected accounts offered by pwMS, and bias interpretation of the analysis. All authors had prior knowledge of psychological models applied to numerous health conditions..~~ The exclusion of non-English speakers may mean findings do not extend to pwMS from different cultural backgrounds.

Overall, our data indicate there may be benefits to talking through pain- and treatment-related beliefs with pwMS. This process may uncover pain-related anger, and provide the opportunity to rectify idiosyncratic pain-beliefs, which influence ineffective management strategies and perpetuate vicious cycles of distress and reduced functioning. Future quantitative research would enhance our understanding

of these key issues within a representative sample, observing changes using a longitudinal design.

Acknowledgements

This study was funded by a grant awarded to Professor Rona Moss-Morris by the Multiple Sclerosis Society UK. We would also like to thank the Multiple Sclerosis Society for assisting with recruitment, as well as Dr Victoria Williams, Joan Regan and Andrew McCarthy at Guy's & St. Thomas' Hospitals, Pauline Shaw at King's College Hospital, and Kitty McCarthy at Woolwich Hospital for their help and support with the study.

References

1. Foley PL, Vesterinen HM, Laird BJ, et al. Prevalence and natural history of pain in adults with multiple sclerosis: Systematic review and meta-analysis. *Pain*. 2012.

2. Merskey H and Bogduk N. International Association for the Study of Pain. Task Force on Taxonomy. Classification of chronic pain: descriptions of chronic pain syndromes and definitions of pain terms. Seattle: IASP Press, 1994.

3. O'Connor AB, Schwid SR, Herrmann DN, Markman JD and Dworkin RH. Pain associated with multiple sclerosis: systematic review and proposed classification. *Pain*. 2008; 137: 96-111.

4. Pöllmann W and Feneberg W. Current management of pain associated with multiple sclerosis. *CNS drugs*. 2008; 22: 291-324.

5. Stenager E, Knudsen L and Jensen K. Acute and chronic pain syndromes in multiple sclerosis. *Act Neurol Scan*. 1991; 84: 197-200.

6. Kerns RD, Kassirer M and Otis J. Pain in multiple sclerosis: a biopsychosocial perspective. *J Rehab Res Dev.* 2002; 39: 225-32.

7. Beard S, Hunn A and Wight J. Treatments for spasticity and pain in multiple sclerosis: a systematic review. *Health Tech Assess*. 2003; 7: 124.

8. Douglas C, Windsor C and Wollin J. Understanding chronic pain complicating disability: finding meaning through focus group methodology. *J Neurosci Nurs* 2008; 40: 158-68.

9. Osborne TL, Jensen MP, Ehde DM, Hanley MA and Kraft G. Psychosocial factors associated with pain intensity, pain-related interference, and psychological functioning in persons with multiple sclerosis and pain. *Pain*. 2007; 127: 52-62.

10. Osborne TL, Turner AP, Williams RM, et al. Correlates of pain interference in multiple sclerosis. *Rehab Psychol*. 2006; 51: 166.

11. Douglas C, Wollin JA and Windsor C. Biopsychosocial correlates of adjustment to pain among people with multiple sclerosis. *Clin J Pain*. 2008; 24: 559-67.

12. Saverino A and Solaro C. Pain in individuals with multiple sclerosis, knee prosthesis, and post-herpetic neuralgia: learning from focus group patients' experience. *Clin J Pain*. 2010; 28: 300-8.

13. Riazi A, Thompson A and Hobart J. Self-efficacy predicts self-reported health status in multiple sclerosis. *Mult Scler*. 2004; 10: 61-6.

14. Jopson NM and Moss-Morris R. The role of illness severity and illness representations in adjusting to multiple sclerosis. *J Psychosom Res*. 2003; 54: 503-11.

15. Vaughan R, Morrison L and Miller E. The illness representations of multiple sclerosis and their relations to outcome. *Bri J Health Psychol*. 2003; 8: 287-301.

16. Martin S, Daniel C and Williams ACdC. How do people understand their neuropathic pain? A Q-study. *Pain*. 2014; 155: 349-55.

17. Bennett M. The LANSS Pain Scale: the Leeds assessment of neuropathic symptoms and signs. *Pain*. 2001; 92: 147-57.

18. Lublin FD and Reingold SC. Defining the clinical course of multiple sclerosis results of an international survey. *Neurology*. 1996; 46: 907-11.

19. Bowen J, Gibbons L, Gianas A and Kraft GH. Self-administered Expanded Disability Status Scale with functional system scores correlates well with a physician-administered test. *Mult Scler*. 2001; 7: 201-6.

20. Osborne TL, Turner AP, Williams RM, et al. Correlates of pain interference in multiple sclerosis. *Rehab Psychol*. 2006; 51: 166-74.

21. Guest G, Bunce A and Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods*. 2006; 18: 59-82.

22. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006; 3: 711-101.

23. Glaser BG and Strauss AL. *The discovery of grounded theory: Strategies for qualitative research*. Transaction Books, 2009.

24. Patton MQ. *Qualitative evaluation and research methods*. SAGE Publications, inc, 1990.

25. Foster NE, Bishop A, Thomas E, et al. Illness perceptions of low back pain patients in primary care: what are they, do they change and are they associated with outcome? *Pain*. 2008; 136: 177-87.

26. Spain L, Tubridy N, Kilpatrick T, Adams S and Holmes A. Illness perception and health-related quality of life in multiple sclerosis. *Act Neurol Scan*. 2007; 116: 293-9.

27. Fernandez E and Turk DC. The scope and significance of anger in the experience of chronic pain. *Pain*. 1995; 61: 165-75.

28. Kalso E, Aldington D and Moore R. Drugs for neuropathic pain. *BMJ*. 2013; 347.

29. Heckman-Stone C and Stone C. Pain management techniques used by patients with multiple sclerosis. *J Pain*. 2001; 2: 205-8.

30. Pakenham KI and Fleming M. Relations between acceptance of multiple sclerosis and positive and negative adjustments. *Psychol & Health*. 2011; 26: 1292-309.

31. McCracken LM, & Vowles, K. E. Psychological flexibility and traditional pain management strategies in relation to patient functioning with chronic pain: an examination of a revised instrument. *J Pain*. 2007; 8: 700-7.

32. McCracken LM and Velleman SC. Psychological flexibility in adults with chronic pain: a study of acceptance, mindfulness, and values-based action in primary care. *Pain*. 2010; 148: 141-7.

33. Eccleston C, Williams ACDC and Morley S. Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database of Systematic Reviews*. 2009: Art. No.: CD007407.

34. Veehof MM, Oskam M-J, Schreurs KM and Bohlmeijer ET. Acceptance-based interventions for the treatment of chronic pain: a systematic review and meta-analysis. *Pain*. 2011; 152: 533-42.

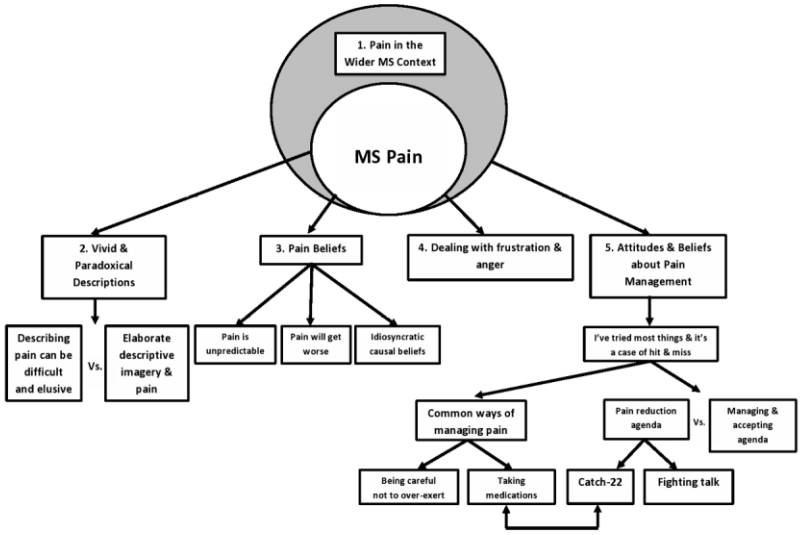
35. Knoop H, van Kessel K and Moss-Morris R. Which cognitions and behaviours mediate the positive effect of cognitive behavioural therapy on fatigue in patients with multiple sclerosis? *Psychol Med*. 2012; 42: 205.

Characteristics of the sample (total N=25)

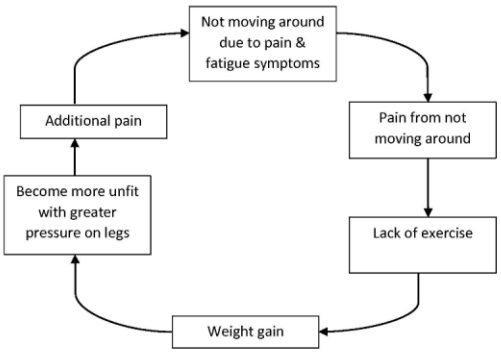
Characteristics	Number (%)
Sex:	
Male	6 (24)
Female	19 (76)
Age (years):	
18'30	4 (16)
31'40	5 (20)
41'50	5 (20)
51'60	5 (20)
61'70	6 (24)
Ethnicity:	
White'British	17 (68)
Black African'British	2 (8)
Black Caribbean'British	2 (8)
Asian'British	2 (8)
Mixed (White'Asian)	2 (8)
Years of education:	
1'11	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)

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

"I think it is all just swirled into one MS pain is wrapped up with a lot of other	*things."*
	"Everything comes together. They [symptoms] all happen around the same time, and that normally starts to occur the more tired I get."
! "	*"Like pins sticking into my toes."*
	"Feels like somebody has just stood on my hands."
	"Imagine a hundred times worse than you could squeeze in a bear hug."
	"It's really hard to describe these things!"
	"I am not too sure how it feels or how to describe it I think that I have only recently understood how it feels."
# $	
$	*"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."*
	"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."
	"Pain is like the brain or my nerves are saying, okay you need to do something different."
	"So I'm taking it [Simvastatin], not for pain but for high cholesterol, and it and it may have affected my pain."
	"It's so unpredictable and you have no idea when and where, if and how."
	"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 envisage it getting worse."*
	"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."
& " % $ ▪ %	*"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!"*
	"Oh, I just find it frustrating because I can't do the things that I want to do."
	"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 F0ing pain ever go away?!"
( ) ▪ $ %	
*+! % + $	*"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."*
, $- %	*"Well if it is really bad, I just stay in bed and I rest."*
%	*"Find me a wonder drug for pain."*
. % % /	*"I'm not very good at giving in to things and I'm not very sensible sometimes."*
, -	*"The actual painkillers and medication you take can end up debilitating you just as much as the pain."*
% %	*"I will have to adapt to leading my life with it there".*


1. Pain in the Wider MS Context
MS Pain
2. Vivid & Paradoxical Descriptions
3. Pain Beliefs
4. Dealing with frustration & anger
5. Attitudes & Beliefs about Pain Management
Describing pain can be difficult and elusive
Vs.
Elaborate descriptive imagery & pain
Pain is unpredictable
Pain will get worse
Idiosyncratic causal beliefs
I've tried most things & it's a case of hit & miss
Common ways of managing pain
Pain reduction agenda
Vs.
Managing & accepting agenda
Being careful not to over-exert
Taking medications
Catch-22
Fighting talk

!"


Not moving around due to pain & fatigue symptoms
Pain from not moving around
Lack of exercise
Weight gain
Become more unfit with greater pressure on legs
Additional pain

! " " #$%