

Living well with fibromyalgia: a case study to explore person-centred management

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Fibromyalgia is a debilitating, multifactorial condition that can be difficult to manage. The mechanisms and management of fibromyalgia are discussed through the use of a linked case study, with emphasis on improved physical activity levels. Pain and fatigue can decrease motivation and affect adherence to exercise, and emotional distress may act as a barrier to rehabilitation. A collaborative approach helps individuals build the strength to cope with the challenges of living with this complex and disabling chronic pain. This article discusses the safe and appropriate use of medication, together with techniques that enhance the therapeutic alliance to meet this challenging condition.

LEARNING OUTCOMES TO SUPPORT PHYSIO FIRST QAP

- 1 Improve understanding of differential diagnoses for widespread pain.
- 2 Improve knowledge of neurobiological mechanisms in exercise induced hyperalgesia.
- 3 Improve understanding of person-centred rehabilitation.
- 4 Be aware of indications for medication and safe prescribing in fibromyalgia.

Introduction

Fibromyalgia is a debilitating, multifactorial condition that can be difficult to manage (Soni *et al* 2019). The neurobiological evidence involved in abnormal pain processing in people with fibromyalgia, and the potential mechanisms implicated in the development of a pain vulnerability, have been explored (Denk *et al* 2014). Epidemiological data highlights that there are medical and psychological co-morbidities associated with the condition and that exercise induced hypoalgesia may be impaired (Rice *et al* 2019), making management of patients with fibromyalgia complex.

The aim of this article is to discuss the mechanisms and management of fibromyalgia through the use of a linked case study, with particular emphasis on how individuals living with fibromyalgia can improve physical activity levels. The case study is a composite of a variety of people the author has worked with clinically with details altered to maintain anonymity. Guidelines recommend that exercise is a key pillar of the management of fibromyalgia (MacFarlane *et al* 2016; Sluka *et al* 2018) and that medication forms the second line of clinical management (MacFarlane *et al* 2016). Despite this, medication and medical interventions are sometimes used as first line therapies in clinical practice, so issues regarding the safe and appropriate use of medication will also be discussed. As pain and fatigue can decrease motivation and affect adherence to exercise, techniques to enhance therapeutic alliance and foster a collaborative client-therapist relationship will be included to help meet this challenge in clinical practice.

Case study: Laura

Laura is a 43-year-old woman who attended for a rehabilitation assessment, having been referred from a spinal clinic

where she had received a diagnosis of resolving radicular pain. I welcomed Laura with a smile, explained what to expect in the consultation and invited her to ask questions. This develops a therapeutic alliance, via a warm, open and personable approach that is key to person-centred care (Miciak *et al* 2018), and appears to influence the outcome of rehabilitation (Hall *et al* 2010).

As a method for clinical history taking, the Calgary-Cambridge model recommends ascertaining the biopsychosocial context, an expression of ideas from the patient about their condition and asking them about any concerns as well as expectations they have regarding treatment outcome (Henrique 2015).

PATIENT HISTORY

During my consultation with Laura, it transpired that she had widespread pain affecting her spine, arms and legs. This pain had been present for most of her adult life but had worsened since an acute episode of radicular spinal pain in the previous year. She had a number of other symptoms including unrefreshing sleep / difficulty sleeping through the night, all day fatigue, headaches, sensitivity to noise and irritable bowel

syndrome. She was taking the following medications:

- morphine sulphate oral solution 10 mg/5 ml – prescribed as one 5 ml dose up to four times a day
- gabapentin 600 mg – three times a day
- amitriptyline 75 mg once a day.

She was also using cannabidiol (CBD) which she had purchased online.

Laura lived with her partner and teenage son. Owing to the long hours of standing required, she had stopped working in a shop, and she was increasingly concerned about her progressive disability, poor memory and word finding difficulties. Laura described her mood as low.

We discussed whether she had received any form of therapy for low mood and Laura explained that she had accessed talking therapies when she was in recovery for alcohol misuse. Having lost a parent during her adolescence, Laura had, in her late teens and early twenties, used alcohol as a form of self-medication, but had now been abstinent from alcohol for 15 years.

Exposure to early life stress may contribute to pain vulnerability and development of fibromyalgia (Denk *et al* 2014; Burke *et al* 2017).

Laura was open to rehabilitation and psychological support as part of her management plan and asked if she might have any other serious problems that had been missed. She had read about lidocaine infusions for widespread pain and wondered whether this might be something useful for her.

Laura had no allergies or sensitivities. She denied features of spondyloarthritis, psoriatic or peripheral spondyloarthritis such as hot and swollen joints. She also had no characteristics of psoriasis, uveitis, photosensitive rashes, alopecia, inflammatory bowel disease, enthesopathy, or recent infection. Her pain did not improve with exercise or anti-inflammatories (McAllister *et al* 2017). Results of blood tests

for rheumatoid factor and anti-CPP antibodies were negative, indicating that rheumatoid and other forms of inflammatory arthritis were unlikely (NICE 2020). There was no family history of inflammatory joint disease, and no sign of butterfly rash, fever or leukopenia, which decreased suspicion of systemic lupus erythematosus (Kuhn *et al* 2015). Laura had noticed weight gain and reported her medication to be ineffective. She had started to escalate morphine use, taking up to seven doses a day, and sometimes drinking from the bottle.

EXAMINATION

On examination there were no deficits of reflexes, power or sensation, and tender points revealed a count that 12 of 18 tender points in the body were painful. The tender point count can be used as part of the diagnostic criteria for fibromyalgia.

The fibromyalgia diagnostic criteria utilise a widespread pain index score (rated 10) and a symptom severity scale, for which Laura had a score of 6. These results, combined with the generalised pain present for more than three months, are consistent with a diagnosis of fibromyalgia (Wolfe *et al* 2016). I explained to Laura that the widespread pain symptoms were consistent with a diagnosis of fibromyalgia and that a number of medications she was taking were sedatives (NICE 2021a; NICE 2021b). In addition, the medicine gabapentin is associated with memory loss (NICE 2021a), which may have been confounding her problems. Laura had risk factors for opioid overuse, and the fact she was not experiencing pain relief despite the doses she was taking suggested they might indeed be ineffective.

I use elements of motivational interviewing to facilitate self-determinism (Elwyn *et al* 2021) via the OARS model:

- Open questions – to elicit trust and foster collaboration (Miller & Rollnick 2002)
- Affirm – with comments such as “it

sounds like this is very difficult for you”

- Reflect – asking the patient to discuss what they might have already tried and how that had affected them, e.g. “I can hear you have tried to increase activity, but this was painful?”
- Summarising – reviewing the discussion and conclusion with the patient, e.g. “medications help the pain but also interfere with doing the things that are important”.

With Laura, this approach led on to a discussion about the role of physical activity in fibromyalgia. It was also an opportunity to highlight that, although significant numbers of fibromyalgia patients admitted for treatment undergo invasive procedures such as lidocaine infusions, the evidence for this treatment approach is weak (Soni *et al* 2020).

Evidence-based management methods

Guidelines recommend that exercise is a key pillar of management of fibromyalgia (MacFarlane *et al* 2016; NICE 2021c), and there are a number of reasons for exercise and physical activity to be indicated as beneficial. For example, Sluka *et al* (2018) propose that regular physical activity alters central pain inhibition and the immune system, resulting in a protection from peripheral insult. The Hunt longitudinal population study from Norway, cited by Sluka *et al* (2018), found that chronic musculoskeletal pain was reported 10%-38% less frequently in individuals who took moderate exercise activity between one and three times a week compared to those who undertook no physical activity.

In pain-free individuals, muscle nociceptors are activated with fatiguing exercise which normally triggers the descending pain inhibitory system. A different central nervous system response occurs during activity in physically inactive states. In this scenario, muscle insult via exercise to fatigue results in increased activation of the NMDA receptor. This results in increased facilitation meaning there is more current (activity) through the channel. Research suggests that NMDA 

receptors facilitate pain. In studies where the NMDA receptor is blocked, inactive animals did not develop pain with exercise (Sluka *et al* 2018). At the same time, there is an increase in expression of serotonin transporters which clears serotonin more frequently, resulting in a reduced inhibition of pain and, therefore, pain is increased. In physically active animals, the opposite scenario occurs; with the activation of opioid receptors resulting in less activation of the NMDA receptor, and a reduction in serotonin transporter expression (Sluka *et al* 2018). This is a potential mechanism that might explain why people with fibromyalgia find physical activity and exercise painful. In addition, further research from animal studies suggests that there are neuroimmune alterations in active animals that lead to reduced expression of pro-inflammatory cytokines and increased expression of anti-inflammatory cytokines (Lesnak & Sluka 2020).

Low-grade systemic inflammation is a hypothetical mechanism in persistent pain. This is supported by research indicating that there are higher levels of circulating inflammatory cytokines in people with fibromyalgia compared to controls (Sluka *et al* 2018). These higher circulating levels may be linked to stress, depression, fatigue and sleep disorder. However, findings related to levels of circulating cytokines have been mixed (Ortega *et al* 2009). Whilst there are few studies of cytokine response to exercise in which participants with fibromyalgia are included, Ortega *et al* (2012) show that aquatic aerobic exercise conducted three times a week for 60 minutes a session resulted in reduced inflammatory cytokines, improved function, and emotional wellbeing for this population. Sluka *et al* (2018) argue that repeated exposure to exercise may restore normal pain modulation and prevent hyperalgesia.

In their Cochrane review, Bidonde *et al* (2019) concluded that exercise consisting of a mix of resistance, flexibility and aerobic may improve quality of life, function and decrease pain and fatigue.

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However, their findings suggest that pain reductions are modest and rehabilitation programmes require considerable dedication from the participants.

Laura had attempted exercise classes but found they caused her symptoms to flare up, illustrating the challenge of increasing activity.

Patient-centred care

People with fibromyalgia have reported that they feel stigmatised by health professionals, particularly if they are taking opioids (Quinter 2020), and those with lived experience of fibromyalgia also describe their perception of physiotherapists as being in a position of power and, at times, disregarding their expressed needs and preferences (Furness 2020). It is therefore important that we adopt a personalised care framework for the clinical management plan for our patients that focuses on treating each one as a whole person and supports them in managing their condition.

SHARED DECISION MAKING

Physiotherapists working within pain services have skills in psychologically informed practice (Denneny *et al* 2019; Wilson *et al* 2017; Jacobs *et al* 2016), and psychologically informed physiotherapy is advocated as best practice in the biopsychosocial management of chronic pain (Booth *et al* 2017; Foster & Delitto 2011; Main & George 2011). In harnessing our skills, we have the potential to improve adherence, improve access to rehabilitation by adopting an inclusive approach, and build on the preparation required to ensure our patients get the best from multidisciplinary treatment. When applied to pain, the biopsychosocial approach acknowledges that it may be present in the absence of positive tests and results, and that the pain

experience is influenced by contextual, biological, psychological and social factors (Adams & Turk 2018). Although not all physiotherapists are trained or confident in psychologically informed practice (Holopainen *et al* 2020), shared decision making and personalised care can be applied by any physiotherapist. Shared decision making involves providing expert advice and working collaboratively with each patient to come to an agreement about what treatment suits them best (Personalised Care Institute 2021). It also requires considering a person's preferences, beliefs and values (NICE 2021d). Shared decision making and achieving a rapport with your patient can certainly help to build positive experiences for people living with fibromyalgia (Doebel *et al* 2020).

AUTONOMY

Autonomy has been defined as an individual's ability to think, decide and act independently (Gilon 1985) and this is literally self-determination (Stirrat & Gill 2005). Recognition of autonomy is key in shared decision making, but many individuals with depression do not access the care (Matthews *et al* 2021). Where we encounter individuals with depression in the clinical setting we may need to allow additional time for them to consider their options and provide hope for a better future, as there may be lower self-efficacy, i.e. confidence to undertake a course of action in individuals with chronic pain and depression (Tsuji *et al* 2019). There is also a tension between autonomy and paternalism, where some patients would like healthcare professionals to make the decisions (Nuttall & Rutt-Howard 2020), and it should be noted that self-rated shared decision making is affected by educational attainment and communication preferences vary across demographic and cultural characteristics (Matthews *et al* 2021).

Working with Laura

In view of this information, I spent time listening to Laura's experience and needs, and how she often felt under threat when attempting physical activity but was keen to increase her strength so that she could undertake tasks such as unloading shopping and gardening. We explored whether she had experienced any positive experiences of activity and she mentioned that she had once enjoyed a yoga class. She also enjoyed country walks, but this was something she was unable to manage at that time.

We agreed to start with stretches and three or four dynamic resistance upper and lower limb exercises at approximately 30%-40% of maximal voluntary contraction, which is the recommended starting level of activity for people with chronic pain (Booth *et al* 2017). The purpose was to commence activity that could decrease threat, increase a sense of agency and self-efficacy, and that was linked to her goal.

Laura was in charge of how many repetitions and when to progress, with the advice that the aim was to gradually increase the exercises with time, and to take it at her own pace, perhaps increasing by one repetition every one or two weeks. We also spent time in the session tracking Laura's physical and internal thoughts and feelings in response to the exercise. For example, if she developed tension in her facial muscles during an exercise, this might act as a cue to alter the range of movement and remind her to use her breathing. When her internal thoughts were telling her "this is too much" we discussed treating the activity as an experiment, keeping note of whether it was possible for her to manage other tasks that day.

People with fibromyalgia and other chronic pain often struggle, and resist their painful sensations, which is a normal human reaction to their system feeling "under threat". The techniques I used with Laura can help to provide a way for the patient to feel safe and soothe a "threatened" system. We also

explored whether it might be useful for her to have support for her emotional wellbeing. In order to minimise any stigma with this approach, I explained that low mood is very common in people living with persistent pain owing to its impact on many areas of the person's life. Laura chose to focus on physical rehabilitation but felt reassured that she had options for talking therapy should she wish to pursue this at a later date. At review appointments she had found evidence that she could achieve that level of activity and was open to progressing.

In addition to the exercise programme, I signposted Laura to Versus Arthritis (www.versusarthritis.org), the Footsteps Festival (my.livewellwithpain.co.uk) and Fibromyalgia Action UK (fmauk.org) that could all help her to increase her knowledge about her condition and where to access support (Doebel *et al* 2020).

Reducing medication

Despite Laura being prescribed morphine and gabapentin, neither are recommended for chronic pain (NICE 2021d). Substance misuse and pain conditions have the greatest ratios of being associated with prescription opioid addiction. However, mood disorders and anti-depressants are also associated (Klimas *et al* 2019).

Advanced practitioners with qualifications in independent prescribing may be able to oversee this process during rehabilitation, or the tapering programme might be overseen by a GP or pain clinic. Information related to opioid tapering is also available at my.livewellwithpain.co.uk. It should be noted that long-term and / or high dosage opioid use requires tapering to

be at a slower pace than a 10% reduction per week, and specialist advice from a pain team may be indicated.

Cannabinoids are safer than opioids as they do not result in respiratory depression in overdose (Rang *et al* 2016). However, despite potential useful application and relative safety, medicinal preparations of CBDs interact with amitriptyline, gabapentin and morphine with the effect of depressing the central nervous system (NICE 2021e). Cannabinoids are sold legally as a food supplement, rather than a medicinal preparation, at < 0.2% Delta-9-Tetrahydrocannabinol. However, many products are not properly authorised (Lloyds Pharmacy 2020), and if cannabidiol is used as a medication manufacturers should, theoretically, apply for a licence (GovUK 2016).

Laura had not self-identified as being addicted to opioids, but having discussed the options with her and highlighted the additional risks of CBD interactions, she decided that she wanted to taper the morphine and gabapentin. She worked successfully with the pain team and reported that, while it had been a challenging experience, her fatigue levels and emotional wellbeing were much improved.

Conclusion

The Calgary-Cambridge history taking model can guide assessment and provide information on the biopsychosocial context, allowing the patient to raise concerns and treatment expectations. Where pain is widespread, a careful history and physical examination is required to explore differential diagnoses. Careful questioning about use of prescription

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medications, drugs and alcohol may reveal factors that can inform clinical management. Previous substance misuse, use of antidepressants, pain, and mood disorder have the greatest likelihood ratios of being associated with prescription opioid addiction. Shared decision making involves providing expert advice and working collaboratively with individuals to reach agreement about treatment. Motivational interviewing techniques can facilitate self-determinism, and techniques to enhance therapeutic alliance, such as personalised care, foster a collaborative client-therapist relationship that is linked to positive healthcare experiences. Physical rehabilitation strategies can be adapted so that the patient perceives it as safe and meaningful. Emotional distress may act as a barrier to effective rehabilitation, so a supportive and collaborative approach helps individuals build a strength and resilience to cope with the challenges of living with complex and disabling chronic pain.

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About the author

Leila is a Consultant Physiotherapist with the Optimise Pain Rehabilitation Unit. The service delivers multidisciplinary pain management programmes, physiotherapy-led intensive programmes, individual physiotherapy, and exercise classes. She has worked in musculoskeletal outpatients in primary and secondary care for six years following her general rotations. She developed an interest in preventing long-term disability in moderately disabled patients with back pain. She started back fitness and mini-pain management programmes within the community.

Leila is an Honorary Lecturer at Brookes University. She was awarded a Masters Degree in Pain Management in 2011. She

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Leila is a member of the Physiotherapy Pain Association, British Pain Society and International Association for the Study of Pain. She was a committee member of the British Pain Society's Pain Management Programme Special Interest Group from 2009-2012 and is currently a Physiotherapy Pain Association Executive Committee member.

Leila has contributed to this article on behalf of the Physiotherapy Pain Association.

References

Full reference details can be found on our website at <https://www.physiofirst.org.uk/resources/in-touch.html> 

REVIEW SUPPORTING QAP

It can be difficult to improve the outcomes for patients with fibromyalgia, but the author highlights some great tips to help us achieve this improvement. The article sets out how we can help these patients become less dependent on medication, explain exercise as the first line of therapy, and have confidence that we are ideally placed to help them. As I read this article, I identified a training opportunity for me personally; that learning more about motivational interviewing could help my interaction not only with the patient with fibromyalgia, but with all my patients. This article also underlines the importance of working closely with other health professionals to manage fibromyalgia patients, particularly where their GOAL is to taper off pain medication.

Reviewer

Byron Clithero