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PAIN NEWS

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NICE and Pain Medicine: not so nice?

Pain: a neurological viewpoint

Women in Pain Medicine

Self Management of chronic pain in a time of Covid

Virtual medical consultations

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PAIN NEWS MARCH 2021

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Treating pain nicely, part 1: the unique nature of perception and towards effective utilitarianism

Rajesh Munglani* and Paul Wilkinson*



Our view of the world is determined only by what we are able to see, hear and how we interpret those sensations.¹

There is an allegory where Socrates describes a group of people who have lived their whole lives chained to the wall of a cave facing a blank wall. The people watch shadows projected on the wall from objects passing in front of a fire behind them and they give names to these shadows. The prisoners cannot see any of what is happening behind them, they are only able to see the shadows cast upon the cave wall in front of them. The sounds of the people talking echo off the walls, and the prisoners believe these sounds come from the shadows. The shadows and the sounds are the prisoners' reality but are not accurate representations of the real world.

Socrates goes on to explain how we can be like a prisoner who is freed from the cave and comes to understand that the shadows on the wall are not reality at all. Like this one freed prisoner, our aim is to be free and understand and perceive the higher levels of reality.

However, there are the other inmates of the cave who do not even desire to leave their prison, for they know no better life and will never know it. The freed prisoner would think that the world outside the cave was superior to the world he experienced in the cave and will attempt to share this with the prisoners remaining in the cave. The returning prisoner, whose eyes have

become accustomed to the sunlight, would be blind when he re-enters the cave, just as he was when he was first exposed to the sun. The prisoners, according to Plato, would infer from the returning man's blindness that the journey out of the cave had harmed him and that they should not undertake a similar journey. Plato concludes that the prisoners, if they were able, would therefore reach out and kill anyone who attempted to drag them out of the cave. The allegory contains many forms of symbolism and is used to instruct on the nature of perception.²

The journey we have been on, and what we have perceived, not only changes what is truth for us but also divides us from our compatriots who have not shared the same journey and therefore cannot share the reality that is manifest to us.

A natural inference is to understand that others may hold a truth diametrically opposite to our own and yet neither of us may be wrong. Thus, in Socrates' example, phenomena do not have objective reality understandable by one observer but the true nature or meaning can only be constructed from multiple perspectives. Given the biopsychosocial nature of pain and multidisciplinary assessment, arguably we work in a world of collaborative, co-constructed reality. This has very significant implications for how we should approach evidence.

For the past 70 years, patient care has been dominated by evidence-based medicine (EBM) with its emphasis on randomised controlled trials (RCTs) and clinical guidelines to standardise medical decision-making. This population-based approach relies on results averaged or otherwise derived from RCTs. These have served medicine well. We are unlikely to fall into the trap of a type 1 error (a false positive) though probably more likely to end up with a type II error (a false negative).¹

Intuitively, type I errors can be thought of as *errors of commission*, that is, the researcher concludes that something is factually true when it isn't. For instance, consider a study where researchers compare a drug with a placebo. If the patients who are given the drug get better than the patients given the placebo by chance, it may appear that the drug is effective, but in fact the conclusion is incorrect in the population as a whole. Conversely, type II errors can be thought of as *errors of omission*. In the

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example above, if the patients who got the drug did not get better at a higher rate than the ones who received the placebo, but this was a fluke untrue in the wider population, that would be a type II error. The consequence of a type II error depends on the size and direction of the missed determination and the circumstances.³ Treatments that are effective in proportionately fewer patients or only in subgroups are more likely to be viewed as ineffective. So, should society be concerned about the omission of a treatment that helps for example only 1 in 10 individuals? Perhaps not on the surface, but this should depend strictly on context. If 10 similar treatments were omitted by this process and they were the only treatments available, outcomes could be devastating as all 10 patients could potentially have been otherwise helped.

The forthcoming National Institute for Health and Care Excellence (NICE) guidelines may conclude that drugs or treatments are not effective and yet in our clinical experience, we may conclude that they collectively help a substantial minority of individuals. Crucially, we cannot currently predict which drugs may help an individual person, many clearly do not respond and yet some respond markedly. The normalisation effect of RCTs and thus the ignoring of individual responses mean that the opportunity for people who may well benefit from a treatment may be lost. Temporary pain relief to enable engagement with rehabilitation is also not an outcome that would be measured or easily valued using this experimental approach, nor would the value of treatments of low efficacy that prevent progression to more efficacious but much more expensive treatments be a statistical outcome. Important questions clearly exist:

- Should individuals miss out on what may be a life-transforming pain-relieving treatment because the outcome is not good enough for the group in general?
- Do we completely ignore the suffering of an individual so that the greatest good can be done for the greatest number of people for the least amount of money, as money is limited?
- How do we develop strategies to minimise the impact of placebo effects if we do decide to treat?
- Importantly, NICE do emphasise the importance of decision-making in individual patients. In other words, one size does not necessarily fit all.

Let's now take a step back on these issues, philosophically.

So far, our analysis is centred around outcomes of experimental trials and potential errors. But what if, like in Socrates' allegory, we do not know the limits of what we can see through our experimental lens? In other words, to what extent can we rely on experimentally derived statistical evidence in pain medicine? There are some compelling philosophical issues that suggest, unlike many other specialities, we cannot rely on this approach.

The paradigm underpinning experimental methodology for the past several centuries is derived from Positivism. This was developed by the French philosopher Auguste Comte⁴ and refined by other groups. Key positivist principles that underlie experimental research are as follows:

1. A belief in objective reality.
2. Knowledge of the subject can be usefully and strictly acquired from data that is directly experienced/measured by independent observers.
3. Observation of phenomena is subject to natural laws and applied logic.
4. Empirical testing in trials can be undertaken; the environment can be controlled, subjects 'matched' between experimental groups, and relationships among variables analysed by mathematical means.
5. Finally, using inductive and deductive hypotheses derived from a body of scientific theory, the findings can be extrapolated to other groups in the wider population.

So, what about pain? Generally speaking, the more complex and unpredictable a phenomenon, the less likely these conditions will apply. There are over 30 psychological variables that may contribute to the pain experience, multiple influencing cognitive factors, highly variable presentations of disability and multiple potential neurophysiological mechanisms, not to mention the impact of variable secondary pain conditions. We also could quote solicitous or confrontational family behaviours and a variety of social issues. Arguably, 50% of the variance in outcome of pain after back surgery can be determined by one, just one, variable, namely catastrophisation, that is a factor which is almost never controlled. The authors argue that it is doubtful that any of these positivist principles actually ever truly, fully apply! Curiously, a Court viewing such evidence might simply rule it too uncertain or flawed and treat it as inadmissible!

To move forward, we need to switch towards a constructivist view of the reality of pain. We need to use and strive for the acceptance of research methodologies that match this co-constructed reality. We need to think about triangulation of evidential sources, audit trails to improve accountability, acceptance of, and strategies to use and enable trust in immersed (not independent) observers: that is, us as healthcare workers. Ultimately, our professional judgements need to be evidence-based in no less rigorous a way but using more appropriate, new frameworks of assessment.

We suggest that utilitarianism may offer a useful philosophical framework. It is close to our subject of pain as the consideration of the dimensions of pain, suffering and pleasure underpins this philosophy.

Utilitarianism is seen as a powerful and persuasive approach to ethics in the history of philosophy. It encourages actions that

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maximise happiness and well-being for the group of relevant individuals. The basic idea is to maximise *utility*, defined as *well-being*. Jeremy Bentham described *utility* as ‘that property in any object, whereby it tends to produce benefit, advantage, pleasure, good, or happiness ... [or] to prevent the happening of mischief, pain, evil, or unhappiness to the party whose interest is considered’. A related concept is of consequentialism, that results of any action are the only standard to judge right and wrong.⁵

Utilitarianism is generally held to be the view that the morally right action is the action that produces the most good.

The Classical Utilitarians like Jeremy Bentham and John Stuart Mill identified the good with pleasure, so, like the Greek philosopher Epicurus, they were hedonists about value. They asserted we ought to maximise the good, by promoting ‘the greatest amount of good for the greatest number’.⁶

How might the principles of utilitarianism apply to the current discussion? On one hand, we could say that if we’re going to maximise the benefit for a relevant group of people then all treatments need to be tried, and to discard the ones that do not help, thereby not missing out on some individuals benefitting from treatment. In this way, one could argue that the imperative to achieve maximum good or relief of suffering has been achieved. Another is to look at patient pathways rather than the ethics of no treatment or treatment and furthermore explore how we measure a meaningful patient outcome.

On the other hand, one could say that by offering only limited likely effective treatments, there is overall more money for effective treatments to go around, and also if the proposed treatments were to have any negative side effects, then we are minimising the chances of those.

The question then arises, ‘How do we weigh up these competing factors?’ We must ask the following questions, but fundamentally it boils down to a point of view:

- How limited is the pot of money? Are we underspending on the NHS or on pain services?
- How many people are we missing out on if we limit the availability of treatments? How many people are we causing to suffer either intentionally or unintentionally by simply withholding treatments because there is a prohibition, for example, on providing Lidoderm patches, opioids, gabapentin or spinal injections?
- How many people are saved from suffering by not offering treatments that are only likely to be beneficial to a few but have significant and/or long-term side effects? (e.g. medicinal cannabis, long-term opioids or brain stimulation for neuropathic pain).

Conclusion

Over the next two editorials we will be exploring these issues further and discussing the urgent need for a paradigm shift. There is a significant danger of patients with chronic pain or indeed ourselves as healthcare professionals being imprisoned in a Socratic cave. Patients may end up having little or no treatment because the complex phenomenon of pain and required treatment approaches are not perceived correctly.



Plato's allegory of the cave by Jan Saenredam, according to Cornelis van Haarlem, 1604, Albertina, Vienna Public domain Wikipedia

Note

- i. Type I and type II errors are derived from statistics: a type I error is the rejection of a true null hypothesis (also known as a ‘false positive’ finding or conclusion; example: ‘an innocent person is convicted’), while a type II error is the non-rejection of a false null hypothesis (also known as a ‘false negative’ finding or conclusion; example: ‘a guilty person is not convicted’). Much statistical theory revolves around the minimisation of one or both of these errors, *though the complete elimination of either error is a statistical impossibility*. By selecting a low threshold (cut-off) value and modifying the alpha (p) level, the quality of the hypothesis test can be increased.

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Jenny Nicholas



Here we are, the first issue of Pain News in 2021!

In this issue, we once again take some time to consider the impact of COVID-19 on pain services and our patients, with articles focusing on the patients experience of virtual consultations, attending pain clinics during these times and the role of self-management.

- Chris Bridgford: Self-management. Abandonment or empowerment
- Shreya Mehta: A snapshot of patient satisfaction with virtual consultations in community pain in East London
- Jim Blake: Remote pain clinics consultations from a patient and carer's perspectives

With the forthcoming publication of the new National Institute for Health and Care Excellence (NICE) Guidelines for Chronic Pain, this issue also includes articles which look at the processes NICE used in their development of these guidelines, as well as some personal experiences of being involved in developing other NICE guidelines, with articles as follows:

- The end of Pain Medicine as a professional specialty? A response to NICE and its managerialist attitude, Dr Mike Platt
- The NICE guideline on Chronic Pain – The NICE guideline we didn't need but which is ok, Dr Truro Nurmiko

- The NICE Guideline NG59. Low back pain and sciatica in over 16's: assessment and management. A personal view of my involvement by Dr Chris Wells.

And we finally round up the issue with a few Book Reviews for your interest.

- Innovative approaches to chronic pain. Understanding the experience of suffering and pain and the role of healing.
- The pain free mind-set

We do hope that you enjoy this issue of Pain News, and we are always glad to hear your feedback!

What's new for 2021?

Going forward into 2021, we are looking to develop some themed issues of *Pain News*, and the Editor and I will therefore be putting out calls for articles on various topics that we would very much welcome your contributions on.

The first two topics that we are requesting articles on are; **'sex and pain'**; this might encompass desire for sexual intimacy while in pain, body image issues in pain and how it can affect sex life, linking of sexual desire to the basic human need for communication, **and 'self-management of pain'**; this might encompass, what resources do patients find helpful on the Internet?, peer support in self-management, to name a couple of examples.

If you would like to contribute an article on this topic, please contact us in the first instance at: newsletter@britishpainsociety.org with the proposed premise of the piece and we will review before you submit your full article.

President's message

Arun Bhaskar



Dear Friends

I trust this finds you well.

The crisp clear mornings are progressing on to sunny days and Spring is upon us as evidenced by the crocuses and daffodils adding colour to the birdsongs providing the right ambience. As I sit down to write my first President's message for 2021, after a long months covering most of last year when we were all busy dealing with the pandemic, there is now an air of optimism and good

reason to feel like that. The R-numbers are heading in the right direction with a decreasing number of hospital admissions and deaths due to Covid-19. The Government have already announced the plans for a phased easing of the current lockdown restrictions. Most of our colleagues who had been redeployed to assist in Covid wards and intensive care are now back in their departments. On a personal note, some of my friends and colleagues who had been personally affected by Covid, directly and indirectly, are very much on the mend. Hopefully, in the coming months we hope to see more of each other and I look forward to those times.

First of all, let me start with some good news. I had written in my last piece the circumstances under which we had to postpone the 2020 ASM and due to the onset of the second peak, we were unable to have any meetings last year. We were hopeful that we may be able to hold a face-to-face meeting later in the year, but the advice of the Council and the Scientific Programme Committee was to have a 3-day virtual meeting earlier in this year. I am sure most of you have heard by now that we are holding our ASM on 27-29 April and it will be on a virtual platform. Dr Stephen Ward and the Scientific Programme Committee have put together a very exciting programme. My thanks go to them and all the speakers who have kindly agreed to continue their support to the British Pain Society ASM. I would encourage all of you to register for the ASM and

continue to support the Society and I am sure this will be a great educational and networking event. The AGM that would be normally held during the ASM will now be held at a later date and it is also very likely to be a virtual AGM as we had in September.

There are some major issues that will impact on pain clinics and how we will have to adapt our working environment in the future and also on how we engage with our patients and colleagues in primary care and other specialities.

Most of the pain services around the country have been hugely affected by redeployment of staff and non-allocation of clinic space and theatres. This issue may continue for some time as most surgical specialities will be competing for these limited resources once services are resumed. Currently, we have been managing patients through virtual clinics and direct patient contact was limited to emergencies and one-stop assess and treat clinics. The vast majority of our patients who had been waiting for several months will need to be prioritised and this will likely strain already overstretched hospital services and also primary care services.

We should also be preparing to adapt our clinics for managing symptoms of Long Covid. The National Institute for Health and Care Excellence (NICE) guidance on Chronic Primary Pain is scheduled to be released during the first half of April and the consultation process of the draft guidance had raised some concerns. It will be a priority to ensure that this guidance is interpreted correctly by various CCGs and we will work alongside our primary care colleagues to minimise any disruption to the treatments of our patients.

I had mentioned in previous communications that we are in the process of setting up a virtual educational platform that could impart knowledge and training for not only BPS members and other multidisciplinary colleagues involved in pain management, but also to other specialities, healthcare professionals in the primary care as well as patient groups. The Education Committee and the Education SIG along with some very dedicated Council members have put in a lot of effort get this going. We will be having further discussions on these important topics in the coming weeks on how we support each other and this project.

On the topic of collaborative working, there are a couple of initiatives I would like to bring to your attention. There is a Joint Meeting with the RCGP on 'One Day Essentials of Pain Management' on 23 April 2021. I would like to thank Prof. Sam Ahmedzai and Dr Martin Johnson for putting together a fantastic programme and would request you to support the meeting. Prof. Richard Langford and I are leading on a project looking at pathways and best practice for interdisciplinary MDT working in the management of osteoarthritis. This project which is going to be divided into three phases is being led by Dr Amelia Swift and consists of experts from the field of Pain

Management, Orthopaedics, MSK, Physiotherapy, Psychology, Nursing and Rheumatology. We shall update you about the developments in the coming months.

There are several challenges ahead of us to deal with the aftermath of the pandemic and it is important that we look after ourselves and each other. We need to ensure that we come through this stronger to look after our patients who need our help and support in this trying times. We look positively towards the future in arranging face to face meetings and events as we used to do before, and I am sure those days are not far away.

Bluebell Wood at Dawn by Peter North

(Front Cover photo)

Trying to get a good photograph in a forest or wood is usually very difficult because the scene is often very cluttered with so many trees and the image usually lacks any sense of depth or interest. In this image, the mist and fog transform the scene by obscuring a lot of busy detail and, more importantly, render the tree trunks into various shades of grey as they recede into the distance. The presence of the rising sun back-lights the scene nicely, adding a focal point and giving the image both a sense of mood and calm. I was keen to make sure that individual bluebells could be seen in the foreground so I made sure that the low camera position and depth of field captured them clearly while those in the distance merged into a gentle blue haze broken by patches of green.

<http://melbournphotoclub.com>

Self-management – abandonment or empowerment

Chris Bridgeford, *Chairman, Affa Sair*

The situation for chronic pain sufferers in Scotland is now at an all-time low. Like everywhere in the United Kingdom, NHS Scotland has had to concentrate on the Covid pandemic and so chronic pain sufferers have found their Pain Clinics closed and treatments such as lidocaine infusions halted without confirmation when they may start again. This has driven some patients to travel to England and access private practice there to get their infusions for a total cost of around £1,000 a time. Some Pain Clinics, including in my own region of NHS Grampian, have been offering virtual consultations using the 'Near Me' System – a medical version of Zoom.

In my part of the world, this is a very welcome and long called-for innovation. The main Pain Clinic for NHS Grampian is in Aberdeen. A round trip of 150 miles for me. Thankfully, in the first year of Affa Sair's existence a pain service was reinstated at our district hospital in Moray, saving patients from my immediate locale having to endure the 3-hour return journey, often by public transport. However, for any procedure recommended by the clinicians, sufferers are still made to travel to Aberdeen. Even worse, lidocaine infusions are not available in NHS Grampian because the clinicians there say they don't find any evidence for their efficacy. This is grossly unfair to the estimated 95,000 sufferers in the Grampian region as the treatment is available in 7 out of the 14 Scottish Health Board areas.

It is beyond doubt that during Covid, chronic pain sufferers will be at the bottom of the list as usual for any improvements in their treatments. Eight months in, Scottish Pain Clinics are only carrying out virtual consultations – no treatments for people suffering out of control pain whether Covid rages or not. It strikes me that to leave people suffering so much in the 21st century is completely immoral. I find it incomprehensible that professionals with a vocation for healing allow the faceless government advisors and NHS managers to put policies and budgets ahead of well-being. Such is the influence of these clandestine characters that people in total despair find themselves denied appropriate help available to the rest of society.

It is a sad truth that people not in chronic pain find it impossible to understand, or in some cases, believe how vicious it is.

The two phrases currently being forced on sufferers in Scotland are 'lived experience' and 'self-management'. I don't see the need for the first when the terms 'patient' or 'sufferer' tells it as it really is. What is included in 'self-management' is never explained but it has become the current buzzword when treatment is mentioned.

It would seem the term 'sufferer' is too brutal and negative for politicians so the gentler 'lived experience' is used to give a cosy, unchallenging feeling. The politicians and advisors don't want any brutal realism spoiling the numerous workshops and committees making decisions that have excluded the opinions of actual pain sufferers.

The 'self-management' phrase may be self-explanatory but the Scottish Government, their Advisors and other proponents of the ideology have never explained what treatments it covers. Until its meaning is explained, how can we judge its usefulness in helping over a million Scots suffering intractable pain which they wake up with and then try to go to sleep with every day and night until they die?

In my personal lifelong journey with pain – 42 years of continuous pain one day after another – I have had no real help from the NHS apart from ever more potent pharmaceuticals. Opiates are currently thought of as the devil's work by the medical profession. This is the same profession (spurred on by the chance of lots of money from the huge pharmaceutical companies in America) which told us the drugs were a wonderful way to control the pain. What happens in America soon happens around the world, of course. For me, in my long journey with chronic pain, it is a personal decision on the good and bad of opiate use. I do not think they should be used as a first line of defence for chronic pain, but neither should they be forcibly removed. The long-term way to help a chronic pain sufferer is through information not prohibition.

So, what sort of methods could be included in Self-Management Treatments?

The treatments I have used throughout the years are Reiki, Alexander Technique, Acupuncture, Meditation, Counselling and Psychological methods including Psychiatry. They all have one thing in common – they cost money. The most expensive of these was Psychiatry at £75 an hour, some 10 years or so ago. Nowadays, the more common private Psychology sessions come in at £150 an hour. Reiki and Acupuncture treatments currently start at £40/50 an hour. These are just not affordable for chronic pain patients reliant on hard-won benefit payments which can be withdrawn on a whim. I have also used equipment and aids (all at a personal cost) such as Infrared Lamps, TENS units, heat pads, CBD Oil and capsules, Musselflex Gel (Green-lipped mussel extract) and Capsaicin cream, various shaped pillows, expensive mattresses – anything to give me even a moment's relief. None of the treatments and very few of the aids are available free of charge on the NHS.

Manchester University PhD Medical Student Joe Parsons and I are currently working to develop a Self-Management Programme which will have the respect of chronic pain sufferers, by not making the patient feel cast aside. Initially, those taking part must have face-to-face contact with the programme instructors and this contact must be carried on at intervals throughout the programme. Outwith the initial and follow-up 'in-person' sessions, the remainder should be available virtually so that patients do not increase their pain in travelling long distances. A question and answer system should be provided so patients can ask individual and private questions. These questions need not be answered immediately but a reply guaranteed within a certain amount of time.

We feel a successful self-management programme should include the following.

Meditation/mindfulness

These sessions should be available online with standardised video or audio files to reduce cost and ensure these resources are available long term. The same should be done for treatments like Yoga, Tai Chi and basic physiotherapy exercises.

Physiotherapy

Individualised physiotherapy regimes would be developed in an individual session with a physiotherapist. This can reduce the long-term reliance on repeated physiotherapy referrals. The idea would be to have this initial consultation with provisions of what to do if you feel like the physio is too much (how to reduce the intensity of the exercises) or what to do if you feel like you can do more (how to increase the intensity). This would ideally be followed by online consultations initially monthly and then slowly decreasing the regularity until there is a biannual

in-person physio appointment. As much as this results in continued physiotherapy, it reduces time and cost with repeated referrals and hopefully the patient will benefit in a way which means they no longer feel they need the help of the other pain management services.

Psychotherapy

It is crucial that there be an individual psychotherapy session. This is very important in identifying those who could receive genuine benefit from psychological support. It is also key for so many patients to feel heard, particularly by medical professionals. This should be in the form of a casual chat so that it ends up being patient-led, as this will not only allow the patient to feel heard, but it will allow the psychotherapist to identify any potential areas in which they can help. This needs to be designed to ensure that the patient realises the psychotherapy is part of a full treatment regime and is not a way of suggesting that the pain is 'all in their head' – frequently heard from many chronic pain sufferers not fully understanding what the health professional means.

Alternative therapies

Alternative therapy sessions where patients discuss their experiences with and have the opportunity to access treatments such as Acupuncture, Chiropractic, Reiki, Alexander Technique, Wim Hof method and Hydrotherapy.

Diet

A session with a dietician can be important as chronic pain sufferers may genuinely benefit from certain exclusion diets, but it is important that the dietician can confirm which of these diets are beneficial and which are nonsense. In addition, the dietician would help to prevent issues with comorbidities.

Peer advice

It is imperative that those taking part get help from sufferers who have battled chronic pain for many years. An initial coping technique session could be done as a group discussion forum. As with the other disciplines in the programme, online reviews must be available.

Navigating the benefits system

Benefits advice sessions to discuss government benefits and other potential sources of income and support for individuals with chronic pain is a necessity as remaining employed is often incredibly challenging. The current tests are ridiculous and humiliating for people who have genuine health problems. This could potentially be provided by Citizens Advice staff and also feature in the 'Peer advice' section.

Self-management – abandonment or empowerment

Hobbies

A facilitating passions session where we determine what people's passions are and how we can ensure that they can maintain these even with health complications. If people don't have passions, we can have sessions where creative outlets such as drawing, painting, writing, computing and crafting can be experienced.

Pharmacists

A medication forum run by a pharmacist would be useful in discussing the mechanism by which drugs work, their successes in different people and in different conditions so that patients can be more informed in their drug choices. This will give the patients room to discuss their own personal experiences with these drugs so that peers feel that they are not just getting statistics but a more personal touch on the experiences a cocktail of drugs can bring.

Whether you are an advocate of self-management or not, it is clear that an efficient and successful programme needs to be available within our NHS. Otherwise patients will take a scattergun, often futile approach to improve their health. Many patients will be led down dark avenues by unscrupulous con-artists looking for a fast buck from desperate souls. With professional advice denied them, patients could well end up taking dangerous drugs disguised

as supplements and interfering with the efficacy of prescribed medications. Only budgets and the unscrupulous will benefit from pain sufferers being cast adrift from NHS services they pay for through their taxes.

There have been welcome changes recently in the make-up of Scottish Government Advisory Groups. First, the National Advisory Committee for Chronic Pain has included patient representatives for the first time and have also invited three new third Sector groups to sit on the Committee, The Centre for Integrative Care based in Glasgow, SAMH (Scottish Adult Mental Health) and I'm really honoured to say – Affa Sair – my own charity. I, and many others, have been hugely critical of the NACCP in the past, but we welcome these new developments and certainly Affa Sair looks forward to working progressively with the NACCP to better help Scottish Chronic Pain Sufferers.

Second, a new Chronic Pain Reference Group has been formed under the leadership of The Health and Social Care Alliance (The Alliance). The Alliance have managed to form together a group of chronic pain sufferers from all over Scotland from which five representatives and five deputies have been chosen to bring the members opinions and comments to the NACCP. This is in early stages with Terms of Reference still requiring to be formalised as I write but inaugural patient representatives have been chosen to serve for a period of 2 years.

Women in neuromodulation UK [WiNMOD UK] report

Rosie Allan *Corporate Communication EMEA Corporate Communications, Boston Scientific*

Everything started with a common mission: eradicate chronic pain. This disease is a major social issue today, with approximately 100 million people across Europe suffering from it. Chronic pain affects indifferently men and women. Neuropathic pain occurs in about 1 in every 10 adults over age 30. The prevalence rate and people identified varied depending on the method of identification of neuropathic pain. Neuromodulation is a NICE recommended treatment for intractable neuropathic pain. Women are underrepresented in the field of Neuromodulation, with less than 10% of UK implanters being female.¹ While this is an issue in itself, this has direct implications for the diverse group of chronic pain patients. Treating chronic pain needs to be a collective approach, as a diverse group is better equipped to tackle this challenge. To discuss and address this issue, six female doctors specialising in the field of neuromodulation met for the first installment of Women in Neuromodulation UK – or WiNMOD UK – to share their common challenges and identify ways to increase female representation in a traditionally male-dominated environment.

The passionate debates and discussions at WiNMOD UK throughout the day were truly inspiring, but what really stood out was the willingness to support young talents through networking and mentoring. From the beginning, the idea of WiNMOD UK was not only to raise awareness of the field's diversity concerns, but also to drive change and actively address the main points to move the industry forward. The participants speak from experience: all of them had to overcome obstacles as they ventured into the world of neuromodulation to be able to change their patients' life.

We hope you enjoy the analysis and the proposals that came out of this inspiring day, which shows how we can pave the way for future female Neuromodulators, in the UK and beyond. We are already looking forward to the next session. Together, we can make a difference!

*Astrid Monteau, Strategic Marketing Director
Neuromodulation EMEA & BUM France
Liz Illingworth, HR Director and moderator on the first
WiNMOD UK*



Introduction and context

Six female doctors specialising in the field of neuromodulation met for an inspiring day at the prestigious Royal Institute of British Architects (RIBA) in London. The day comprised of a discussion of women in neuromodulation and the creation of a working group: WiNMOD UK. The timing of the inaugural meeting in the run up to International Women's Day could not have been better, with a focus on equality for women and the 2020 theme of 'Each for Equal', celebrating women's achievements, raising awareness against bias and taking action for equality.

The objectives of the meeting were threefold:

- Increase and encourage female representation in neuromodulation;
- Ensure more medical students/junior doctors specialise in pain and neuromodulation;
- Increase patient referrals for neuromodulation.

WiNMOD UK comprises consultant pain specialists, anaesthetists and neurosurgeons representing a wide and diverse area of the United Kingdom, including Bristol, Leeds, London, Norwich, Oxford and Sheffield. After an initial introduction, a short amount of time was spent discussing how the group had entered the field of neuromodulation. The answers were varied, but ultimately each one found it fascinating and were passionate about the life-changing impact of neuromodulation on patients' lives. Some of the groups also

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mentioned the importance of mentors and role models – a topic which came up again during the meeting.

The purpose of the WiNMOD UK group and coming together in this meeting was to promote neuromodulation in the United Kingdom and encourage female representation in neuromodulation. The group spent the day discussing ways to move these aspirations forward.

Note: This meeting first took place in February 2020 and the original plan was to publish the proceedings and next steps in a very timely way. When the COVID-19 pandemic began, priorities shifted as the group were pulled into the frontline of treating patients. Thank you to all the group members for their work during this time and continuing efforts during the pandemic.

Why are women under-represented in neuromodulation?

The first discussion addressed the key question: why are there fewer women specialising in neuromodulation? This was followed by what WiNMOD UK could do on a practical level to change this.

Although this is a simple question, the responses are complex. Overall, the majority of medical specialities present a gender imbalance, and according to the most recent statistics from the American Medical Association (AMA), the specialities with the highest female representation include obstetrics and gynaecology, allergy and immunology, paediatrics, medical genetics and genomics, hospice and palliative medicine and dermatology. Conversely, the areas of medicine most populated by male colleagues are orthopaedic surgery, neurosurgery, interventional radiology, cardiothoracic surgery, radiology and pain medicine.¹ The data confirm that there is a clear difference between the fields women and men choose to specialise in.

But why is this the case? Why do women choose certain specialities and not an area such as pain medicine?

I have always found the specialty of neuromodulation fascinating. The ability to change and improve quality of life is so rewarding. As I have been supported and encouraged throughout my career in neurosurgery, I am very aware of the importance of mentoring in this field. WiNMOD UK offers a great opportunity to connect with young female talents and help them to overcome challenges, emphasizing that this field is open to all.

Stana Bojanic, Consultant Neurosurgeon and Spinal Surgeon at the Oxford University Hospitals Trust

1. There are only two ways to enter neuromodulation as a speciality
 - (a) Neuromodulation is a sub-speciality of pain medicine and neurosurgery, the former already being a sub-speciality of anaesthesia. While women do enter anaesthesia as a field, it is another area where women can be under-represented and lag behind in terms of leadership positions.² Some anaesthetists might specialise in pain medicine, but it can be seen as a “step too far” to sub-specialise further into neuromodulation, particularly in relation to attempting to balance family life. Once trainees have chosen anaesthesia, they then have to choose pain medicine as a sub-speciality and then choose neuromodulation as a sub-sub-speciality. The same situation applies to neurosurgery.
 - (b) Interest in neuromodulation requires exposure during training for a trainee to develop skills which they need to further develop post-training. These additional surgical skills are not routinely taught in anaesthesia, so require additional training. There is also a well-known low representation of women in surgery.³
2. Poor branding of pain medicine
 - (a) Pain medicine can often be perceived as challenging as well as negative (e.g. when in clinic you usually see only patients that continue to experience pain, not the ones who are recovering). For many junior trainees, pain medicine is not seen as an interesting enough choice and not enough is known about what it entails. Junior doctors do not hear much about pain as a speciality, so it needs a better representation right down to grassroots level to get trainees interested earlier. If trainees are exposed at an earlier point in their career, the more interested they will be in the speciality, particularly if they hear it from inspiring people who are well recognised in the field.
3. Balancing specialisms with family and personal life
 - (a) Even if women do go down the path of anaesthesia or neurosurgery, by the time you get to the point of further sub-speciality, it has taken at least 6–10 years after your medical degree and some may be thinking of starting a family. It can be difficult to juggle the additional learning involved, as well as surgical skills and attending conferences at this point. Anaesthesia is a speciality in which you don't own patients; you don't have a clinic to manage – so many women in the field will stop here to balance work with family life.

4. Chronic pain is not recognised as a sub-speciality by the General Medical Council
 - (a) Doctors in this area will only be recognised as anaesthetists, the GMC does not go further and recognise the discipline of chronic pain. Similarly for neurosurgeons, they are only recognised as spinal neurosurgeons but not as neuromodulators, although functional neurosurgery is a recognised sub-speciality. In addition, pain medicine is not included in every medical school curriculum, mostly because there is so much else to learn.
 - (b) There is an exit exam that is desired when applying for a consultant post. However, it adds the burden of another difficult and expensive postgraduate exam to take. This may impose additional reluctance from trainees to choose pain medicine and furthermore neuromodulation as a sub-speciality. In addition, accreditation in pain medicine now requires success in the FFPMRCA exam in order to become a Fellow of the Faculty of Pain Medicine. This exam is not a requirement for completion of training in anaesthesia and is often only a desirable criterion for obtaining a consultant post in pain management.

How can the under-representation of women in neuromodulation be addressed? The group had many suggestions, outlined in the section below.

Practicalities: what can be done

- Raise the profile of neuromodulation and pain medicine across the board
 - Beyond gender, all agreed that pain medicine and neuromodulation need elevating at all levels in the medical community. This will help inspire trainees and junior doctors to enter the field regardless of their gender. Groups such as WiNMOD UK can be part of this profile-raising project by showcasing their contribution. Nonetheless, the group all felt strongly that while women are key players here, men should be actively involved in the process too.
 - Pain patients are often not seen as emergency cases in hospitals and there is a lack of bed capacity available for advance procedures. Pain services often therefore do not have admitting rights for in-patient beds, so complex patients often attract a significant workload to ensure medical cover in the perioperative period for implant. Chronic pain management is not an acute speciality, so SCS implants are rarely urgent, though can be life-changing. Although this could be attributed to the chronic nature of the illness, certain pain conditions can be presented as acute on chronic flare, warning immediate attention.
- To work in neuromodulation, you need to be passionate about pain patients and realise you can change lives. More awareness raising on this point would certainly help address the low profile given to pain medicine and neuromodulation. A better standing with medical colleagues, as well as better understanding of the economic benefits to the country by treating pain patients (fewer disability benefits, people returning to work, etc.), would certainly help addressing representation and preference issues among other specialities.
- All NHS Trusts in the United Kingdom have communications teams with most of these producing monthly newsletters. There is an opportunity here to propose interviews or stories about neuromodulation, which would be read by colleagues and also help raise the profile and pride of the neuromodulation team. The same could be done from an external point of view to share positive stories about neuromodulation with the media, which would elevate knowledge about this treatment option to the wider population.
- Increase the presence of positive role models
 - The WiNMOD UK group are a collection of experienced and expert physicians in neuromodulation and all agreed that they could and should do something to take on role model and mentoring positions. Activities could include running further workshops or giving lectures about neuromodulation. Industry can also play a part here, by advocating a higher representation of women at industry events and panels. The group would also actively encourage participation in the INS mentor programme.
 - All agreed they should be more visible at the more specialist meetings (or now the virtual equivalents), such as the British Pain Society and especially the satellite meetings. At regional meetings, there should be a push to get neuromodulation on to the programme.
 - As role models, WiNMOD UK members could raise their own profiles more with further personal branding and the use of social media as a tool. The group all felt they could benefit from social media training as a way to promote professional activities, which is another activity industry could support with, and that the group are planning for the new year.
 - ESREP is a programme run by universities for final-year students to identify good projects for them to get involved with. Medical students could be offered the opportunity to work with the WiNMOD UK team or other

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neuromodulation specialists on projects which could pique their interest in pain and neuromodulation, such as research into pain and its treatment.

- NSUKI is the Neuromodulation Society for UK and Ireland. The group could work to raise the profile of women in NSUKI and possibly run specific sessions at future NSUKI meetings.
- Examine and improve workforce planning
 - There are 42 UK centres who undertake neuromodulation implants, but what hasn't been forecast sufficiently are the future opportunities, such as which clinicians may be considering retirement in the near future, that is, succession planning.
 - Where are services looking to expand across the country?
 - These data should be looked at by organisations such as NSUKI, potentially with industry support. It would also be very positive for patients, who would benefit from the expansion of services and more doctors with expertise in pain management and neuromodulation.
- Support women to open doors – for themselves and each other
 - Every member of the group had experienced different and unique situations in the workplace when it came to gender and this included positive as well as negative ones. All agreed women should be enabled and empowered to react to negative situations and not simply let them go, whether it is their direct experience or witnessing these.
- Improve childcare options
 - More support could be considered towards supporting both male and female partners in the workplace when it comes to childcare options and aspects of staff well-being.
- Industry partnerships
 - In the pre-COVID era, events such as the BMJ Careers Fair, aimed at junior doctors, would have been an ideal place to host an exhibition booth focused on pain medicine and neuromodulation with the objective of profile raising. NSUKI, as the face of neuromodulation in the United Kingdom and Ireland, ordinarily hold regular events such as trainings and regional sessions, which could be more strongly promoted to trainees to bring them in earlier.
 - Industry could offer financial support to these types of events, such as organising breakfast sessions or booth support. However, with the world currently facing lockdowns and many restrictions to prevent the spread of COVID-19, events are mostly on hold and with no idea when these will be lifted, industry will also need to look at new and innovative ways to support activities in a more virtual world.

It is clear that there are many options that could be taken to support the growth and advancement of women to enter the field of neuromodulation and raise the profile of this life-changing treatment. These now need to be examined and a plan created to prioritise the next steps in a practical, timely and efficient way.

Is pain approached and perceived differently depending on gender?

After the thorough discussion of the under-representation of women in neuromodulation, it was time to focus on the complex point of pain perception based on gender. A quick poll of the group to ask this question resulted in an overwhelming **YES**. It was also noted as a side point that even the design of clinical trials favours men. Caroline Criado Perez's bestselling book *Invisible Women* includes a whole chapter focused on the medical community's approach to women, sharing quite alarming statistics such as the under-representation and often exclusion of female samples in pre-clinical and clinical trials. For example, women make up only 25% of participants across 31 landmark trials for congestive heart failure between 1987 and 2012.⁴

Furthermore, there is a lot of data on the implications of this from a pharmacological perspective but not enough data exists for non-pharma treatments.

Another survey of the WINMOD UK group found that the biggest impact on the perception of pain was either gender-dependent biological processes, such as hormones, or genetics/psychosocial factors. A discussion took place to examine these in more detail, for example, some female patients might appreciate a female consultant in discussing certain aspects of their pain.

Gender biological processes

A wealth of literature cites multiple biopsychosocial mechanisms which have been proven to contribute to gender differences in pain perception, and awareness of this factor is growing. These can include the following:⁵

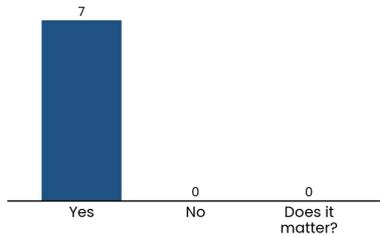
- Sex hormones;
 - The menstrual cycle;
 - The menopause (which can affect pain sensitivity);
 - Some oral contraceptives;
- Different pathological conditions of men and women;
- Immune cell types⁶ and the immune system response;
- Anatomical development.⁶

Psychosocial factors

- People – and often women – can take the approach of 'pushing through' to cope with pain.

Is pain perceived differently depending on gender?

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- Who a person is and their overall quality of life – this can also be different between men and women.
- Childhood factors, for example, how pain was reacted to as a child.
- History of drug use and/or abuse.

How pain is perceived by patients also depends on their goals. Some patients want nothing more than to return to work or to be more mobile, but others are focused on the pain and about keeping benefits or other assistance received.

Fundamentally, a pivotal article published in 2015 by Sorge et al. in *Nature Neuroscience* showed that even though everybody's pain might look similar from the outside, it cannot be assumed that it is the same on the inside.⁷

A more recent article from 2018 in *Practical Pain Management*, 'The Many Gender Gaps in Pain Management', highlights that 'Thoughtful, effective pain management must therefore consider two important concepts: how being a female patient impacts the pain experience, and how the experience of female clinicians can impact pain medicine'.⁸ The article also notes that female healthcare professionals are more likely to follow evidence-based guidelines and provide preventive health services. So is pain therefore approached differently by doctors depending on their gender?

The group agreed that this can be the case. One member of the group related an example of coccydynia, which was previously treated in isolation as a musculoskeletal complaint, but subsequently identified to be only one symptom of chronic pelvic pain syndrome with visceral hypersensitivity throughout all pelvic organs. The experience of the female consultant might have influenced the direction of pain management approach, as a spinal cord stimulator device trial was recommended.

Other similar cases were discussed, demonstrating that appropriate enquiry and consideration of pelvic pain might reveal neuropathic visceral pain which can be amenable to neuromodulation as an effective therapy.

Tactfulness and sensitivity are required to obtain more personal details with patients and there can be differences in consultation techniques between colleagues; one needs time to discuss sensitive topics, it cannot be done in 30 minutes. It was also felt that pain physicians do not receive a lot of training in this area, understanding whether people want to talk about these or not is more a feeling you learn over time and with experience.

To conclude this part of the discussion, it is clear that women both perceive pain differently to men and as a physician, treat it differently. The WiNMOD UK group are committed to furthering understanding of women's perception of pain and with the ultimate aim of treating all patients' pain – especially women's – in the most effective and sensitive way.

What's next for women in neuromodulation?

The Women in Neuromodulation meeting took place in February 2020, with the aim to start addressing identified opportunities swiftly. Unfortunately, COVID-19 disrupted these plans both at industry and predominantly at NHS level. However, the group agreed that the continuation of WiNMOD UK discussions and activities must continue and resume as soon as possible to keep the momentum going.

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Next steps for further follow up included the following:

- The publication of this article to highlight the formation of the WiNMOD UK group and their objectives.
- Further communication of this article – through external channels such as social media, the UK&I professional organisations and internal channels such as the group's NHS Trusts.
- Sharing of job plans with the group for planning and awareness.
- Continuation of research. The majority of the group undertake evidence-based work and are committed to this and further sharing of their findings.

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- Looking for opportunities at (now virtual) events such as the BMJ Live, International Neuromodulation Society (2021), British Pain Society sessions or other events where pain or career advice is offered, as a way of meeting objectives around raising the profile of neuromodulation as a career option.
- Attending local activities (no doubt many of which are also now virtual), such as Grand Rounds in hospitals, or local spine and neurosurgery meetings, to elevate personal presence and that of neuromodulation.
- Increasing personal social media presence and branding as a way to share key content and messaging about neuromodulation, both as a career discipline and a treatment option. Training is planned in Q1 2021.
- Communicating to male peers about the WiNMOD UK group to ensure these colleagues are brought into the discussion; WiNMOD UK is focused on the under-representation of neuromodulation in general, as well as among women.
- The group agreed that an annual meeting would be very useful. For 2021, a link would be sought to the International Neuromodulation Society's Women's Group and it was suggested that all female pain and neurosurgical trainees could be invited to widen the audience.

It is clear to see from the lively, passionate and informed discussion at the initial meeting that there is a lot more to come from this group.

Conclusion

Inspiring, encouraging, promising, empowering. Just a few of the words used to describe the initial WiNMOD UK meeting. When surveyed to ask what had stood out the most, the responses were similar in their positive outlook:

- 'Enthusiasm, engagement, passion for neuromodulation – the future is bright'.
- 'As a group we can bring a lot in the field'.
- 'Knowing that you are not alone, the future is optimistic'.
- 'This is a great group of like-minded motivated neuromodulators'.

It is now imperative that this enthusiasm is harnessed so that the group can make a difference. COVID-19 may have delayed the initial follow-up and meant reprioritisation has been required, but it is clear that this is a productive and knowledgeable group of doctors with a strong mission to advance neuromodulation overall.

If you are interested to learn more or join future WiNMOD UK activities, please contact

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Note

- Data based on NSUKI membership.

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A snapshot of patient satisfaction with virtual consultations in community pain in East London

Shreya Mehta *City of London School for Girls*

The COVID-19 global pandemic has changed the way we manage our patients, as the current restrictions on face-to-face consultations have necessitated remote appointments that range from telephone follow-ups to audio-visual consultations. As per the National Health Service (NHS) digital, it is estimated that up to half of the 102 million appointments, from March to July, were by video or phone call. This new provision has been a challenge both for patients and healthcare professionals, with a rapid, steep learning curve being achieved within weeks to allow for delivery of patient care safely.

Methodology

On my work placement at Essex Lodge, a general practitioner (GP) surgery at the heart of Newham, London, I telephonically followed up all patients who had virtual appointments in the pain clinics in the last week of August (17–24 August inclusive). They ranged from appointments with consultants, GPs with special interests, physiotherapists and psychologists. We asked them a questionnaire about their experiences with the virtual/telephone follow-ups and collated the responses. The project was registered and approved as part of a quality improvement and effectiveness project at Barts Health NHS Trust. All patients were contacted with their prior permission telephonically, and the questions were asked on the phone about their experiences with the service. Despite our best efforts, we were faced with some inevitable problems regarding technological issues, unavailability of patients and language barriers, which undermined the communication element of the survey.

Results

A total of 76 patients were ‘seen’ over a period of 7 days at the GP surgery in pain clinics, of which we were able to contact 58 patients (76.3% response rate). The breakdown by speciality included GPs (34.5%), psychologists (22.4%), pain consultants (22.4%) and physiotherapists (19%), highlighting the multidisciplinary nature of the service spread across all the domains (Figure 1).

Figure 1.

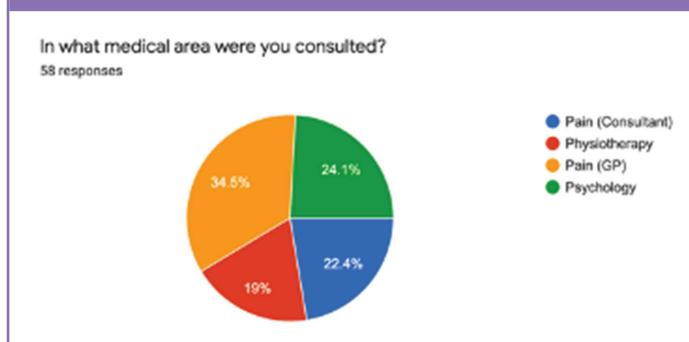
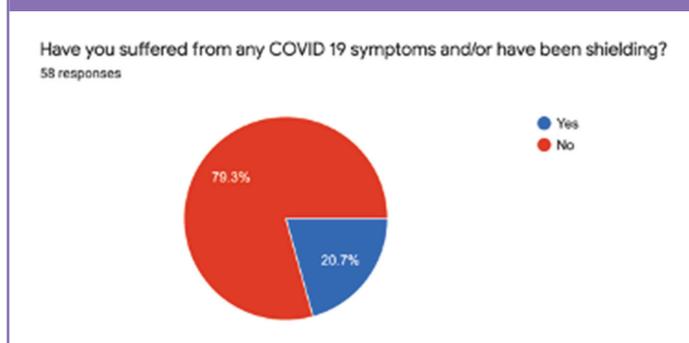


Figure 2.



Of the total 58 patients, the majority (79.3%) were not known to be shielding or demonstrating any COVID-19 symptoms (Figure 2).

This survey demonstrates that 63.8% of the 58 respondents would prefer face-to-face appointments for both the first-time and follow-up appointment (Figures 3–6). This preference for physical appointments is echoed by the notion that the majority of respondents found that it is very important for them to see the healthcare professional

A snapshot of patient satisfaction with virtual consultations in community pain in East London

face-to-face, with a total of 26 patients (44.8%) expressing their preference for face-to-face consultations with any healthcare professional (Figure 7).

Regarding the individual areas in which the patients were consulted, it seems that the speciality with the highest patient satisfaction rate (derived from the mean) is physiotherapy followed by psychology, pain consultant and then GP with special interest (Figure 8).

Discussion

The government is now driving back the face-to-face initiatives, with GP practices being told they must ensure that patients can be seen face-to-face when they need such appointments. NHS England is currently writing to all practices to confirm that they are communicating the notion that doctors can be seen in person if necessary, as well as virtually. The Digital First Primary Care team at NHS England has developed an extensive range of resources to support the purchase, implementation and use of online consultations to GP practices. The Faculty of Pain Medicine has outlined its priorities indicating that although the assessment should be conducted in line with Core Standards for Pain Management, the modes of assessment should be based on patient needs respecting patient choice. They have recommended that the pain doctors will need to adapt and learn

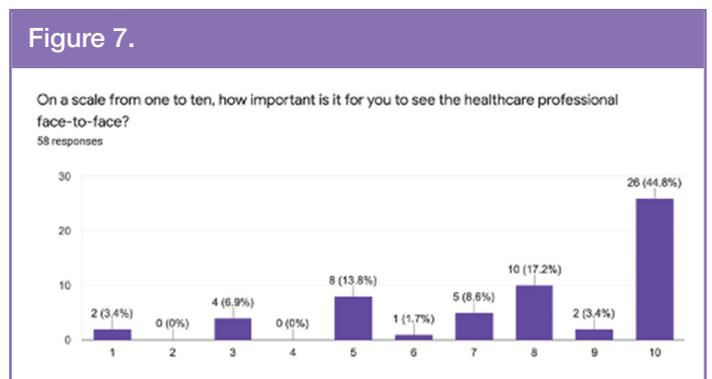
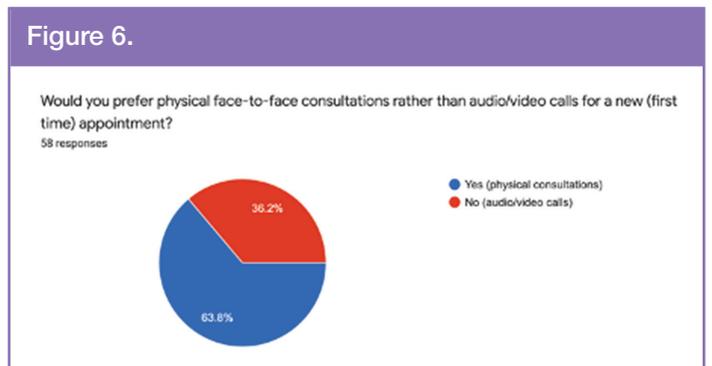
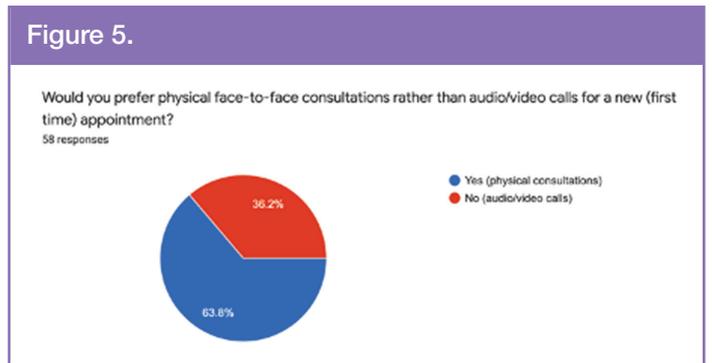
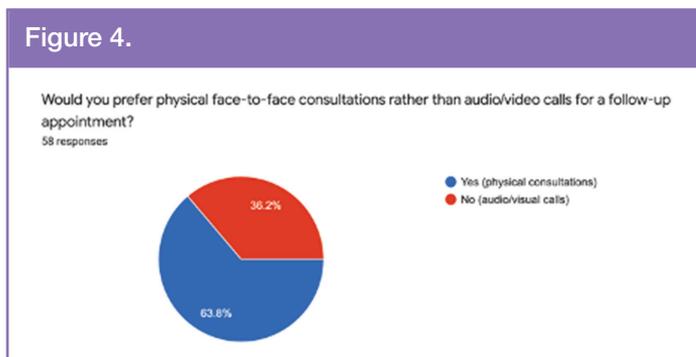
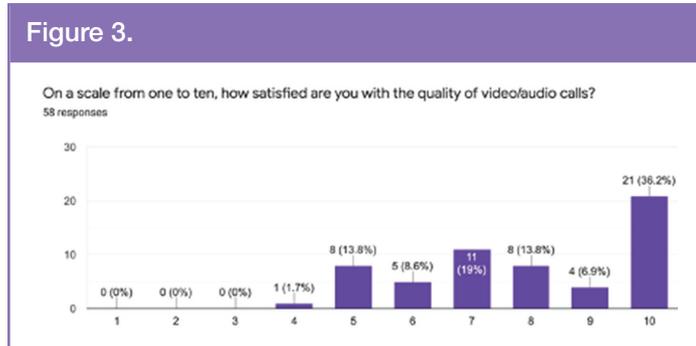


Figure 8.

	Mean satisfaction with their appointment (out of 10)	Range of values
Pain consultant	7.5	5–10
Physiotherapy	8.5	5–10
Psychology	8.3	5–10
GP with special interest	7.2	4–10

GP: general practitioner.

A snapshot of patient satisfaction with virtual consultations in community pain in East London

from their experiences, gaining an understanding of the limitations and benefits of video and telephone remote consultations.

Following some easing of COVID-19 lockdown restrictions, many surgeries, including Essex Lodge, have been allowing a small intake of patients to physically visit the surgery instead of being called online. If the restrictions lessen in the future, it would be advisable to assess whether all patients would like to start coming to the GP surgery in person to be examined, or whether some patients would like to continue with the online consultations. The shift to online calls may imply that, in the near future, there could be a smaller influx of physical patients and that perhaps we are looking at a hybrid model: a combination of face-to-face and audio/visual consultations in tandem. Nevertheless, the role of face-to-face consultations remains undisputed, with a strong preference of patients indicating their wish to be seen in person.

Currently, the NHS guidelines state that although remote consultations still should be used when appropriate, 'reasonable adjustments' can be made for 'specific groups when necessary'. This newfound encouragement of face-to-face appointments by the NHS may be a promising sign for patients who do not prefer audio calls.

In an era of investigations and sophisticated imaging, having a 'human touch' with a physical consultation is invaluable. It is not an understatement that patients value face-to-face appointments, as non-verbal communication plays an equally important role in conjunction with verbal communication. The actions/facial expressions that doctors make on a day-to-day

basis when talking to patients may be a critical factor in maintaining/creating a sense of doctor-patient rapport, which is vital to effective patient communication. Patients may also feel a sense of reassurance when seeing the doctor face-to-face, as the physical interaction would make them feel as though they are being actively 'acknowledged' by the healthcare professional.

Physical appointments may also help to maintain a healthy mental wellbeing for the patient by encouraging the patients to go out, preventing loneliness and other undesirable states of mind caused by isolation (which is inevitable during a global pandemic). Moreover, this may particularly help patients with chronic pain as they would now mobilise for their appointments.

During COVID, we have changed how we deliver our healthcare and outpatient consultations beyond recognition. Remote consultations are here to stay but the value of face-to-face consultation, particularly regarding chronic pain, cannot be refuted, and this survey supports the value of the face-to-face consultation perceived by the patient.

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I would like to thank the staff of Essex Lodge GP Practice, Newham, London, who were very helpful during my work placement, especially Dr H Nandra and Mr F Qureshi.

Reference

1. NHS. Classification: official, <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/09/C0765-access-gp-practices-letter-14-september-2020.pdf>

Remote pain clinics consultations from patient and carer perspectives

Jim Blake

The person in question is my wife, an adult lady who had a severe stroke in 2012 and suffers constant neuropathic pain with loss of mobility and feeling on the whole of the right side of her body. As her husband, and with wide medical interests, I have followed her course. This article is written with her permission.

Initially – well before the pandemic – she had face-to-face appointments and was given some psychological support including mindfulness and meditation. She also derived benefit from volunteering at TALK, which helped recovering stroke patients with aphasia. Other support groups can be equally effective in helping to reassure and in putting pain into better context and focus.

Following consultations with pain experts at King Edward VII Hospital and UCL, the patient embarked on lidocaine infusions at our local NHS Acute Hospital. Over a period of 5 years or so, the infusions (about 5–6 per year) have greatly helped to improve her sleep and so her daily strength and ability to cope with the constant pain. She only takes occasional additional painkilling medication to assist her to get to sleep.

My wife is very well educated in IT and Communications with a Master's Degree in Computing Sciences. She is entirely comfortable talking on a telephone or video call of whatever type. While consultations can, arguably, benefit from using remote technology, regrettably most treatments (and infusions

in particular) cannot. A significant factor in providing treatments has been the availability of space, doctors, and the time taken to sanitise and reduce the risks of infection.

Resource limitations have meant that the Pain Service was an early casualty in reconfiguring the hospital to accommodate Covid-19 patients.

We would commend the continued use of a hybrid solution mixing virtual and face-to-face consultations. There is no doubt that effective and simple technology is a significant benefit in encouraging reluctant patients to participate in a virtual consultation if that is appropriate. Some psychological support might be possible via this means.

A frustrating factor has been the uncertainty associated with the re-starting of the Pain Clinics and this has been caused by the fact that the course of the Pandemic has been hard to forecast. Potential patients who are being invited to a virtual video or telephone consultation may often need support or even assistance to establish the consultation. This factor should not be overlooked.

We are looking forward to a time, following mass vaccinations, when actual treatments will be possible and the normal resources back in place. It is my experience that pain, as well as being extremely debilitating and damaging, leads many patients to be excessively stoic and I believe this needs to be recognised in our communications with them.



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Post-traumatic pain: a neurological perspective

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Summary

Chronic pain is common in patients involved in physical trauma. Acute pain typically maps closely to the region of injury, so it is relatively simple to understand, diagnose and treat.

Unfortunately, this acute pain often becomes chronic – this is much harder to understand, diagnose and treat. Chronic pain flows from acute pain but is mainly generated and maintained by peripheral and central sensitization. This is typically triggered by inflammation associated with local injury. The clinical clue to the presence of sensitization is pain that persists, amplifies and spreads. This is more likely to occur if a peripheral nerve has been directly injured as part of the trauma – this is neuropathic pain. The clinical clue to the presence of neuropathic pain is that the pain is sharp, shooting and is often associated with sensory disturbance and subtle motor symptoms. These ‘peripheral’ changes can trigger changes in the brain that further amplify the pain, reduce mood, alter cognitive function and change how patients respond to analgesia, especially opiates. The clinical clue to the presence of this ‘supraspinal’ underlying the pain is further amplification of pain, the development of depressed mood, complaints of difficulty focusing and remembering, and requests for increasing pain relief. This element of chronic pain is more common in patients with complex medical and psychiatric histories.

Introduction

In the last 8 years of clinical practice, much more of my time has been spent with patients who have been subject to physical trauma; this has largely been head injury cases. It was during this time that I really began to pay attention to the importance of post-traumatic pain. This was because it was rare to encounter an isolated head injury without any peripheral injury, and even in the minority of cases where patients suffer an isolated head injury, patients with ongoing symptoms are rarely without head-related pain. In the majority of cases, there is a complex aetiology, with potential contributions from head injury per se, orofacial pain and neck pain.

When there is a significant peripheral injury – typically this would be to the neck or upper limbs, the abdomen, lower back or lower limbs, or occasionally in combination – there is often chronic pain.

My experience in clinical practice indicates that it is hard to easily compartmentalise the strictly ‘neurological’ elements. A good example of this would be a patient who has sustained a traumatic sacral plexopathy secondary to a complex pelvic fracture, where there is likely to be an overlap between neurological injury, chronic pain, and psychological or psychiatric injury.

In these circumstances, chronic pain typically dominates the clinical picture, especially in relation to the day-to-day disability and functional impairment experienced by a patient. My experience of these cases has been that patients who present with complex, multifactorial symptoms have often been assessed by a wide range of practitioners, each of whom approaches the assessment in a different way. There are also typically polarised opinions about the aetiology of any pain that may be present and, in turn, the diagnosis, management and prognosis for their condition.

What is clear is that regardless of the disputes about aetiology, the reality for patients has been poor outcome often with frank deterioration in their clinical state over years. The topic of chronic pain is a very dynamic research field, which I hope holds the promise to unravel much of this uncertainty and disagreement. These experiences have challenged my own knowledge of and diagnostic approach to the assessment of post-traumatic pain.

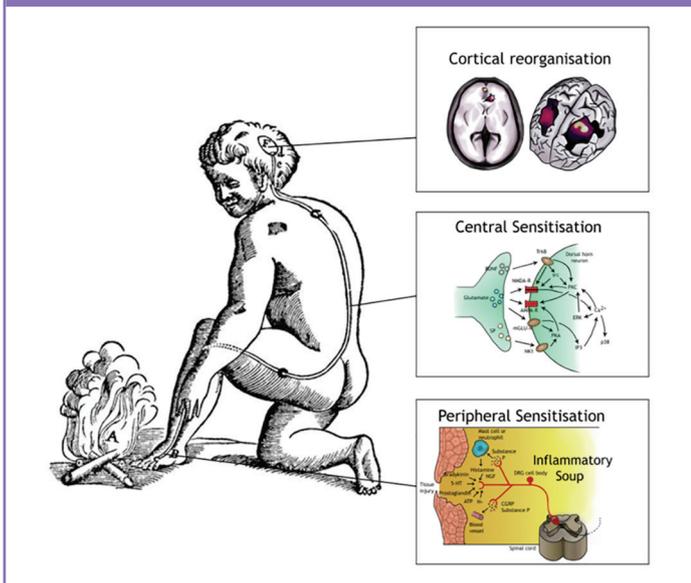
This article summarises my synthesis to date and starts off with perhaps the least difficult aspect of chronic pain – its classification into different sub-types:

- Cancer-related pain;
- Postsurgical or post-traumatic pain;
- Secondary headache or orofacial pain;
- Secondary visceral pain; and
- Secondary musculoskeletal pain.

In this article, I will be focusing on the presence of post-traumatic pain, pain secondary to headache and orofacial pain. Within those areas, I focus on a neurological perspective contributing to the formulation of a clear diagnosis and ongoing patient management. There will also be an emphasis on how

Post-traumatic pain: a neurological perspective

Figure 1. The Cartesian illustration with additional images emphasise the modern evidence that all components of this system undergo reorganisation following an injury that gives rise to a persistent or chronic pain state



informed clinical assessment is currently still the primary tool available to help interrogate the underlying pathophysiology processes creating and maintaining the pain. This will undoubtedly change as more sophisticated diagnostic modalities enter day-to-day clinical practice.

Background

Research in the field of chronic pain has revealed an increasingly complex underlying pathophysiology. The molecular details can be slightly overwhelming, but, in my opinion, the high-level insights from this work are crucial to making sense of the clinical presentation of patients with chronic pain. Figure 1 provides an overview:

At a high level, it is possible to group the areas where these new insights have been identified as follows:

- Peripheral (injury outside the central nervous system) pathophysiology;
- Central (spinal cord level) pathophysiology; and
- Brain (supraspinal level) pathophysiology.

Although this section will focus on the supraspinal aspects, it is important to note that a key newly identified factor underlying both the peripheral and central pathophysiology is the crucial

role of immune systems. I would recommend two articles^{1,2} that provide comprehensive and readable reviews of general and neuropathic pain, respectively. This pathophysiology is currently 'hidden from view', which means that despite the emerging investigative techniques,³ the presence of these complications can currently only be inferred from clinical assessment. This requires clinicians to understand the relevant pathophysiology, which is a key aim of the majority of this article.

While there is a definite overlap with immune system involvement in supraspinal elements of chronic pain,⁴ there are additional non-immune elements relating to the supraspinal pathophysiology that are particularly important to consider. In order to do that, I need to introduce the current definition of pain, which is as follows:⁵

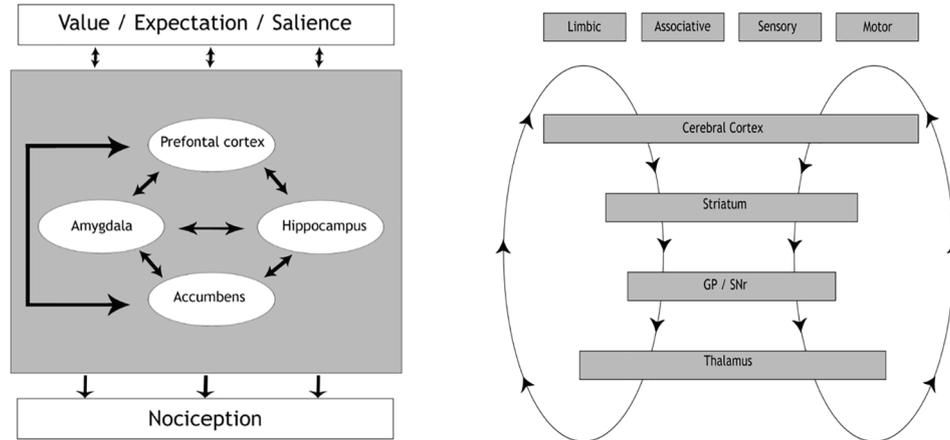
An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.

This definition implicitly includes issues of *perception*, *subjectivity* and *consciousness*. These concepts strike fear into the heart of most neuroscientists, meaning that such a definition is almost guaranteed to court controversy. However, in my view, neuroscience as a whole is aligning in understanding these concepts; there is a compelling shift towards viewing the brain as a self-organised hierarchical entity, best conceived as a 'prediction machine' that develops a model of the world grounded by action.⁶ The role of perception, subjectivity and consciousness is all accommodated within this framework.⁷

Furthermore, such concepts are aligning within factions of the pain field in what is likely to be considered a significant shift in our understanding of the aetiology of pain. To help bring this to life, Baliki and Apkarian make the critical distinction between *nocioceptive processing* and the *conscious experience of pain*.^{8,9} While this might appear esoteric, this distinction turns out to be critically important in making sense of pain.

First, pain has traditionally been conceived as being caused by the degree of nocioceptive input, so pain equating to nocioceptive processing implies pain is simply a 'read-out' in the brain of the amount of nocioceptive input an injury is inducing. However, as the definition of pain above implies, pain is *an experience*. This means that there is a process in the brain, requiring the involvement of many additional functions, that is turning nocioceptive input, or drive, into the conscious experience of pain. This helps to explain, for example, why it is that the threshold and magnitude of pain as a conscious

Figure 2. Brain circuitry and temporal dynamics which determine conversion of nociception to conscious pain perception



subjective experience are most commonly driven by nociceptive activity *but* can be readily modulated by mood and attention, monetary reward, simple changes in instructions and through expectations. This is because generating the conscious experience of pain requires interaction among memory, attentional and affective brain circuitry as well as in afferent sensory inputs. These are the supraspinal elements, which are illustrated in Figure 2.

This insight starts to provide an explanation for the daily clinical observation that pain experience is poorly correlated to the simple amount of nociceptive input both acutely and chronically and, in fact, can be centrally generated with normal nociceptive input.

Supraspinal elements and pain

In the pain literature, brain aspects tend to be referred to as supraspinal aspects of pain processing. There is now a vast amount of literature characterising distinctive patterns of brain activity in different aspects of pain, with clear differences between acute and chronic pain brain activity; as a result, this field is starting to mature.¹⁰ The conclusions set out by those authors provide a useful illustration:

This research can be briefly summarized regarding processes controlling these four stages: 1) Limbic-emotional circuitry define predispositions; 2) Emotional-learning mechanisms underlie and control the transitional stage (3), which is a consequence of the interaction between predispositions and injury-related nociceptive inputs to the nervous system. Moreover, maintenance or chronic pain (4) is a new brain state, with distinct anatomical and functional properties.

More details can be seen in Figure 3 (a short video link available in Apkarian¹¹ provides further commentary on the results within this graphic).

Baliki and Apkarian propose that to make sense of why *specific* patients develop chronic pain from exactly the same underlying level of nociceptive drive, four elements need to be considered:

The predisposition phase: In this phase, specific brain white matter regional properties (highlighted as red on the brain marked A in Figure 3) impart risk for developing chronic pain following an acute episode of back pain. It is also likely that limbic brain structural properties may impart risk for pain chronification (e.g. the shape and/or size of the hippocampus).

The nature of the injury or inciting event: The type of injury or inciting event is also relevant, as different structures drive different levels of nociceptive input, different injuries can result in either nociceptive or neuropathic pain or both, and the degree of associated soft tissue inflammation can vary. The presence or absence of peripheral and central sensitisation also influences the outcome.

The transition phase: The strength of information exchange between the prefrontal cortex and accumbens, after an end-organ injury, determines long-term pain chronification. The Baliki and Apkarian paper indicates that '*The transition process is the influence of predisposing brain factors in combination with the injury-induced nociceptive signals that control mesolimbic learning mechanisms, which together determine the extent of prefrontal-accumbens information exchange*'.

Post-traumatic pain: a neurological perspective

Figure 3. Transition to chronic pain may be deconstructed to four component phases: predisposition, injury or inciting event, a transition period and a maintenance phase

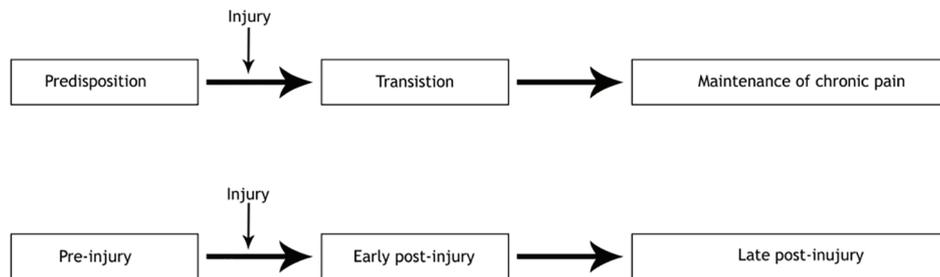
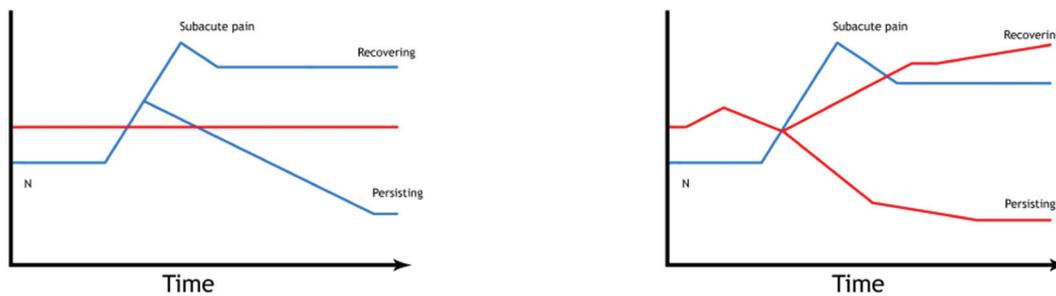


Figure 4. Transitioning from subacute to chronic pain. The left image depicts the classic viewpoint where nociceptive signal amplitude controls transition to chronic pain. The right image is the view advanced here: for a similar injury, with equivalent nociception relayed to the brain, individuals with corticolimbic risk factors will persist to chronic pain, whereas resilient ones will recover



Chronification phase: This gives rise to condition-specific subjective pain-related brain activity patterns, as well as increased information exchange within the hippocampus and between the hippocampus and the cortex, reorganisation of brain grey matter regional similarity and distortions in information sharing in resting-state brain activity; specifically, the brain activity phase relationship between the default mode network and the rest of the brain shows chronic pain type-specific patterns.

Figure 4 illustrates the importance of these insights; in cases where patients have suffered a similar injury, with equivalent nociception relayed to the brain, individuals with corticolimbic risk factors will persist to chronic pain, whereas resilient ones will recover. It is important to note that the time course of this transition process is only weeks to several months.

The neurological implications of these findings are significant, particularly in relation to the use of medication to manage

chronic pain. The evidence from studies using rodent models examined drug combinations for neuropathic and inflammatory pain, testing the concept of early combination, peripheral and central treatment as a strategy to prevent the transition to chronic pain. The findings suggested that a combination treatment, using dopamine and nonsteroidal anti-inflammatory drugs, was more effective in preventing chronic pain changes than either of these treatments used alone. They also hinted at the possibility of a new definition of chronic pain:

Rather than defining pain by its sensations, we propose a definition that emphasizes the neurobiological mechanisms that control behavioral adaptations, and we hypothesize that persistence of pain is likely mediated through the reorganization of the cortex by corticolimbic learning mechanisms. We therefore posit that chronic pain is a complex web of sensory and emotional experiences, coupled with behavioral adaptations. Specifically, we posit that the chronic pain state is a consequence of a change in

value related to nociceptive afferent information impinging on the cortex, with limbic emotional learning mechanisms underlying this shift in value and with little opportunity to extinguish these emotional memories.

Figure 5 helps to illustrate this further.¹²

These views are consistent with parallel areas of neuroscience,¹³ and in my view these new insights will make a significant difference to clinical practice relatively soon, as well as helping patients to understand more about the genesis of their pain and the factors that are maintaining it.¹⁴

The injury aspect: a neurological perspective

I will now move on to the non-supraspinal aspects. I want to begin by re-emphasising that there is a synergistic and invisible relationship between the immune system and the development of the changes that drive non-supraspinal aspects of chronic pain, which means that clinical assessment is the best way to interrogate the presence of these changes.¹⁵ It is also important to unpack the nomenclature of the peripheral aspects of chronic pain, which can be classified as *nociceptive* or *neuropathic*, depending on whether the integrity of the somatosensory nervous system is compromised by the underlying disease. There are neurological aspects to both, which I will explore below.

Neurological aspects of nociceptive pain

Nociceptive pain results from the activation of receptors (nociceptors) sensitive to noxious stimuli of some form, for example, chemical mediators released during inflammation. It is a period of extended or intense exposure to such stimuli that enhances the responsiveness of nociceptive nerve fibres. This process, termed *peripheral sensitisation*, involves ‘*a shift in the activation threshold of nociceptors and upregulation of voltage-gated sodium channels*’.¹⁶ This results in ‘*increased action potential firing and transmitter release in the dorsal horn of the spinal cord, where somatosensory information is processed*’.

The process of peripheral sensitisation most commonly results from inflammation-associated changes in the chemical environment of the nerve fibre. Tissue damage is often ‘*accompanied by the accumulation of endogenous factors released from activated nociceptors or non-neural cells that reside within or infiltrate into the injured area (including mast cells, basophils, platelets, macrophages, neutrophils, endothelial cells, keratinocytes, and fibroblasts)*’.¹⁶ These factors are collectively referred to as the ‘inflammatory soup’ (see Figure 1), and although its name may suggest otherwise, this is a very well characterised process.

In my view, perhaps the most striking condition that flows from initiating this mechanism is chronic regional pain syndrome (CRPS),¹⁷ and the propensity for aberrant activation to lead to maladaptive immune responses will be highlighted throughout this article.

Peripheral sensitisation generates widespread symptoms via *central sensitisation*. Central sensitisation occurs in the dorsal root horn of the spinal cord, which generates an exaggerated response to painful stimuli (hyperalgesia) and contributes to pain elicited by normally non-painful stimuli (allodynia). This ‘pain hypersensitivity’ produces structural changes in the brain over time, suggesting that process is relevant to a very broad spectrum of clinical conditions and particularly those associated with chronic pain.¹⁸

Neurological aspects of neuropathic pain

The pathophysiology of neuropathic pain is fundamentally different from nociceptive pain, although they can both result in central sensitisation. In neuropathic pain, a peripheral nerve lesion evokes stimulus-independent (ectopic) activity in nerve fibres. This results in innate immune cells reacting at the lesion site in the *dorsal root ganglion*, where the cell bodies of peripheral somatosensory neurons reside, and in the dorsal horn of the spinal cord. The active microglia of the *dorsal horn* then releases chemical mediators to modulate the activity of neurons in the vicinity, and the evidence in the literature suggests that ‘*One of these mediators, brain-derived neurotrophic factor, reduces the inhibitory effect of γ -aminobutyric acid (GABA) and glycine. Disinhibition opens polysynaptic connections in the dorsal horn, further enhancing the abnormal input from the lesioned nerve*’.¹⁸

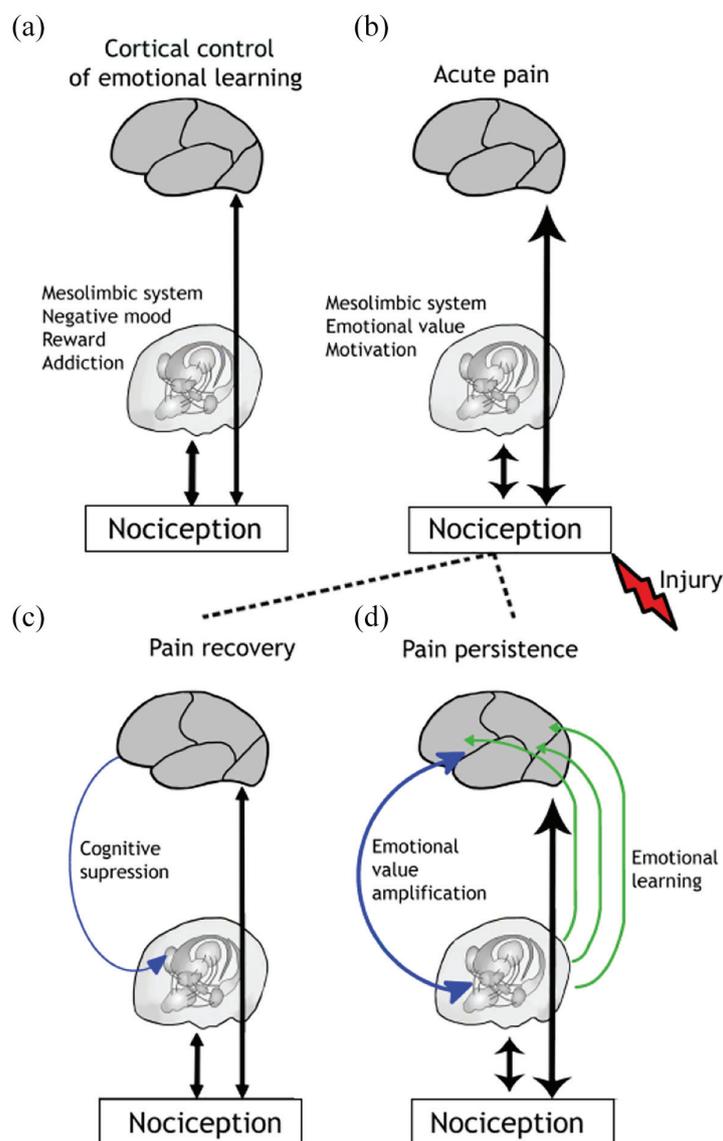
As indicated above, it is possible for this process to result in central sensitisation. The literature describes how

Worsened by a relative deficit in transmitter uptake, increased glutamatergic transmission causes excitotoxic cell death, reducing the number of inhibitory interneurons. Their loss and a shift in descending modulatory pathways from the brainstem produce a profound imbalance between inhibition and excitation.

Peripheral and central sensitisation and the clinical pain phenotype

The findings of the accumulated research in this area¹⁶ suggest that ‘*Any sensory experience greater in amplitude, duration and spatial extent than that would be expected from a defined peripheral input under normal circumstances, qualifies as potentially reflecting a central amplification due to increased excitation or reduced inhibition*’. There are a number of

Figure 5. Chronic pain depends on the corticolimbic properties interacting with nociceptive inputs. (a) In healthy individuals, afferent signals from the periphery are constantly relayed to the mesolimbic system and the cortex but are rarely brought to awareness because of corticolimbic gating processes. Nociceptive signals unconsciously provide learning and behaviour-modifying signals to the limbic cortex but only occasionally evoke conscious perception of pain at the cortex. (b) Following an injury that gives rise to a large and persistent increase in nociceptive barrage, the properties of the corticolimbic circuitry dictate long-term outcome. (c) Reverberating corticolimbic circuitry can, through interindividual differences in cognitive abilities or anatomical/functional network properties, suppress limbic activity and facilitate recovery from suffering with pain and the diminution of symptom severity coupled with tissue healing. (d) Alternatively, a heightened emotional valuation response, driven by predispositions of the corticolimbic anatomical/functional properties, would lead to reorganisation of the gating circuitry, which provides a learning signal that in time carves a cortical chronic pain profile. The dynamics of corticolimbic reverberating loops depend both on the pre-existing limbic brain circuitry and on the reorganisation following the inciting event, and these interactions will determine the likelihood of either recovering from or transitioning to chronic pain



changes that could result in a central amplification or reduced inhibition, including a reduction in threshold, spread of sensitivity to normal tissue, an exaggerated response to noxious stimuli or pain that continues after a stimulus has been withdrawn. From a clinical perspective, this means that patients who present with ‘*dynamic tactile allodynia, secondary punctuate/pressure hyperalgesia, temporal summation and sensory after-effects*’ may be experiencing central sensitisation. As a result, clinical assessment of patients presenting with chronic pain must include assessment of the following:

- A spread of pain sensitivity to areas with no demonstrable pathology;
- After-sensations;
- Pain that enhances temporal summation; and
- The maintenance of pain by low-frequency stimuli (e.g. touch) that normally do not evoke any ongoing pain.

To support the clinical assessment of patients with chronic pain, it is important that clinicians are aware of these elements and have a framework to enable their assessment of the key clinical features for chronic pain generically and by specific injury type. The following sections, which focus on specific neurological conditions that are often associated with the presence of chronic pain, aim to provide the starting point for such a framework.

Peripheral nerve trauma

In this section, I will focus on trauma-related peripheral nerve injury. I have explicitly chosen not to comment on iatrogenic peripheral nerve injury¹⁹ and complications of peripheral nerve injury in the setting of limb amputation, as these are special cases and dealt with elsewhere.²⁰

Traumatic peripheral nerve injuries exist on a spectrum, the effects of which range from mild discomfort to lifelong impairment. The mildest form of injury is called *neurapraxia* and is secondary to focal demyelination without damage to the axons or the connective tissues. Typically occurring from mild compression or traction of the nerve, neurapraxia results in a decrease in conduction velocity. Depending on the severity of the demyelination, it is also possible for patients to experience a range of effects, spanning from asynchronous conduction to conduction block, which is responsible for causing muscle weakness.

The next level is called *axonotmesis*, which involves direct damage to the axons in addition to focal demyelination. Patients are more likely to experience a good outcome in the presence of ‘*an intact endoneurial tube without any damage to the surrounding connective tissue, distal the injury to the*

neuron as proximal lesions, close to the neuronal cell bodies, often trigger programmed neuronal cell death’.²¹

In my experience, diagnosis in cases of traumatic peripheral nerve injury is not usually controversial, as the clinical pattern of the injuries is so stereotypical and the traumatic cause of the injury is so proximate. Unfortunately, more severe injuries typically result in chronic neuropathic pain; not only is this difficult to treat but it can also cause a considerable decline in a patient’s quality of life.

However, there are several more controversial issues associated with peripheral nerve trauma. The first is in the case of a ‘double-crush’ injury (i.e. where one peripheral nerve pathway suffers two minor injuries), as there is an increased susceptibility of a nerve to develop a compressive neuropathy when a proximal compressive lesion of the same nerve is found. For example, a patient with a proximal neck injury may generate central sensitisation, which can result in a pre-existing asymptomatic nerve compression becoming symptomatic. The concern about overuse of this term has also been extensively reviewed.²²

The other controversial clinical scenarios are in the development of CRPS and peripherally induced movement disorders, which are frequently associated with chronic pain. In both scenarios, careful studies have established the veracity of these entities,^{23,24} their peripheral aetiology²⁵ and the possible role of maladaptive immune activation.²⁶

Plexopathy

Both lumbosacral and brachial traumatic plexopathies are well recognised in the clinical literature,^{27,28} which reveals a wide spectrum of injury is possible. In my experience, diagnostic formulation can be more controversial than in the case of peripheral nerve injury, especially when the clinical pattern is dominated by pain and widespread sensory disturbance. This is particularly the case given the diagnostic limitations of imaging and neurophysiological investigation in these particular groups.

Brachial plexopathy

Trauma is one of the most common causes of brachial plexopathy, with these injuries most likely to result from a motorcycle accident or a high-speed motor vehicle accident, fall from a significant height secondary to traction or from a direct blow. Upper plexus injuries are commonly seen if the arm is at the side at the time of the inciting event, with lower plexus lesions identified in cases where the arm is abducted and raised overhead violently.

The evidence suggests that ‘*pre-ganglionic site of injury is usually associated with nerve root avulsion, with rootlets torn*

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from the spinal cord, and thus carries a poor prognosis', and this has certainly been my experience in clinical practice. Along with motor and sensory deficit at the shoulder and/or upper limb, the presence of signs of Horner's syndrome suggests complete lower trunk plexopathy as the sympathetic ganglion for T1 is in close proximity to the brachial plexus.

Controversy typically arises in relation to the clinical syndrome of irritation of the brachial plexus, even though it has been well characterised²⁹ in the literature, which describes the following:

- Persistent diffuse pain or paraesthesia in the upper arm, aggravated by carrying, lifting, overhead elevation or repetitive use of the arm;
- A positive Tinel's sign; and
- Reproduction of pain or paraesthesia by manoeuvres stressing the brachial plexus with the shoulder at 90° of abduction in external rotation or with a traction manoeuvre.

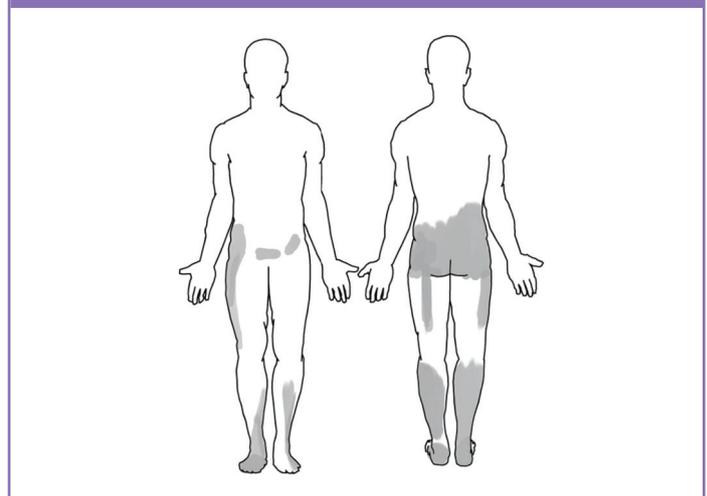
The mechanism of injury in these cases is most likely to be flexion and extension of an outstretched arm as part of a whiplash injury. The mean date of onset of this syndrome has been identified as day 6 after injury, with a range from 0 to 36 days.

As I have outlined above, neurophysiological investigation usually results in findings that are described as normal, 'indicating that nerve-conduction studies relate to events in the largest myelinated fibres and not to changes in the behaviour of non-myelinated fibres'. It is also the case that magnetic resonance imaging (MRI) is typically normal despite 'intraoperative findings of scarring in and around the brachial plexus in patients with a stretch-type lesion after a whiplash injury'.²⁹ It should be noted that the presence of this syndrome is frequently associated with the development of CRPS, with a significant proportion of patients developing chronic pain as a result.

Lumbar sacral plexopathy

Lumbosacral plexus (LSP) injuries are considered rare events and are typically associated with a high-energy accident and lumbosacral fractures. Although these are serious injuries, they are usually managed conservatively as spontaneous recovery is typical, surgery is complex and improved outcome is not necessarily a given. In my clinical experience, neurological assessment typically takes place at a later time point and can be contentious in the context of lumbar or sacral fractures, as the clinical picture is dominated by pain and sensory disturbance. As neurological involvement is often delayed until after the transition period to chronic pain and delineating the nature of the ongoing injury can be controversial, it is important to appreciate the following elements:

Figure 6.



- Neurological deficits and pain following high-energy displaced lumbar or sacral fractures are common;
- The pattern of chronic pain is surprisingly diffuse, covering most of the lower back as illustrated in Figure 6;
- Neurological recovery after displaced lumbosacral fractures is poor and can be considered permanent if neurological symptoms remain 1 year after injury;
- Bladder dysfunction is common, often subclinical, can be of delayed onset and in many cases also deteriorates over time;
- Disturbances in sexual function are frequent and their causality is multifactorial;
- There is a close association between pain and poor self-reported health, indicating the importance of pain management in these cases;
- A considerable number of patients cannot return to work after displaced sacral fractures; and
- Despite high rates of impairments, the majority of patients are independent in their activities of daily living and ambulation.

These syndromes require careful assessment, with appreciation of the complex temporal dynamics of the symptoms, their propensity to evolve through time and the limitation of existing diagnostics.

Traumatic radiculopathy: lumbar/sacral-cervical. In my experience, isolated traumatic radiculopathy is relatively uncommon. However, when present and with symptoms that do not settle, diagnosis can be controversial, especially

if the dominant clinical symptoms are pain and sensory disturbance. The pathophysiology of radiculopathy is surprisingly complex,³⁰ so it is important to understand accurately in order to create an accurate diagnostic formulation. In addition, occasionally traumatic radiculopathy is associated with a dramatic and seemingly inexplicable syndrome such as CRPS and spinal segmental myoclonus (SSM); again, understanding the relevant pathophysiology is helpful in unpicking these cases.

The terms radicular pain and radiculopathy are sometimes used interchangeably, although they are not synonymous: with radicular pain, only radiating pain is present, whereas with radiculopathy, in addition to pain sensory and/or motor loss can also be objectified. Both syndromes frequently occur together and radiculopathy can be a continuum of radicular pain.

Patients with radiculopathy typically present with a chief complaint of pain, which they may experience as sharp, dull, piercing, throbbing or burning. Although the distribution of pain along a dermatome can determine the affected levels of dorsal roots, the *variation in radiation pattern is large* across all vertebral levels. The dermatome with the best match between the distribution of pain and the vertebral level is the S1 dermatome. If present, the dermatomal distribution of paraesthesia is more specific to the injured nerve root than the pain. Radiculopathy is often associated with central sensitisation, which is more likely when the aetiology is traumatic, and this can significantly amplify the pain and sensory disturbance present.

Weakness is far less common following a radiculopathy than either pain or sensory disturbance. If present, motor dysfunction typically recovers gradually within 1 or 2 weeks of the inciting event, whereas pain behaviours are more likely to persist for at least 6 weeks to 3 months. Although motor weakness is seldom observed during the acute or subacute post-injury period, patients with low back pain and sciatica report fear of movement and substantial decreases in activity level.

For the clinical assessment of radiculopathy to be informed by the pathophysiology, it is necessary to consider the role of the *spinal nerve roots and dorsal root ganglions* in the development of this condition. Because the dorsal root ganglion is more sensitive to mechanical compression, and associated ischaemic changes, than nerve roots, it is considered a key player in radiculopathy. Chemical injury can also result in radiculopathy.

Although mechanical and chemical injury do not differ in terms of pain behaviours or histopathological changes, it is helpful to understand both of the mechanisms in further detail

as these mechanisms interact over time, especially after trauma.

In *mechanical injury*, also referred to as *compression injury*, increased intraneural pressure results in reduced intraradicular blood flow, which in turn leads to intramural oedema. This process drives electrophysiological changes of dorsal root ganglion neurons, reducing mechanical and thermal withdrawal thresholds. In addition, compression of the periradicular venous plexus can exacerbate ischaemia, further damaging the dorsal root ganglion and the dorsal nerve root, primary afferent fibres causing spontaneous pain and hyperalgesia. There is also the potential in compression injury that *'the presence of periradicular fibrosis will compound the nerve root pain by fixing the nerve in one position, thereby increasing the susceptibility of the nerve root to tension or compression'*. This means trauma can be even more impactful in the presence of pre-existing degenerative disease.

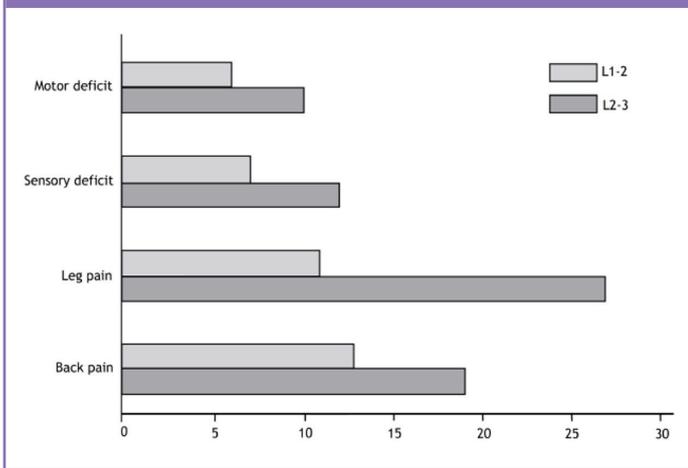
Crucially, although some intimate contact between the herniated disc material and the nerve root is required, at some point in time, the degree of pain that is experienced by a patient is not necessarily related to the size of the disc herniation seen on MRI or the amount of thecal sac deformation. In order to make sense of this, it is typical to assume that an element of the inflammatory cascade from local inflammation or disc products is responsible via chemical injury.

In *chemical injury*, the application of autologous nucleus pulposus induces electrophysiological changes and similarly enhances dorsal root ganglion neuron excitability, as well as reduces mechanical and thermal withdrawal thresholds and nerve blood flow and causes *'histological changes such as axonal degeneration, intramural edema, and Schwann cell edema in the nerve root and DRG'*. Indeed, research has indicated that *'upon systemic exposure, the NP component of intervertebral disc tissue initiates a specific immune response, likely a consequence of its immune privileged avascular location bounded by the annulus fibrosus'*.

It is clear, therefore, that a clinical assessment for radiculopathy needs to include a timeline of the first 3 months following the inciting event. This should take into consideration any pre-existing pathology, whether the patient experienced motor dysfunction acutely which settled and whether these factors have spread during that time beyond the initial distribution, with clinical features consistent with central sensitisation. Mapping the pattern of any sensory disturbance and pain (with appropriate map distributions in mind) would also be necessary.

In my clinical practice, disputes over diagnostic formulation in cases with a possible traumatic upper lumbar radiculopathy have

Figure 7.



been a recurring theme; this has been a particular feature where I have been asked to assess a patient months or years after the inciting event, and it is necessary to review contemporaneous clinical records or investigations undertaken by other clinicians in order to inform my present-day diagnosis. More importantly, the functional impact of the symptoms associated with this type of injury means that it is essential to unpick the patterns that are typically associated with this presentation.

Clinical features in an upper lumbar radiculopathy

Figure 7 represents the expected findings on neurological assessment of a patient with an upper lumbar radiculopathy (L1-2, L2-3).

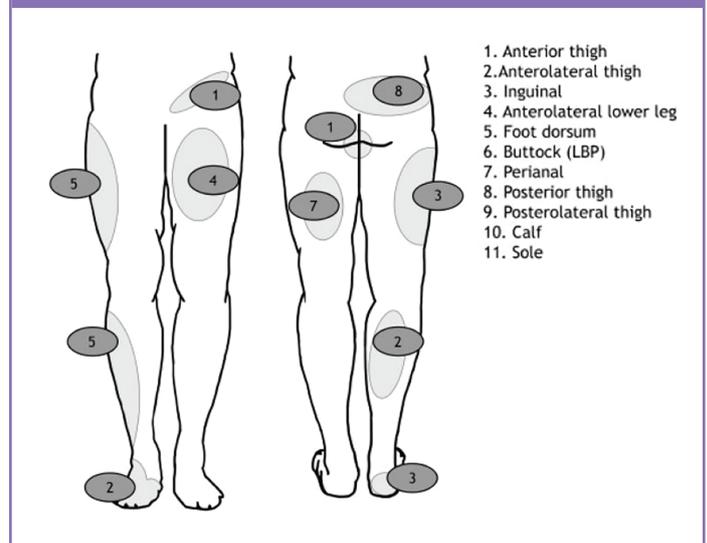
The key points to note are that motor deficits are less common features of this radiculopathy. However, sensory disturbance, leg pain and back pain are all common features.

Figure 8 also shows the typical distribution of pain in patients with upper lumbar radiculopathy, which is surprisingly widespread:

My clinical experience suggests that lesions in the L2 region are differentially painful and disabling for patients. It is likely that this is because the ‘*main afferent fibres of the low back pain pathway and part of those of the radicular pain pathway are thought to involve the L2 spinal nerve root, presumably via sympathetic afferents*’,³¹ which make them a critical pain hub in this region.

As outlined above in this article, peripheral nerve injury has been associated with the development of CRPS, and the same can also be said of radicular injury. This is more likely to occur in the setting of a traumatic injury.^{32,33} In addition, traumatic

Figure 8.



radicular injury can also be the trigger for segmental myoclonus,³⁴ which is usually painful.

Spinal cord injury

With respect to local spinal cord injury, I refer to the first systematic review and meta-analysis³⁵ to consider the prevalence of neuropathic pain after spinal cord injury. Rates of neuropathic pain in total were found to be high, at 50%. At the level of the injury, the prevalence was 19% and the below-level was 27%. Neuropathic pain appears to be more prevalent 6 months after injury when compared with acute spinal cord injury. Evidence also suggests that at-level neuropathic pain develops more commonly in the acute stage after spinal cord injury, with below-level neuropathic pain beginning to increase after 1 year. Neuropathic pain was found to present more frequently in participants with tetraplegia and older patients, which suggests that clinically these populations should be prioritised when screening for neuropathic pain following spinal cord injury.

Potential mechanisms for neuropathic pain development after spinal cord injury

The systematic review posited that *peripheral mechanisms* suggest that at the site of spinal cord trauma, the surrounding nerve cells can exhibit inflammatory and neurochemical changes. This, in turn, leads to augmented responsiveness to peripheral stimulation or neuronal hyperexcitability, which may give rise to at-level neuropathic pain. This is supported by the findings in the review that demonstrated that at-level neuropathic pain was more common in acute spinal cord injury.

In addition to neuronal hyperexcitability, activation of residual spinothalamic pathways by inflamed damaged axons in the tract may cause below-level neuropathic pain. This process has a longer time of onset, which is likely to explain why below-level neuropathic pain develops later within the first year after injury; again, this is supported by the findings of this review.

SSM

SSM³⁶ originates from one or a few adjacent segments of the spinal cord. Research in this area has identified that pain is likely to arise from a loss of inhibition of spinal interneurons, leading to hyperexcitation of anterior horn cells. SSM is typically rhythmic or semi-rhythmic, approximately 1–2 Hz in frequency, usually stimulus-insensitive and involves one or, less commonly, two limbs or truncal/abdominal muscles. While there is no systematic study in the literature on the frequency of SSM among different spinal segments or myotomes, the literature in this area suggests that there is likely to be a correlation with the anatomical location of the lesion, or lesions, within the spinal cord.

It is also the case that differentiating SSM from myoclonus originating from the periphery (nerve roots, plexus or peripheral nerves) can be challenging. One important distinction is that in peripherally generated myoclonus, the distribution of muscles involved corresponds to the nerve roots, plexus or peripheral nerves, whereas SSM typically involves multiple muscles innervated by one to three adjacent spinal levels and can be bilateral. In this setting, contrast-enhanced MRI spinal imaging is essential. Symptomatic treatments include clonazepam, valproic acid and levetiracetam.

Traumatic orofacial pain

I commonly encounter orofacial pain in my head injury practice. This presentation is well characterised.³⁷ In common with other peripheral nerve trauma, complications arising from facial fracture are usually uncontroversial; as these injuries typically generate sensory deficits, it is accepted that they can also generate chronic pain.

My experience in clinical practice suggests that a more challenging condition is myofascial (MMP) temporomandibular joint (TMJ) dysfunction, which is a musculoskeletal disorder affecting the jaw muscles, the TMJ and/or associated structures. It is the most common cause for chronic pain in the orofacial region.

The cases that I have been involved in have typically been triggered by whiplash, with the pain starting shortly after the whiplash trauma and persisting at follow-up. Although it can be associated with neck pain, at the baseline assessment some patients do not report neck pain but do report pain in the orofacial region. This condition is characterised primarily

by regional, unilateral pain – which is typically present around the ear, the angle or body of the mandible, and the temporal region – and tenderness from the jaw-closing muscles. It often results in masticatory dysfunction. The pain is described as being dull, heavy or aching and may fluctuate during the day.

Reaching a diagnosis of MMP is based on the history and clinical examination of the patient, and evidence in this area suggests that referral patterns '*include intraoral, auriculotemporal, supraorbital, and maxillary areas disorders*'. Although MMP is typically a unilateral pain syndrome, it may also occur bilaterally, particularly when associated with generalised disorders such as fibromyalgia. MMP is mostly chronic and unremitting.

In addition to experiencing pain, patients may report fullness of the ear, dizziness and soreness of the neck. Dizziness has been associated with pain in the sternocleidomastoid muscle and ear stuffiness with spasm of the medial pterygoid. Examination usually reveals limited mouth opening (<40 mm between front teeth) and deviation of the mandible on opening.

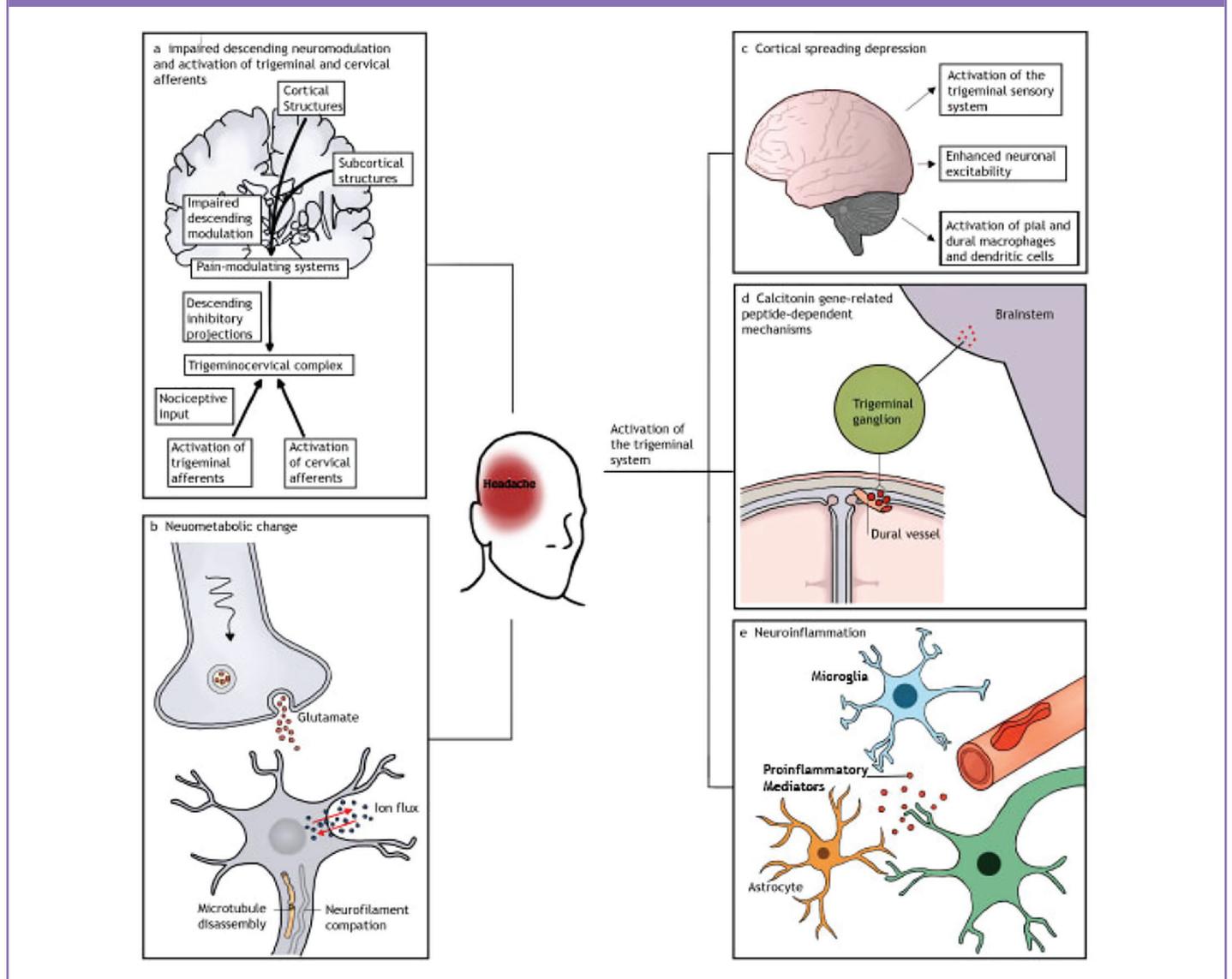
Localised tender sites and trigger points are distinguishing features of MMP patients. The research in this area suggests that the '*masseter muscle is most commonly involved (>60%), and the medial pterygoid and temporalis muscles are tender in about 40–50% of cases, commonly unilaterally*'. There is also evidence that the '*sternocleidomastoid, trapezius, and suboccipital muscles are usually tender in 30–45% of patients, very often bilaterally*'. As I have indicated above, there is often a contribution of systemic co-morbidities such as fibromyalgia, hypothyroidism or connective tissue disease.

Treatment is difficult as it requires specialist maxillofacial input. However, the primary clinical difficulty I have encountered is recognition of the condition because of the controversy surrounding chronic pain after whiplash, which can delay getting appropriate specialist input and treatment. It is interesting to note that similar myofascial changes are now being detected in deep neck muscles in patients with chronic neck pain following whiplash injuries.³⁸

Post-traumatic headache

Post-traumatic headache (PTH) is a common symptom, which can be defined as onset of headache within 7 days following trauma to the head. If the headache persists beyond 3 months of onset, it is characterised as persistent PTH. The research in this area indicates that 30% of mild traumatic brain injury (TBI) patients continued to complain of headache at 3 months post-trauma. It has become also folklore that PTH was much more

Figure 9.



common following mild TBI as opposed to moderate or severe TBI, but a large prospective study of TBI revealed that PTH had a similar incidence across every TBI severity.³⁹

Although there is a wide spectrum of potential mechanisms, these can most easily be simplified by differentiating between PTH in head injury cases without brain injury and PTH in head injury cases with brain injury.

In patients who have sustained a head injury without evidence of an associated brain injury, the mechanisms include those detailed below, in Figure 9.

The figure suggests that the most plausible mechanisms in these circumstances are the following:

- *Activation of extracranial dural afferents:* concussion could trigger sensory activation of extracranial nerves and meningeal sensory fibres, which in turn convey information through the trigeminal nerve to deep brain structures;
- *Nociceptive drive from cervical afferents:* a nociceptive drive from upper cervical afferents, as most concussions involve a rotational injury.

In the setting of head injury with associated TBI, the above mechanisms can be present. However, there is now strong evidence for additional brain injury associated mechanisms, with the latest research suggesting that these include the following:⁴⁰

- Impaired descending modulation;
- Central trigeminal sensory system activation;
- Cortical spreading depression;
- Neuroinflammation; and
- Calcitonin gene-related peptide-dependent mechanisms.

The prognosis for patients varies in relation to the presence or absence of an associated TBI, with research suggesting that the prognosis is good in cases without an associated brain injury and far less favourable for patients who have both head injury and brain injury. It is worth noting, however, that there are emerging treatment options⁴¹ that may result in patients with head injury and brain injury experiencing a significant reduction in what are typically disabling symptoms.

Consequently, the focus on treatments is increasing. Botox therapy can be very useful in patients who fail first-line treatment, and there is now interest in the potential application of calcitonin gene-related peptide monoclonal antibody treatments for migraine.⁴² Both Botox and monoclonal antibody treatments require specialist input, but are worthy of consideration.

TBI and pain

The section of this article describing the supraspinal elements of pain makes it clear that brain function is crucial to generating chronic pain. In addition, it is clear from the studies of PTH following TBI that brain injury can lead to pain syndromes. Therefore, it seems logical to assume that TBI could cause pain beyond PTH.

One topic that occurs frequently in such cases is the issue of whether chronic pain from outside of the brain causes the symptoms that are typically present following a TBI. It is now clear, from a large, well-designed prospective study of this issue,⁴³ that TBI generates specific functionally significant TBI-related symptoms. However, it remains critical to recognise that TBI and peripheral injury, if present together, are synergistic.⁴⁴ In addition, in patients with TBI, the transition to chronic pain involves brain structures that can cause depression and anxiety, as well as cognitive slowing that is similar to that seen in TBI. Unpicking this complexity requires a careful dissection of the pattern of symptom development.

When considering the potential of TBI to generate pain beyond PTH, it is important to appreciate that there are different TBI subtypes. A good example of this is the difference between *head injury from acceleration/deceleration injury* and *blast injury*. The evidence suggests that blast injuries may have different and progressive underlying mechanisms,⁴⁵ which may be crucial in determining their propensity to generate or magnify pain syndromes.⁴⁶

A 2008 systematic review focused on the prevalence of chronic pain after TBI⁴⁷ concluded,

Chronic pain is a common complication of TBI. It is independent of psychologic disorders such as PTSD and depression and is common even among patients with apparently minor injuries to the brain.

This provides strong support for the notion that TBI independently contributes to chronic pain. Furthermore, in a study of central pain following TBI, the authors confirmed the presence of central pain and determined the presence of certain characteristics:

- At a relatively late onset (6–9 months after the inciting event);
- Almost exclusively unilateral;
- Reported as pricking, throbbing and burning in nature; and
- Painful regions also exhibited very high rates of allodynia, hyperpathia and exaggerated wind-up.

The characteristics of the chronic pain described in this study resembled those of other central pain patients, although patients who had suffered a TBI displayed several unique features. The authors identified that the '*sensory profile indicated that damage to the pain and temperature systems is a necessary but not sufficient condition for the development of chronic central pain following TBI*'. The finding also suggested that neuronal hyperexcitability may be a contributing factor to the chronic pain.

With respect to the contribution of TBI to pain in a large military cohort, Song et al.⁴⁸ in their study 'Five-year pain intensity and treatment trajectories of post-9/11 Veterans with mild traumatic brain injury' found that five pain phenotypes emerged:

1. Simple low-impact stable pain;
2. Complex low-impact stable pain;
3. Complex low-impact worsening pain;
4. Complex moderate-impact worsening pain; and
5. Complex high-impact stable pain.

The study also uncovered clear differences in pain treatment between those with and without mild TBI, suggesting that

Post-traumatic pain: a neurological perspective

tailored chronic pain interventions were necessary for those veterans who had sustained a mild TBI.

Finally, I note two case reports of patients developing CRPS after brain injuries that help bring the pathophysiology of these conditions to light.⁴⁹

Case 1: A 54-year-old male suffered from *direct head trauma*. At approximately 2 months after the accident, he began to feel pain (burning sensation) and swelling of the dorsum of the right hand and wrist. On 2-month diffusion tensor tractography, partial tearing of the corticospinal tract (CST) was observed at the subcortical white matter in both hemispheres (much more severe in the left CST).

Case 2: CRPS-1 in a non-hemiplegic upper limb after an ischaemic stroke. Diffusion tensor tractography showed markedly decreased fibre numbers of CST and spinothalamic tract (STT) not only in the affected hemisphere but also in the unaffected left hemisphere.

Conclusion

It is evident from my own clinical practice that having a thorough understanding of the neurological aspects of pain, and the underlying pathophysiology, is crucial. Not only is the presence of chronic pain following traumatic injury common, as a disabling symptom that also has the potential for inciting controversy during the process of diagnostic formulation, it is particularly challenging for patients. Reaching the correct diagnosis and exploring the potential treatment options arising from that can make a significant difference to the day-to-day lives of patients with chronic pain.

As this article has demonstrated, the associated research is extensive, and the factors associated with the aetiology of chronic pain in relation to the neurological conditions I have outlined are complex, dynamic and – to a large extent – invisible. However, in my view, the research has reached a tipping point that means it is no longer possible to ignore the conclusions; the role of these findings in changing the current paradigm of clinical diagnostic formulation in this field of medicine cannot be underestimated.

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The end of pain medicine as a professional specialty? A response to NICE and its managerialist attitude

Michael Platt

In 2005 I wrote an MA in Bioethics on 'Managerialism vs Professionalism in Modern Healthcare'. The conclusion of this suggested that Managerialism is focussed on cost containment, patient throughput and patient safety, with no consideration of patient care or suffering. Managerialism evolved from the management of armed forces and thence, with the industrial revolution, the need to manage complex processes, and now since the 1990s and Margaret Thatcher, has evolved to manage everything in our society (New Managerialism). This shines through in these National Institute for Health and Care Excellence (NICE) guidelines for chronic pain, which are focussed on cost containment at the cost of patient suffering and care. Professional clinicians profess a 'vocation' or calling, in this case to care for those who are unwell and suffering due to chronic pain, in the best way they know how. These guidelines have had no input from currently practising Pain physicians, all of whom are aghast at their implications, and which appear to be utterly non-patient focussed, and prevent consultants from actively treating their patients with medications and procedures that we know work, despite the lack of outcome studies, often because NICE looks at specific data about specific treatments in isolation from other simultaneous treatment techniques. When professionals are doing their utmost to help those with pain and suffering, using drugs and interventions in a multi-disciplinary setting, with physiotherapy, psychology and often occupational therapy, to be told that they can no longer do these things to help their suffering patients, when clearly patients are maintaining their lives and feeling better, it is truly a blow to the core of their values and a personal affront to many who have been working successfully in the specialty for many years.

The problem with research in chronic pain is that chronic pain is often associated with complex syndromes, which means that there are few models that are simple enough to measure pain and what helps relieve it in different conditions. Two simple examples are facet joint injections and acupuncture. NICE have severely limited the use of injection of spinal facet joints for chronic back pain, as well as acupuncture, saying they don't actually work. However, the

majority of pain clinics are multi-disciplinary, and use such techniques to relieve pain for long enough to enable exercise and physiotherapy, which are actually what makes the pain better, by strengthening core muscles and removing the stress on the lower back and other muscles. We know this works as it is often used to treat athletes, who exercise to maintain fitness. However, NICE, who simply looked at published data which just examines the effects of the procedures themselves, ignored the multi-disciplinary nature of most pain treatment and decided it is not cost-effective to do. This probably reflects the increasing reductionism in medicine – looking always for the single magic bullet that will cure pain and suffering, when we know the body is far more complex.

Even more troubling is the care of those with pain and suffering caused by more complex syndromes such as Ehlers-Danlos syndrome, a disease that covers a wide spectrum of issues due to genetic defects centred around collagen. At one extreme is the simple hypermobility (EDS Type III), where the individual has hypermobile joints that may cause no problem, apart from occasional dislocation, which can be very distressing. At the other extreme, there are those with autonomic dysfunction causing heart rate irregularities (PoTS – postural tachycardia syndrome); gut paresis with slow gut transit times; Marfanoid-type arterial aneurysms, due to collagen weakness; hoarseness and difficulty swallowing due to laryngeal weakness and defects; in addition to debilitating fibromyalgia and poly-arthritis pain. The sheer multitude of different problems elicited in such syndromes can make dealing with pain and suffering in these individuals even more challenging, because they will not respond to simple remedies or interventions. These patients often need regular lidocaine infusions, facet joint injections and other interventions including neuromodulation, combined with physiotherapy and occupational therapy just to maintain their general functionality. Apparently, NICE are going to prevent us doing many of these interventions 'because they don't work', despite the fact that we use these techniques in order to keep patients out of hospital and to maintain their normal lives, bringing up their children and maintaining professional jobs.



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The end of pain medicine as a professional specialty? A response to NICE and its managerialist attitude

Another reason as to the lack of good data, thus far, is the sheer genetic variation in the community. A human being is made up of a highly complex nerve anatomy, with some 85–100 billion nerve cells. Each nerve communicates with up to 500 other nerves using complex neuro-chemical transmitters, of which there are over 450 different ones. These are released in specialised ‘synapses’, or nerve junctions, triggering the next nerve either positively (causing further transmission along that nerve) or negatively (inhibiting it). Different patients have different genetic constructs of their nervous systems. For example, if two patients have identical pain in a finger due to nerve damage, Patient A responds well to drug A, but Patient B has no positive response. If the drug is pregabalin, a calcium channel inhibitor in the GABA system of the central nervous system, it means that his particular pain pathways involve this system, but not patient B, who will need a drug affecting a different mechanism such as a nor-adrenaline re-uptake inhibitor. It is not possible currently to predict which patient will respond to which drug as epigenetics is still developing, so it may be that several different drugs with different mechanisms of action on pain nerve transmission will need to be tried in different patients. Randomised controlled trials can get around this genetic variability, when studying the effects of different treatments on patients, but study sizes would need to be vast to cater for all the genetic variations possible, as well as catering for the population variability in different parts of the world and individual countries. In any case, one cannot know which drug a particular patient will respond to, without knowing their physiological make-up.

There is still much that we do not know about the human body. The endo-cannabinoid system is a case in point. We are lacking some one hundred years of research in this area, but those of us who are working in it are astounded at its involvement in most systems of the body. It is intimately involved in homeostasis, affecting sleep, mood, appetite,

digestion, blood cells, central nervous system function and pain. It appears to significantly affect many of the difficult syndromes we seek to treat, including Ehlers–Danlos, and there is much research currently ongoing which is starting to demonstrate its effects and thence the effects of cannabis medicines on the body and on pain in particular. However, NICE have again been remarkably conservative in their response and will once again be seen to be lagging behind world trends.

NICE also appear to be returning to pre-Cartesian times, separating brain and mind from body, when we know that the brain is intimately involved in bodily pain, involving the mind, regardless of the source of the pain. The pain pathways are closely allied to the emotional centre of the brain in the limbic system, enabling torturers to do their work. To artificially separate chronic primary pain (involving emotional distress) from other pain is completely arbitrary and ignores the fundamentals of how the nervous system is set up, and also the sheer complexity of the nervous system. To attempt to prevent the use of medications we know are very useful for patients with different types of pain, all of whom respond in different ways reflecting their genetic diversity and different ways the nervous system is set up, is adding insult to injury and allowing patient suffering to progress unchecked.

I very much despair for the future of Pain Medicine in this country thanks to these ill-considered NICE guidelines, and fear that we are seeing the end of a very necessary and needed specialty, mainly thanks to those who have no understanding of the complexity of chronic pain and who appear to have no concept of the ethos of medicine and the ethics of caring for those who suffer. This also significantly impacts on those of us who seek always to do the best for our patients, but seem to be prevented from doing so due to out-dated managerial ethics that ignore patient suffering and the need to care for them properly.

The NICE guideline on chronic pain – the NICE guideline we didn't need but which is OK

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When I was invited by the Editor to comment on the latest NICE draft guideline (GID-NG10069), I decided to study the decision-making process involved and not just the outcome. The proposed guideline has prompted a lot of consternation among us pain clinicians. Early discussions around it made me question if the critics had looked at the problem from all angles.

I felt it was worthwhile reviewing the whole guideline-making process from inception through various stages until the draft went out to consultation in August 2020. I wanted to see if I could pinpoint any bias somewhere along the line that led to an outcome that is not acceptable to the pain community: choice of topic and scope outline, search strategy, evidence accumulation policy, rigour of review, interpretation of results and conclusions. Was the literature search done in accordance with the remit? Did they ensure the committee could be provided with sufficient data? How transparent is the process in general? How clearly was the outcome of the review and recommendations communicated? I reckoned I could draw many conclusions by simply tracking the process from the beginning, without re-reviewing all the material and judging from the outcome where there are issues that raise concern – for example, if similar reviews have come up with contrasting conclusions. There are several contemporaneous systematic reviews that in the past have performed similar reviews and which afford a convenient material for comparison. The Cochrane PaPaS Review Group has already made public their critique of the current draft guideline, focusing on pharmacology, acupuncture and pain management programmes.

How it gets started

The NICE Website describes the guideline process as follows: (a) a guideline topic is referred to NICE from NHS England. (b) Stakeholders register an interest in the guideline and are consulted throughout the development process. (c) The scope is prepared by the National Guideline Centre (NGC). The NGC establishes a guideline committee. (d) A draft guideline is produced after the group assesses the available evidence and makes recommendations. (e) There is a stakeholder

consultation on the draft guideline. (f) The final guideline is produced.

NGC, hosted by the Royal College of Physicians, describes itself as a 'vibrant, dedicated and enthusiastic team of over 50 people, the majority of whom have technical expertise as research fellows specialising in systematic reviewing, health economists and information specialists' who work under operational and clinical directors and project managers. NICE commissions it to develop clinical guidelines. According to their website, the guideline remit NICE received from NHS England was simply: Chronic pain: assessment and management.

There are already several NICE guidelines on chronic pain and one wonders where, why and how the new draft originated. The reasons listed on the NICE guideline development methodology site consist of three items:

1. Previous guidelines do not cover the whole topic.
2. Commissioners, professional organisations and people using the services prioritise it.
3. Health and care burden related to the topic is significant, and an additional guideline could have the potential to improve outcomes.

It underlines that there is always a process before a decision is made to go ahead with a new guideline. A topic selection oversight group at NICE will have considered the specific issues related to chronic pain and discussed them with NHS England (and possibly the Department of Health and Social Care, and Public Health England) and an agreement will have been reached as to proceed with the production of the guideline. As justification for the current task, the guideline scope emphasises the costs to society from treatment, work loss and disability claims, modest overall results from current treatments, challenges of communication with patients and their families, need to allocate resources appropriately and minimise iatrogenic harm from treatment. It suggests that with evidence of the effectiveness of chronic pain treatments, health care professionals can have more confident conversations about pain and help to set realistic expectations about what can be achieved.

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Putting all this together, there are clearly processes that involve multiple levels of expertise and decision making before a guideline is planned and produced, at least on paper. The system is hard to criticise unless there is evidence that it is wilfully manipulated. But it is obvious that the checks and balances in the system do not always prevent inadequately justified proposals slipping through and the present guideline proposal (GID-NG10069) is a timely example of this. Some will see it as supportive of patients and health care professionals while others undoubtedly suspect it is a cynical manoeuvre aimed at cost-cutting and less reliance of patients on health care.

What is this guideline about?

It is important to remind the reader here that the committee remit is to evaluate the assessment and management of chronic pain *that is not covered by existing NICE guidance*. There are several guidelines covering chronic pain conditions, both primary and secondary, according to the International Classification of Diseases, 11th Revision (ICD-11; headaches, low back pain and sciatica, rheumatoid arthritis, osteoarthritis, spondylarthritis, neuropathic pain, endometriosis and irritable bowel syndrome). However, the committee doesn't state explicitly that there is a problem with the way the medical community currently manages the 'Cinderella' conditions left without NICE guidance. I couldn't judge whether it is the commissioners or other stakeholders who have raised the issue or whether it is actually NICE itself that feels it must oversee the field entirely.

In any case, the review remit is quite challenging. It had hardly gone unnoticed by the multiple institutions involved that the literature available for review of the chosen conditions is lightweight and conflicting. Anyone seeing the trouble of briefly browsing the PubMed could themselves witness it, if they didn't know it already. And it is also not explained why one part of the remit was built around the concept of 'chronic primary pain', a diagnostic term that did not formally exist before 2018 (and will not be fully expanded until 2022, including specific diagnostic pathways). On one hand, it required the reviewers to exercise substantial discretion in determining if the clinical trial patients met the definition criteria. On the other hand, the new diagnosis was used in conjunction with the diagnosis of 'chronic pain', forming a part of it, and that was all too certain to cause confusion.

That said, both chronic pain and chronic primary pain are clearly defined according to ICD-11 (chronic pain MG30, chronic primary pain MG30.0). The definition of chronic primary pain is loaned verbatim from the ICD-11 (bar one sentence):

Chronic pain in one or more anatomical regions that is characterized by significant emotional distress (anxiety,

anger/frustration or depressed mood) and functional disability (interference in daily life activities and reduced participation in social roles). The diagnosis is appropriate independently of identified biological or psychological contributors unless another diagnosis would better account for the presenting symptoms.

The problem the reviewers faced was how to determine that the patients recruited into their respective studies actually showed emotional distress – many probably did, but very rarely was distress listed as an inclusion criterion in the included publications papers. My spot check showed that in many included papers on fibromyalgia (where the recruitment criteria did not include emotional distress) psychological questionnaires showed groupwise levels of depression and anxiety and that widely crossed the margin to the normal range. Strictly speaking, therefore, the review included patients with chronic primary pain and unspecified chronic pain (i.e. MG30.0 and MG30.Z). At the same time, it did not include all chronic primary pains because previous guidelines (that remain valid and cannot be overruled by the new guideline) already include some (e.g. MG30.02, chronic primary low back pain). I suggest it would have helped the reader if the chronic primary pain undergoing review had been made more easily identifiable – perhaps just adding a plus sign, or 'variant' to its name (CPP+, or CPP variant) and adding an explanation to the definition.

The guideline is effectively divided into two parts, one that covers all chronic pain and one that covers only chronic primary pain (I will use the latter term here without the plus or classification numbers, as in the guideline). The method outline follows the division between the two categories (Methods, pp. 10–16). Following the scope the NGC formulated 14 review questions, 8 concerning all chronic pain and 6 concerning chronic primary pain only. Two questions dealt with clinical and cost-effectiveness of interventions for (all types of) chronic pain: pain management programmes and social interventions. Two questions were related to safety of opioids and gabapentinoids in chronic pain, the rest had to do with communication and barriers of provision of care to patients with chronic pain.

Are these review questions reasonable? Mostly, yes. Surely identifying barriers for psychological treatment and social treatments and communication challenges with chronic pain patients has merit. Evaluation of clinical and cost-effectiveness of pain management programmes and psychological interventions from extensive research conducted over the years is appropriate as well, considering the manpower and costs involved in these interventions. And looking at the long-term safety of opioids and gabapentinoids is justifiable, in all chronic pain, considering their controlled drugs status. But once you start scrutinising how the committee dealt with the topic of

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Table 1. Questions addressed in the review.

All types of chronic pain (MG30)

What psychological factors may be barriers to successfully managing chronic pain?

What social factors may be barriers to successfully managing chronic pain?

What biological factors may be barriers to successfully managing chronic pain?

What are the best methods of communication between healthcare professionals and people with chronic pain?

What is the clinical and cost-effectiveness of pain management programmes for the management of chronic pain?

What is the clinical and cost-effectiveness of social interventions aimed at improving the quality of life of people with chronic pain?

What is the long-term safety of opioids for the management of chronic pain?

What is the long-term safety of gabapentinoids for the management of chronic pain?

Chronic primary pain only (MG 30.0, MG30.Z)

What is the clinical and cost-effectiveness of exercise interventions for the management of chronic primary pain?

What is the clinical and cost-effectiveness of psychological therapy for the management of chronic primary pain?

What is the clinical and cost-effectiveness of acupuncture or dry needling for the management of chronic primary pain?

What is the clinical and cost-effectiveness of electrical physical modalities for the management of chronic primary pain?

What is the clinical and cost-effectiveness of manual therapy for the management of chronic primary pain?

What is the clinical and cost-effectiveness of pharmacological interventions for chronic primary pain?

chronic primary pain, you will be forgiven for experiencing a sudden wave of doubts. Numerous pain conditions that go under the generic diagnosis of chronic primary pain (MG30.0 and MG30) have variable clinical presentations and natural courses; what only ties them together is a variable emotional response and lack of known aetiology or pathophysiology. It is widely optimistic to think that pain conditions are caused by mechanisms that would respond to a given treatment across the board (and to be fair, no justification is presented). On the face of it, an analysis of clinical and cost-effectiveness of a pharmacological treatment seems an impossible task. To an extent, it is more manageable in the case of non-pharmacological interventions, for example, exercise, psychological support, acupuncture, electrical therapy and manual therapy and where the target organ is not critical for success.

So, what precisely are the chronic primary pain conditions reviewed for this guideline? In PICO section of the Evidence Review (J) Pharmacological Management, there are five secondary level diagnoses listed and a more descriptive, detailed list is found in the description of the search strategy

(Appendix B) comprising complex regional pain syndrome/ causalgia/algodystrophy/Sudeck/reflex sympathetic dystrophy; fibromyalgia/myofascial pain syndrome/fibrositis/myofascial pain syndrome; vulvodynia/ vestibulodynia/dyspareunia/vulvar vestibulitis/vulvitis; interstitial cystitis; prostate, vulvar or perineal pain/prostatodynia/pelvic pain syndrome; loin pain haematuria syndrome/LPHS; burning mouth syndrome; temporomandibular pain; and non-cardiac chest pain.

Note that non-specific low back pain is not included, and neither are headaches or irritable bowel syndrome. The search produced 417 controlled clinical trials, 34 of which were accepted for the final review ((J) Evidence Review, Appendix C). Nineteen trials concerned fibromyalgia, six urogenital pain syndromes (four female, two male) and the rest single controlled trials for other chronic primary pain conditions ((J) Evidence Review 1.4.1, 1.4.3).

Review of drug trials for chronic primary pain

The drugs included in the meta-analyses were not reviewed individually but lumped together according to class, whether a

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gabapentinoid, SSRI, SNRI, tricyclic, tetracyclic, cannabinoid or opioid. There was an obvious need to do this, as the data consisted of a myriad of trials by one drug only, which had to be assessed for outcome at short term (<3 months) and long term (>3 months) against several outcomes and across multiple pain conditions. Individual trial drugs were pooled together into classes and categories, with little regard for their precise mode of action. At one extreme, a drug category of 'antiepileptics' was formed that could potentially include all the dozen or so compounds with completely different pharmacology. (As it turned out, only gabapentinoids were included in that category.) Lumping all chronic primary pain conditions together complicated the matter further. This 'double-pooling' meant, for example, that efficacy of SSRIs (fluoxetine, sertraline, etc.) was assessed in a heterogeneous population of patients with fibromyalgia, pelvic pain, non-cardiac chest pain and somatoform disorder (the latter a dubious inclusion). While one understands that this was felt to be the best solution out of the maze of multiple drugs and diagnoses, there cannot be any doubt that the approach was based on very optimistic generalisation. And surely no one can argue that the situation could not be foreseen.

The only deviation from the principle was a separate analysis of gabapentinoids in fibromyalgia. The reviewers only accepted one clinical trial for it, a high-quality large study comprising three controlled clinical parallel-group trials each with three treatment arms (placebo, mirogabalin and pregabalin).¹ It showed superiority of pregabalin over placebo in two of the three studies whereas mirogabalin did not. The improvements in pain, quality of life and functionality were, however, small, and their clinical importance unclear. Five other conventional parallel-group placebo-controlled trials, previously rated high quality by a Cochrane review group,² were not included. This was strongly criticised by PaPaS. A common reason for the exclusion was use of placebo run-in periods, which among statisticians has raised concerns of resultant compromise of external validity of the study – especially as the details of the excluded placebo responders were not presented in the excluded studies. Be that as it may, the exclusions did not substantially change the outcome. The Cochrane review by Derry et al.² concluded that 1 in 10 patients with moderate to severe fibromyalgia taking pregabalin (300–600 mg daily) experiences a 30%–50% reduction in pain over 12–26 weeks. On this basis one could at best give a weak backing for its use in this indication – were it not for its new status as a class C drug under the Misuse of Drugs Act. It is difficult to argue against the current do-not-prescribe recommendation by the NICE Committee unless a strong justification is found (e.g. that there is a method to identify the 10% who are likely to benefit from it).

With very few exceptions, all clinical trials concerning antidepressants, nonsteroidal anti-inflammatory drugs (NSAIDs), cannabinoids, local anaesthetics and other drugs were small and of low or very low quality, irrespective of the target population (which commonly was females with fibromyalgia). I note that PaPaS has made a case for duloxetine for fibromyalgia, which I agree with. But I understand and have sympathy for the committee's recommendation covering all antidepressants for the broad indication of chronic primary pain – even if the review failed to show clinically meaningful superiority over placebo for any of them. What is of interest is the committee's reference to the antidepressants being in widespread clinical use anyway – a gentle political manoeuvre that should dissuade clinical commissioning groups from following an aggressive cost-cutting policy. The recommendation against NSAIDs and opioids balances out the 'leniency' shown towards antidepressants and undoubtedly is a point that commissioners are meant to take note of. Disagreement over these two drug classes can only be solved with good quality controlled clinical trials. Very wisely, the commission did not endorse cannabinoids, despite the media attention they have received, but also left the door ajar for future modification of the guidance, should research show benefit from them. Overall, NICE guidance for pharmacological management for all intended groups is as useful as it can be, given the limited research available.

Non-pharmacological management of chronic primary pain (and some interventions in all types of chronic pain)

The same is by and large true for recommendations regarding non-pharmacological interventions (exercise, psychological therapy, electrical treatments, acupuncture and manual therapy) for chronic primary pain, especially if one takes a broad-brush view; there are flaws in most of them but not decisive enough to change the bigger picture. The recommendation for the limited use of acupuncture is based on a review of 33 clinical trials; in four of them, the PaPaS Group found inaccuracies in data handling or interpretation – but rectifying them or removing the study from the review would not change the final conclusion. Apart from four studies of moderate quality, all were of low or very low quality (when judging pain relief), and most studies were small. The committee has given the results the softest possible interpretation, allowing it to justify its restricted recommendation on the basis of combined clinical effectiveness and cost-effectiveness. As the recommendation stands, one could see it more as a token gesture rather than support for its clinical utility. Having said that, perhaps it will help managing doctors to make a case for an individualised funding request for

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continuation or repetition of the treatment series involving those very few patients with mild symptoms who significantly benefit from five sessions.

As for the four research questions regarding all types of chronic pain (MG30), there should be little controversy over them. The recommendation for continued research in regard to the Pain Management Programme is surprising in light of numerous systematic reviews on the topic which consistently suggest a small benefit from them (the latest a Cochrane Review update by Williams et al.³ published in the same month). Here, I think a similar tactful decision as with antidepressants would have been in place – a recommendation towards continuation of the current common practice, on the basis that disassembling the nationwide programmes could be more harmful as they are not easily replaced. Continued research after years and years of already published research means diverting resources from more innovative approaches that are clearly needed.

Conclusion

The NICE guideline system is robust, but it doesn't prevent inadequately justified proposals from getting through. The scoping process is sensibly built around the formulation of review questions that allow views from a range of stakeholders to be taken into account. But it is not immune

to incorrect early procedural strategies being adopted and pursued, as the focus on chronic primary pain shows. For this guideline, the committee ended up exploring clinical trial material that was mostly insufficient for any well-justified recommendations. In these circumstances, it did a decent job and even managed to use some political leverage to protect existing treatment practices. Overall, the present guideline will have little impact on clinical practice. It is as good as it can be given the circumstances. I cannot see it threatening the future of Pain Medicine, as some have argued. The pain community will nevertheless have to keep fighting its corner. The ammunition comes from well-designed, adequately powered controlled clinical trials, which is everyone's responsibility. And remember, NICE isn't a foe, it's an arbiter. You don't win by fighting NICE, because the real foes are in the UK political forum.

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NICE? The National Institute for Health and Care Excellence guideline [NG59]

Low back pain and sciatica in over 16s: assessment and management
A personal view of my involvement

Chris Wells (J C D Wells)

The first National Institute for Health and Care Excellence (NICE) Guideline Development Group (GDG) on low back pain (CG88) released a controversial provisional guideline in 2008 which, despite criticism, was reproduced unaltered in the spring of 2009. The British Pain Society (BPS) and the Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists (RCA) were very much against it. A good review of the matter was penned by Arun Bhaskar, now our President.

It was with considerable relief that we heard, in 2013, of a second committee being set up, and the pain consultants' Google group were in no doubt as to who should chair it: Stephen Ward rose to the occasion, applied and (to the great credit of NICE) got the job. Casting round for some support, he suggested I apply, and in spite of huge reservations, I did so. My reticence survived several stormy initial meetings, then things started to look better, although at the end there were interesting attempts to alter the decisions of the majority of members.

What is the process?

NICE draws up a project, selects members internally to work on it, advertises and selects a Chair, agrees a balance of experts, and invites applications. The GDG are selected after interview, and work commences. A huge amount of work goes on 'in house', with a large input and time commitment from the Chair, and other such external members as are deemed appropriate/wish to input (anyone can input throughout, but clinicians often don't have much time, and most input came from one additional member besides the Chair, and then perhaps three to four very engaged health care professionals). The evidence, and decisions regarding it, is discussed in detail at a series of meetings in London at approximately 6-week intervals. A good grasp of statistics is required. I thought my grasp was good (although not compared with Turo's) until I started! Then I had a lot of mugging up to do. A series of votes takes place on predetermined issues with regard to the formulation of the final guideline. Once the process starts, the

volume of reading increases exponentially, documents including minutes, papers, comments, suggestions and arguments are reviewable on a restricted access platform (Claromentis).

The committee included two survivors from the previous GDG and several others (including myself) who might be considered to have 'vested interests'. However, these would certainly pull in different directions and with a good Chair and good scientific advice, might be conducive to producing a balanced view. My relations with some group members were stiff at first and at times, discussions could be combative. One member referred to 'the dark arts of the anaesthetist'. That wasn't minuted. Stephen was a brilliant Chair, well respected and indeed well liked by all, although there was one scurrilous discussion on his (and my) potential conflict of interest as a 'person in private practice', with an intention to derail the final document towards the end of the proceedings. Fortunately, I had by this time taken the decision to retire and move to Portugal, so the arrows were well deflected in my case. Regarding Stephen, the main target, we are lucky to have him, and I'm surprised his work has not been formally recognised by FPM and BPS; perhaps this will come.

The full committee comprised two pain specialised anaesthetists, one orthopaedic and one neurosurgeon, a nurse (one replaced another), a psychologist, a (brilliant) physiotherapist, a professor of epidemiology with huge knowledge of pain, two patient representatives, an osteopath, two GPs and a rheumatologist. There were over 20 NICE staff working on the project over the 3 years, although probably only 7–8 at any one time. Four external experts were co-opted.

In general, work increased towards the individual meetings, eventually 22 in all, from January 2014 to December 2015. The meetings themselves lasted for 6 hours with complimentary food and non-alcoholic drinks breaks. Travel costs (and hotel costs if needed) were refunded. After each meeting, there was a lull, then minutes, discussions, and preparation and comments on the next agenda, both procedurally and scientifically. Given the



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huge and diverse number of papers, this required a huge amount of work from the NICE staff (always professional, usually very serious, but one or two could and did have a sense of humour) and also the Chair. Then after the 22 meetings came further collation, writing (we all played greater or lesser parts, which gave a sense of ownership), revision, stakeholder consultation and a supposedly final meeting on 19 May 2016.

Then came a huge pause in 2016, and some suggested (by 'high up in NICE') revision as there were different interpretations of the evidence. I became incandescent and at one point offered my resignation. Finally, the document was accepted as originally written and agreed by the majority decisions of the GDG on each of the many points. Some points unanimously, some by a significant majority and one by a whisker. Facet RF was accepted as evidence based almost unanimously; most of the reservation from the committee was 'who would/could do it and what would it lead to (particularly cost)?' A registry of all procedures was suggested (opposed by me) which NICE itself eventually vetoed as inappropriate for them to recommend.

The final guideline was released on 30 November 2016 and has recently been reviewed and revised without much change that I can see (and without reference or notification to myself as a member of the original GDG). It is available to view here: <https://www.nice.org.uk/guidance/ng59>

Forms and behaviour

We each had to sign confidentiality forms on selection (as well as many other forms, diversity, etc.). Before the first meeting, there were eight forms of varying detail to complete.

Conflicts of interests

This is an incredibly sensitive issue for NICE. At each visit, we had to declare all payments apart from our incomes, any industry meetings, support, travel, honoraria and so on. All those involved with, or garnering fees from, the pharmacology industry were excluded from the room for any discussions on medication and its usage. Three of us in all. Possibly the ones with most knowledge about drug treatment of such patients. But that is the way these things work, and NICE has been heavily criticised on this point in the past.

How was the process?

Difficult. It requires a huge amount of time and effort, particularly from the Chair. There was a frisson of intrigue and shifting alliances, and some bartering. Points, perhaps less important, have to be conceded to achieve consensus. A generous outlook, if all play fair, helps but different crafts of health care professionals have different beliefs and positions. There was a feeling that those high up within NICE were following the

proceedings closely, not always in full approval, and the GDG certainly did not have free rein to do anything they wished. Economists and research scientists gently harried and directed but allowed a balanced conclusion to be drawn. At one point, there was an external 'leak'. Actually inaccurate, on a matter not at that time decided by the committee, and not from any of the GDG or from NICE. On another occasion, a libellous letter was sent to many HCPs by an unrelated craft, regarding conflict of interests of the anaesthetic members of the group. I wondered about legal action, but decided I had enough to do.

Why is it so difficult to work out what works?

Well, it is a problem suffered by a hugely diverse group of those complicated organisms, humans. Each with their own different symptoms, beliefs, philosophies and so on. The treatments are complex. Meds are simplest of all, but trials would be much better if drug x was tried, versus 40% of drug x, versus 100% of active drug y, versus placebo. Have you ever seen that paper?

When it comes to surgery, or an injection, or pain management or even an exercise programme, there are so many variables (who, how, why, when and where, etc.) it is hardly surprising that the evidence can be thin. But it is out there, and it should be considered.

How was the final product?

Well, read it and decide. It is 819 pages long, with 526 references (a tiny proportion of the ten thousand or so papers that were considered). Personally, I think it is very good (but I'm biased). It reviews the available evidence well and comes to mostly inescapably accurate conclusions. Is it perfect? No, but then the evidence is far from perfect. Would a different committee come to the same conclusions? Clearly not, as the evidence wasn't much different from the first GDG. Is there a better way? Absolutely not. The only way to balance huge, vested interests and biased, not to say blindly inaccurate, clinical opinions is to meet together in this way and balance the evidence as best as possible.

What does it achieve?

Well hopefully, it can be useful in your practice. I'm assuming you have many of these patients and many more waiting to see you. If you work through the guideline, referring if you don't have the expertise to manage any one arm (i.e. Docs to Physios for exercise, vice versa for Facet assessment), then some patients get benefit at each stage. At the end, those who don't can be discharged, knowing there is little point in spending more precious resources on a no-win situation. Then you can see another person from your long waiting list whom you are more likely to help. More satisfaction from treatment outcomes. Less stress from long waiting lists. Nice ☺

Relationships, self-management of long-term health conditions and a new normal in a post-Covid-19 world

Dr Patrick Hill

Understanding the complexities of sustainable self-management for people with long-term conditions, such as chronic widespread pain (CWP), fibromyalgia syndrome (FMS) and chronic fatigue (CFS), remains a challenge. However, there has been a shift in focus towards the often neglected social domain in recent years, which suggests a way forward. This was reflected in the 2019 British Pain Society Pain Management Programmes Special Interest Group, Biannual Conference, hosted by the team from North Bristol NHS Trust, which had the title: 'Placing the Spotlight on the BiopsychoSOCIAL'. In 2021, as we face an unknown timeline with regard to the re-establishment of normal social interactions, exploring the social domain is important, particularly in terms of understanding what we may not be able to achieve through remote clinics or social distance work.

Prior to the Covid-19 pandemic, it was becoming clear that successful, sustained self-management of long-term health conditions in the real world is a determinedly social challenge above all else.¹ Health professionals can help people develop a basic understanding of their condition and some management skills, but it is only through wider social relationships that they can develop expectations of their future.² Fostering the appropriate relationships at the right time to support a developing self-management regime remains a complex challenge for the individual, particularly given the social impact of the pandemic with societies in 'lockdown' and facing social distancing for an unspecified period.

One issue that has received attention in the literature for some time is the fundamental change required in relationships between healthcare professionals and people with long-term conditions, towards a more collaborative venture.³ For example, Sadler et al.⁴ quote studies of people with a range of long-term conditions, including diabetes, multiple sclerosis,⁵ cancer⁶ and multimorbidity,⁷ which report the importance of developing collaborative partnerships with health professionals, in order to develop an understanding of their long-term condition(s) and initiate self-management. However, stroke survivors initially reported that because of the sudden onset and disabling nature of stroke, they were not ready to think

about concepts such as 'collaboration' or 'self-management', as they felt that they were dependent on expert health professionals for support. The implementation of effective multidisciplinary biopsychosocial rehabilitation, the predominant model for supporting long-term conditions in the NHS is fraught with this kind of complexity. As well as getting the timing right, if self-management is poorly understood by the professionals and not well explained, it can have the effect of disempowering the person by making them take an (un) equal share of responsibility for managing the condition.³ Equally, the person interpreting their diagnosis as: 'there's nothing more they can do, I've just got to live with it' or 'they don't want to operate ... they must want to wait until it's got worse', all risk creating a sense of helpless passivity, cycles of low mood and physical deconditioning.

For all parties involved, the concept that various relationships might shift and undergo quantitative and qualitative change is often not well understood or even seen as important. However, there is also a great deal of variation, for example, in conditions such as non-specific low back pain, the 2016 NICE guidance is now clear, that once a diagnosis has been made, red flags excluded and a programme of rehabilitation completed, there is little need for continuing relationships with healthcare professionals.⁸ In fact, others have suggested that at this stage the development of community-based peer support becomes critical for successful long-term outcomes.¹ By way of contrast, people with diabetes need to be in a more flexible but continuing relationship with primary care, to monitor disease progression, adjust insulin doses and review delivery systems, check peripheral vascularity and provide access to secondary care expertise in the event of complications. A broad indication of the change in relationships between professionals, people with long-term conditions and their peers is shown in Table 1.

This transition of relationships is not an issue that is well understood by any of the stakeholder groups. 'Living well' with a long-term condition requires embracing a different paradigm, with a shift in beliefs, expectations, focus, behaviour and relationships, and most health professionals are not trained to facilitate this for people in their care. In any event, for any

Table 1. Relationships between professionals, people with long-term conditions and peers.

Stakeholder	Acute: 0–3 months	Sub-Acute: 3–6 months	Chronic: 6 months+
Health professional	Expert specialists who take control, conduct diagnostic tests, & initiate treatment	Reduced relationship with experts, relationships develop with more generic health professionals	Relationships with generic professionals adjusted to minimal monitoring or withdrawn
Person with long-term condition	Intensive relationships with expert specialists requires only passive involvement; mostly compliance with test schedule and treatment regime	Achieving concordance of goals with professionals becomes important. Start of involvement in self-monitoring & self-care	Person actively self-manages majority of healthcare
Peer group	Existing peer group supportive, but with expectations of recovery and 'return to normal'	Original peer group relationships change, opportunities may arise for new peer support from others with same condition	Increased peer support may emerge from others with same condition. Old relationships adjust to incorporate long-term condition

long-term condition, professional input will always be limited. Department of Health (DoH)⁹ statistics have suggested that on average people with long-term conditions receive professional support for only 3 hours per year. Group-based multidisciplinary biopsychosocial rehabilitation programmes (such as Cardiac or Pulmonary Rehabilitation or Pain Management Programmes) are an effective way of introducing and coaching the skills of effective self-management, but the most they can offer is a few weeks input. Beyond this, peer support becomes increasingly influential and can have a significant impact on behaviour, particularly self-management.¹⁰

As indicated in Table 1, peer support also undergoes unexpected changes for people with long-term conditions. In the initial 'acute' phase of a condition, existing peers (family and friends) often provide high levels of practical and emotional support, with the expectation on all sides that the person will 'get better' and return to 'normal', so that this more intensive practical and emotional support can be withdrawn. Clinical experience would suggest that when this expected trajectory falters, the person's health status can often become confused and when it becomes apparent that they are no longer in an acute crisis, support from existing peers often dwindles,¹¹ meaning that the situation can rapidly become emotionally and socially complex. Often people with long-term conditions start to feel that they have a stark choice in how they can present themselves to the world; as either their 'normal' self or as someone with an illness or disability.¹² Neither of these roles is easy to maintain consistently in the presence of a normally fluctuating long-term health condition such as FMS or CWP. It is perhaps inevitable that many people with long-term

conditions feel pressurised to present themselves as unwell or disabled, as this is a role that is accepted by society. The downside to this is becoming isolated and trapped in vicious circles of low mood, frustration, loneliness, disrupted sleep, increasing medication side effects, physical deconditioning and increasing levels of disability.

Participant feedback from group-based rehabilitation for chronic pain has produced some consistent results over the last 30 years. Meeting other people in the same situation is commonly cited as the element of the programme that people found most beneficial.^{13,14} This has been thought to reflect the significant levels of isolation experienced by people with disabling long-term conditions such as chronic pain and fatigue. However, this social component may be more important than just reducing social isolation. Social restoration is known to be a key antidote to distress, disability and loneliness,¹⁵ but the mechanisms by which social support can have such a positive biopsychosocial effect are not clear.

Previous authors have suggested that the Surawy model¹⁶ can be more widely applied to many long-term conditions,¹⁷ and this model suggests that there may be significant biopsychosocial factors involved in the aetiology and maintenance of long-term conditions. The model suggests that people at risk of transitioning from acute to long-term conditions often have a common behavioural propensity towards 'striving' and can have fragile self-esteem, dependent on external validation from others. Being isolated from peers can therefore create a vulnerability to low self-esteem. As opportunities for getting approval/praise from existing peers get more difficult, the model suggests a risk

of 'boom and bust' attempts at achievement, resulting in more stress and frustration. In a previous study,¹⁸ it was proposed that this is likely to contribute to the overall sense of threat to self-identity, resulting in increased neurological 'wind up', with the person potentially experiencing increased levels of symptoms such as pain and fatigue.

Accepting the Surawy model suggests that establishing and reinforcing a new set of social norms becomes crucially important for the maintenance of the new self-management behaviours introduced during a rehabilitation programme. This is perhaps only possible through maintaining contact with the new peer group established during the programme. Sustaining newly established regimes of activity management, such as regular use of applied relaxation techniques and paced exercise, is difficult for many people, particularly where these are completely new behaviours. If the only other social references available are people without long-term conditions, or comparisons are made with a pre-condition memory of self, these new behaviours are less likely to be maintained.

Health professionals facilitating rehabilitation programmes have a major opportunity to enable the formation of new supportive relationships between participants. Embodied in the early stages of many rehabilitation programmes is the identification of behavioural propensities such as 'striving' that are not compatible with self-management. Group-based programmes can introduce the common problematic behavioural propensities, such as 'boom and bust' attempts at achievement. Sensitively handled, exposing and normalising these behaviours can reduce any shame or criticism attached to this and establish some new behavioural norms, more in line with self-management. 'The best thing was meeting other people' feedback perhaps reflects participants becoming aware that others are experiencing the same limitations and struggles to make behavioural adjustments, such as pacing and applied relaxation, which have previously been outside their normal repertoire. This offers the opportunity to introduce 'a new normal' and particularly validates the concept of self-compassion or being kind to yourself, which is essential, especially if, as Surawy suggests, this is not established in people's existing repertoire and need lots of encouragement and support.

This powerful social process will be effective, as long as participants can relate to the group as peers and don't remain attached to a 'non-condition' reference group or a pre-condition past. If a participant feels unable to relate to anyone or form any new relationships (including with the professional team), they remain at high risk of returning to 'boom and bust' in the desire to maintain old self identity and gain social approval.

Experienced programme facilitators know that a group where everyone bonds well is a rare and unpredictably random thing,

which cannot be easily engineered. When it happens, it seems to result from a complex, chaotic process that emerges from the random bonding of the participants, as relationships form. This would suggest that operating a rehabilitation programme with traditional small 'closed' groups of 8–10, where the opportunity to establish relationships is limited, is therefore high risk with regard to successful long-term outcomes for most participants. Even if a group bonds well, ironically the health system will often sabotage the potential for good long-term outcomes for many programmes, as after so many weeks the professional team will usually disband the group – destroying the key source of social support needed to embed the new behaviours. This remains hidden, as outcome data are commonly only collected for a limited time post programme, although the indications are of a return to baseline in most areas that are assessed.¹⁹

The argument is that to maintain effective self-management behaviour introduced by health professionals, we therefore need to focus on people's relationships with their peers and take a more flexible approach to enable them to form and maintain over time.

One approach that was used in a community setting in Birmingham for people with chronic pain, which offered some opportunities to address this, was the provision of a continuous 'rolling' (rather than a closed) programme of support for self-management.²⁰ A rolling programme is essentially one that keeps running, with participants joining and leaving at regular intervals. This approach has an emphasis on process rather than content. Yalom's²¹ review makes it clear that upwards of 80% of outcomes from any group-based therapy relate to process, rather than content, and in this context the emphasis would be placed on factors such as 'therapeutic alliance' and enabling the development of supportive relationships. Birmingham has a diverse range of different communities and ethnic minorities and this more open approach provided more opportunities for people to find others they perceived as similar to themselves, that they could relate to as peers.

In considering the essential social developments, a more flexible programme structure offers greater opportunities to make new relationships, particularly if they aren't established initially.

This emphasis on developing relationships, rather than the more traditional focus on delivering a psycho-educational approach, carries implications for programme design. For example, larger groups than the standard 8–10 participants, with a more open approach to attendance and the need for reduced formal content, suggesting the need for only a small amount of professional input. Time should be given to enable the establishment of a new culture where activity pacing, relaxation and self-compassion are the norm.

Conclusion

The phrase 'a new normal' is one that people emerging from group-based interventions have often used to describe their future. This is often made as an unprompted reflection as the size of the challenge ahead of them becomes apparent, in terms of sustaining the gains they have made.

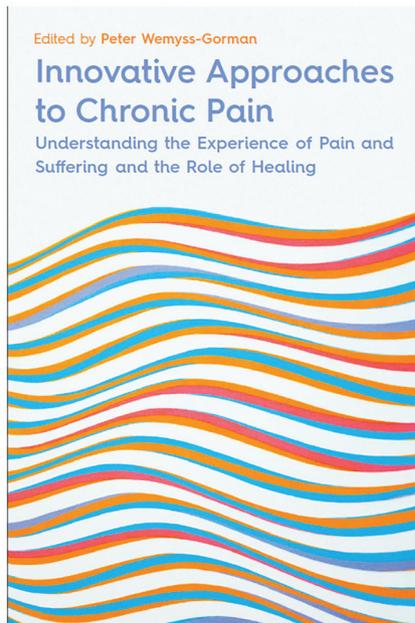
In 2021, we are all facing 'a new normal', and the uncertainty of what this means is not a comfort but a challenge. We have begun to see some of the positive advantages – less travel, reduced pollution and costs of remote working – but all felt the negatives of more social isolation. As many health services shift towards remote contact with their patients, how we can provide this social element is a real challenge.

We ask people with long-term health conditions to embrace a new normal, in other words undertake a fundamental change in their identity and how they live their lives. Covid-19 has made us all recognise how difficult this is.

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Book review



***Innovative Approaches to Chronic Pain*, edited by Peter Wemyss-Gorman. Jessica Kingsley Publishers, 1st edition (21 December 2020), pp.240 (pbk). ISBN-10: 1787751872; ISBN-13: 978-1787751873, £25.99.**

Reviewed by Jenny Jessop

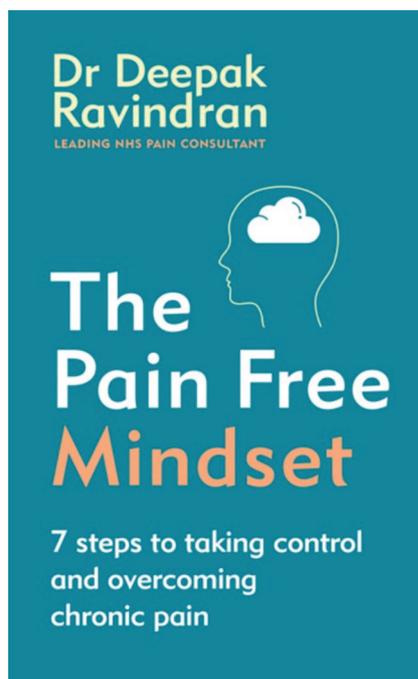
This book consists of an interesting collection of essays by speakers who have addressed meetings of the British Pain Society Special Interest Group for Philosophy and Ethics. Its focus is on suffering, as opposed to nociception and pain. The topics covered range from the place of pain in major religions, to the placebo effect and the importance of the language used in talking to patients with chronic pain and extend to the use of knitting as a therapeutic tool. The overall thesis is that those who deal with chronic pain need to take a much broader approach to their healing role by treating each patient's pain in its entirety as it affects them as an individual. Those who work with chronic pain patients and view them through a biopsychosocial lens will find much in this book to interest them. For some, the focus on the suffering experience and the soft side of healing will take them towards the edge of their

comfort zone, but that is not necessarily a bad thing! The approach is broad but my major comment would be that, while the authors have covered the influences of religion and ethnic cultures, they haven't even touched on the regional influences in the pain experience, which will differ considerably between the Home Counties and, for example, the South Yorkshire ex-mining areas where I have plied my trade. Even understanding pain descriptors there is difficulty if you come from outside the area, and I still only have a monochrome understanding of what a 'naiging' pain is. I know it is as unpleasant as severe toothache, but I have never been able to get any more colour into my understanding. If you ask a patient what he thinks is causing his pain, as advocated by one of the authors, you can bet the farm that the answer will be 'You're the doctor', delivered in a challenging sort of way accompanied by a grin. Nothing in this book really touches on the role of pain in a mining community that has completely lost its traditional jobs and the social cohesion of the pit villages that went with them. In this context, pain from old pit injuries is the currency that allows you to get Disability Living Allowance instead of unemployment benefit when you have no transferable skills and there are no jobs to be had. This is likely to be echoed nationwide post covid, with the inevitable loss of jobs and the emergence of Long Covid as a diagnostic entity. Perhaps that's a topic for another meeting. So who specifically would I like to read this book? It should be required reading for anybody, whatever their professional background, who is coming new into the field of chronic pain, and will counterbalance some of the more biological knowledge base they also need to deal with these patients. It should be read by the colleagues who refer patients to pain clinics, such as the orthopaedic surgeons who tell a patient they have the back of an 80 year old or, equally damaging, that there is nothing wrong with them, and then expect their pain colleagues to deal with the fallout, and the psychiatrists who think treating a patient's depression would be a breeze if only someone would take away their pain. Finally, read it to remind yourself that you're not necessarily failing because you and your team can't sort out someone's pain between you. There might be complex issues that aren't apparent (even to the psychologists) and could be worth looking for. This book may help you spot them and even suggest different ways of dealing with them.

Book review



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***The Pain-Free Mindset*, Deepak Ravindran. Vermilion, 1st edition (4 March 2021), pp.352 (pbk). ISBN-10: 1785043390; ISBN-13: 978-1785043390, £11.49.**

Reviewed by Jenny Jessop

This book is written, by an experienced Pain Consultant, and targeted at chronic pain patients who continue to struggle with their pain after trying a lot of the conventional treatments. In reviewing a book of this kind, I like to look at three tests. First, does this book contain information that is relevant and useful to the target audience? Second, is it presented in an understandable and accessible way? Third, does it pass what I call the Peter test? Peter is my brother, nowadays an aficionado of Google searches to supplement the opinion of his medical advisors, although back in the day he was known to use Chambers dictionary for the same purpose. Would a doctor's heart sink if he arrived in surgery or clinic armed with this book?

I will start by saying that it passes this third test with flying colours. This is a book which sets out to lead patients away from the eternal search for a cure for their pain and to encourage them to take control and institute the lifestyle changes which will enable them to function better. It argues that these changes will, by reversing some of the effects of a maladaptive lifestyle, improve the patient's pain experience. It then provides an extensive collection of approaches which may be much more helpful than continuing to search for a cure. Even my brother couldn't weaponise this. It will be music to the ears of GPs and those who work in Pain Management services, and one could argue that this book should be compulsory reading before a chronic pain referral is considered, since it will enable the patient to turn up to an initial assessment with a much more realistic shopping list.

When it comes to my second test, I do have some worries around the concentration that patients will need to read and digest it. It is a chunky book, running to over 300 pages, and the first 100 pages cover the difference between nociception and pain, and the reasons why operations and procedures may not work for chronic pain. While this is absolutely key to getting patients to understand why an alternative approach might work better for them, it takes some time and concentration for them to get into the nuts and bolts of the approach that is being proposed. When they get there the content is meaty and comprehensive. This makes it an excellent manual but may be a challenge to some readers, given that impaired concentration is a common feature of chronic pain.

However, this book certainly passes my first test. It is packed with full of information that chronic pain patients need to know and can be used either in a way that is complementary to more conventional treatment or as an alternative approach. The author neatly sidesteps putting the patient in the position of feeling they have a binary choice between medical and complementary approaches to pain management, but rather puts them back in control of deciding what works for them to restore their quality of life. In doing so, he does a very good job of conveying to patients what chronic pain management should be all about. This book will give them the toolkit they need to take charge of managing their chronic pain themselves.

Book review

Pain

Irene Tracey



A Ladybird Expert Book

***Pain: A Ladybird Expert Book*, edited by Tracey Irene. Michael Joseph (26 November 2020), pp.56 (hbk). ISBN-10: 0241345537; ISBN-13: 978-0241345535, £6.95.**

Reviewed by Dr Rajesh Munglani

'I don't mind pain so long as it doesn't hurt' – Oscar Wilde

Irene Tracey is probably one of the most well-known figures in Pain Medicine in the world. She is professor of Anaesthetics Neuroscience, vice chancellor, and a warden of Merton College, Oxford, and is director of the Neuroimaging Centre at Oxford. She held the Nuffield Chair of Anaesthetic Science and was a Head of Department of Clinic Neurosciences within the Nuffield. Irene has transformed our view of pain due to her pioneering research in the field of pain and I remember reading, in particular, her pioneering work on the profound functional MRI changes when one gives placebo agents; yet this great

mind has chosen to write the Penguin book on pain, which is 50 pages long and yet exactly half of them are full of pictures – my ideal kind of book!

Irene has taken the whole of Pain Medicine and has transformed it into 25 pages of simple explanations along with 25 magnificent illustrations by the artist Stephen Player. It was a pleasure to read this book.

At the beginning of each page is a question or title and these include:

- 'What is pain?'
- 'Early descriptions of pain'
- 'What hurts us?'
- 'Why does chilli taste so hot and mint cold?'
- 'Fast pain, slow pain, no pain'
- 'The gate control theory'
- 'The brain and pain'
- 'Do babies feel pain?'
- 'Expressing pain: language, gestures and gender'
- 'Measuring pain – culture and societal biases'
- 'Phantom limb pain'
- 'Brain freeze: Weird pain and pleasure'
- 'Blocking pain: Mind over matter'
- 'Placebo analgesia'
- 'Placebos and nocebos'
- 'Chronic pain facts and figures'
- 'Chronic pain symptoms and a bit of science'
- 'Chronic pain and a bit more science'
- 'Headaches: hangovers and migraines'
- 'Emotions as amplifiers and psychogenic pain'
- 'Treatment for acute and chronic pain'
- 'Nature's pharmacopoeia'

Book review

'Analgesia, anaesthesia and pain'

'The dark, bright and future faces of pain'.

These topics each beautifully illustrated by the picture on the opposing page, are then followed by a final reading list. The joy of reading such a book is that the whole of Pain Medicine is essentially covered. I am reminded of the quote from the Dodo at the end of the Caucus race in Alice in Wonderland by Lewis Carroll '*everybody has won and all must have prizes*'. Indeed acknowledgement is given to virtually every aspect of pain medicine. She has recognised all of the key topics and questions to Pain Medicine. For anybody wishing to know the key words and key concepts in a pain precise manner, this is it. Of course, one does need to do more reading elsewhere but this is a good start.

Who is it aimed at? My view is that any intelligent patient who has pain (or carer) who could cope with GCSE Biology could probably get a lot out of this book. The pictures could be understood by a 3-year-old, which is simply brilliant. My only criticism is that there are specialist words in there that are not easily explained, which would need to be in ordinary circumstances. Some require a greater explanation, including '*A Beta fibres, C fibres, central sensitisation*' but that criticism is only given because I think I should make a criticism. There simply is no room in this

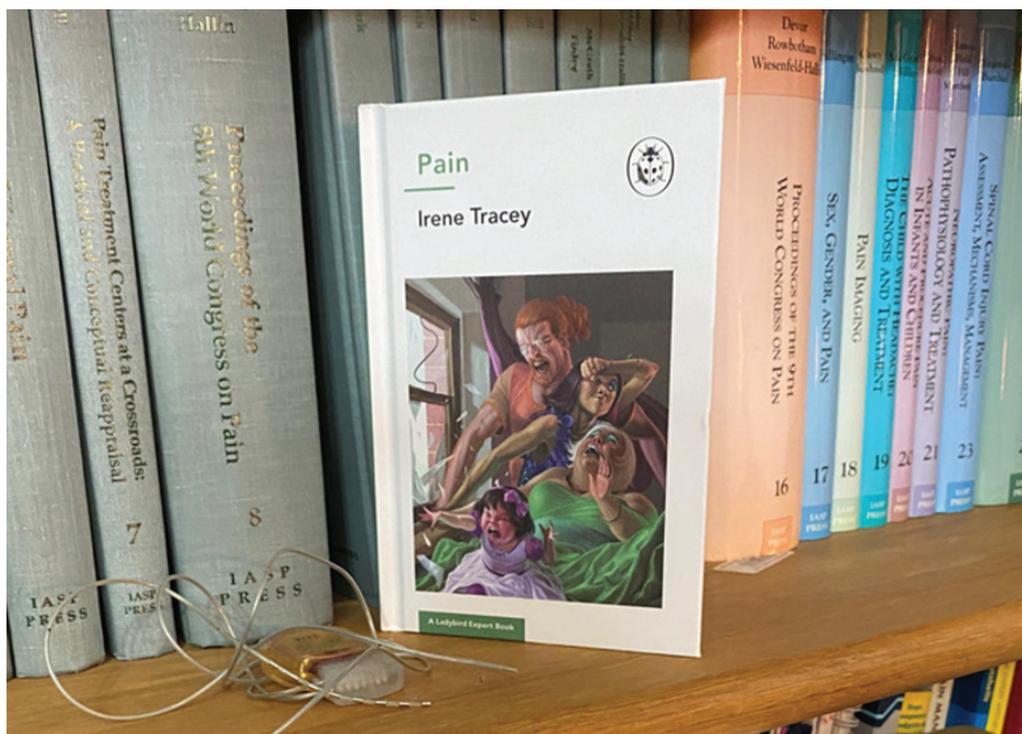
book to do that level of explanation so we will have to turn elsewhere.

I hope this book will reach a wide range of people and in my view should be a primer for every medical student and junior doctor.

Of course, most senior clinicians in pain (whether they are doctors, nurses or psychologists) would understand everything in more detail but the great success of this book is to present profound concepts in friendly bitesize chunks.

One of the questions that I always ask myself when reviewing a book is whether it would have a place on my bookshelf. I would with no hesitation say 'yes' in this case, and indeed to illustrate the point, I have put this book on my bookshelf with a stimulator – for those of you wondering, the small device next to it is a spinal cord stimulator I use as an aid to patient explanation.

I hope that this book receives the wide reading it deserves and perhaps a few of these should be scattered around many pain clinics and PMPs so patients get a chance to browse it. The illustrations might naughtily make their way into some of my slide presentations for pain teaching but I guess I should ask Irene and Steven Player first! And if Santa does not bring you a present next Christmas, perhaps you should buy yourself a copy and put it in your own stocking.



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*120 patients with paravertebral muscle hardening as an accompanying symptom of mostly degenerative spinal conditions.⁴