THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

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THE BRITISH PAIN SOCIETY
PAIN NEWS

contents

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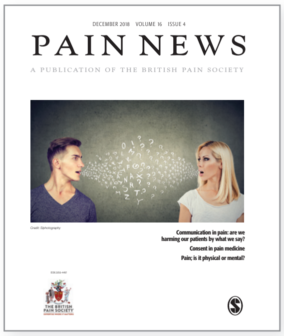

DECEMBER 2018 VOLUME 16 ISSUE 4

PAIN NEWS

A PUBLICATION OF THE BRITISH PAIN SOCIETY

Credit: Siphotography

Communication in pain: are we harming our patients by what we say?

Consent in pain medicine

Pain; is it physical or mental?

ISSN 2050-4497

The Editor welcomes contributions including letters, short clinical reports and news of interest to members, including notice of meetings.

Next submission deadline : 4th January

Material should be sent to:

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https://www.britishpainsociety.org/for-members/pain-news/

THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

The British Pain Society
Meetings & Events

Bringing pain education to life through story telling: Pain Education SIG Study
1st March 2019
Churchill House, London

The British Pain Society are proud to present an interactive study day hosted by the Pain Education SIG exploring how patient stories and service users are contributing to pain education and the challenges encountered when facilitating and contributing in such opportunities.

52nd Annual Scientific Meeting
1st-3rd May 2019
Hilton London Tower Bridge

The British Pain Society would like to invite all healthcare professionals to attend its 2019 Annual Scientific Meeting (ASM), which will be held at the Hilton London Tower Bridge.

The multidisciplinary nature of the Society's is pivotal to the continuing success of its Annual Scientific Meeting. This is reflected throughout the scientific programme, with lecture, workshop and seminar topics chosen specifically to be of interest to all participants, whatever their specialty.

The Social Impact of Pain - Pain Management Programmes SIG Biennial Conference
11th & 12th September 2019
Bristol

Placing the spotlight on the BiopsychoSOCIAL.

Epidemiology of chronic pain; Promoting Social Connectivity; Pain expression in social and cultural contexts; Social Prescribing; The challenge of capturing social outcomes. We need your drive, enthusiasm and energy to explore these factors and consider their application to Pain Management.

Further details for all our meetings can be found on our events listing page:
www.britishpainsociety.org/mediacentre/events/

Editorial

The contagion of pain

THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

Pain News
2018, Vol 16(4) 151–152

SAGE

Rajesh Munglani *Editor Pain News*

Credit: Exdez

Dame Sally Davies, Chief Medical Officer (CMO), allegedly became very concerned about the possibility of long-term widespread use of antibiotics to treat lumbar spinal pain. This was because some studies suggested certain types of disc degeneration might be due to a long-term infection with the organism *Propionibacterium acnes* which was found in one study to be present in 46% of low back pain patients with Modic type 1 changes.[1] While the jury is still out on the significance of these changes,[2] a search on the Internet will find many patients testifying how a course of antibiotics dramatically helped their back pain. A wonderfully easy solution perhaps? The CMO was reportedly worried by the possibility of over and misuse of antibiotics leading to a further rise of antibiotic resistance and its effect on such vital therapy becoming useless in other life-threatening conditions[3] if a large percentage of the general population who suffer from low back pain (up to 50% at any one time) were offered antibiotics.

We recognise that many (infective) disease processes can be associated with intense pain such as Chikungunya,[4] but limiting the 'spread' of pain to only the biologically based mechanisms fails to appreciate other more significant mechanisms that may be also involved in transmitting the experience of pain.

There are some intriguing observations from studies looking at the epidemiology of back in Germany.[5] Prior to division in 1945, the two Germanys shared similar genes and history from 1871 to 1945. Post Second World War, the (Eastern) German Democratic Republic war reported lower life expectancy (by over 3.5 years for men and just under 3 years for women) and also had higher rates of smoking, obesity, and alcohol consumption. Despite this, just after reunification in October 1991, studies in the former eastern states consistently reported a 12%–16% lower prevalence of back pain (27% instead of 39% of the total population in one study) and 10% fewer days off due to back pain (6% in the East compared to 16%) than in the (Western) German Federal Republic. Controversially, projecting these results, in terms of proportions of clinically relevant pain clinic referrals, this might represent perhaps a third to a half of those patients with back pain who might visit a clinic.

Following reunification, there was a merging of the healthcare systems and the five new (former Eastern) Federal States and East Berlin were abruptly were exposed to western political, economic, health care, social security and labour market systems. As expected life expectancy rose in the former East following reunification, and so the difference *decreased* leading to only 0.5 years difference between the two former halves by 2002. This was mainly attributed to improvements in material life conditions, health behaviours and health care.

However, paradoxically, at the same time, the low back pain prevalence rapidly *increased* in the former East during so that by towards 2003, the prevalence was more or less identical to the high levels seen the in the West. Back pain-related work disability also increased from 1991 to 1996 and thereafter has continued to parallel the changes seen in the original states of the (Western) German Federal Republic.

Many biologically based theories were offered for this rather alarming change in prevalence of back pain including the fact that following reunification, there was a migration of 1.5 million healthy young East Germans to the West. The idea being that, by leaving older people who experienced more back pain behind, the prevalence of back pain increased in the remainder in the former East. However, none of these biologically based theories have really provided a satisfactory answer.

Instead, it was proposed by the authors of the study that after reunification, all the social and cultural 'back myths' and misconceptions about back pain pervasive in Western societies were rapidly disseminated in East Germany – a psychosocially infective rather than a biologically infective process.

But what about identical surveys of back pain between similar-wealth Western European countries? One might expect very similar prevalence of back pain. In fact, the prevalence of significant pain using the World Health Organization (WHO) criteria were 22% in the United Kingdom compared to 44.9% in Germany.[6] I would also add that out of all the sampled areas in the United Kingdom, the prevalence rate was the lowest in Cambridge (☺).

Clearly, there are many factors to explore besides genetics and infection. The alarming conclusions of these studies may include that some aspects of individual (illness) behaviour may be negatively influenced by modern medical practise and national social support structures by promoting disabled rather than enabled patients.

It is clear that while pain is an intensely personal experience ('*none of us can feel another's pain' is an oft quoted phrase*), individual and societal belief structure and acceptability about illness (and pain) behaviour may be far more important than biologically determined contribution perhaps, in about a quarter to a third of our patients. To say to these patients affected that their pain is not real in any way, in my view, misses the point about how powerful these mechanisms are. The challenge is to identify and treat appropriately.

Serendipitously, as I wrote this, three papers exploring the harm we may do to our pain patients by the words we use dropped into my *in box*. I invited Peter Wemyss-Gorman to write an introduction to them, which he has entitled *The Language of Pain.*

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5. Raspe H, Hueppe A and Neuhauser H. Back pain, a communicable disease? *International Journal of Epidemiology* 2008; 37(1): 69–74.
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Editorial

In this issue ...

Jenny Nicholas

Pain News
2018, Vol 16(4) 153

SAGE

Jenny Nicholas

Where to start? There has been a hive of activity in preparing this, the December issue of *Pain News* for our members, providing yet another issue of full and varied content.

We begin by debating whether *Access to Pain Relief is a Human Right?* Dr Marcia Schofield and Dr Raj Munglani propose their arguments for and against this question. What are your views?

Language and Pain is discussed across several articles in this issue from authors including Michael Bavidge, Betsan Corkhill, Krithika Anil and Antony Chuter.

We continue the theme of *What does valid consent look like?* In the third and final part, we discuss *Law and implications for practice*. The story concludes by discussing the detailed implications of the change in law in relation to specific pain management scenarios.

Finally, we end this issue with a poem by Kit Loke on *Metaphorizing my pain*.

Enjoy!

THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

ANNUAL SCIENTIFIC MEETING

Save the date!
2019 ASM

1st – 3rd May 2019, Hilton London Tower Bridge
52nd Annual Scientific Meeting

Confirmed Sessions include:

- Compassion focused therapy for pain: how to use self-compassion to soothe pain-related distress, self-criticism and allow pacing of activity
- Acute neuropathic pain update
- Patients as research partners
- How can surgical practitioners deliver effective reassurance to people with back pain who are not offered surgery?
- Addressing the evidence to practice gap in pain management
- Squaring a circle: new models for pain services
- Essential Pain Management (EPM) – a universal structure for teaching pain management to healthcare professionals
- Growing up with chronic pain: trials and tribulations in adolescence
- Benefits of multi-disciplinary decision making in neuromodulation: improving patient satisfaction and outcomes
- Biologics for pain
- Benzodiazepines and opioids – interactions, management and impact on rehabilitation outcomes
- How to maximise the effect of your interventions - selection and technique

Why you should attend:

Network with colleagues
Raise questions, partake in debates and discuss outcomes
Keep up to date with latest research, practice and developments relevant to pain
Meet with poster exhibitors and discuss their research
Find out about the latest developments in industry

We look forward to seeing you there!

Regulars

Dr Arun Bhaskar

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2018, Vol 16(4) 155

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After the summer heat, things are cooling a bit and the autumnal colours are brightening up the evenings indicating the change in seasons. The ASM has been the seminal event that brought together the Society's membership as well as generate the funds that are required to run the BPS offices and activities around the year. Reduction in membership numbers, paucity of industry support, a choice of a variety of scientific meetings and the increasing costs of organising meetings, all have contributed towards reduced attendance at the 2018 ASM in Brighton. When we were planning the 2019 ASM, originally scheduled to be held in Belfast, the feedback we received from delegates and industry colleagues was not very supportive due to travel times and a perception that it is better to organise it in the mainland. This was further debated at Council and among the Executives and it was finally decided to hold the 2019 ASM at the Tower Bridge Hilton, London. We are looking at changing some of the format of the ASM to make it more engaging and also giving great opportunities to network with colleagues as well as industry partners who are showcasing the latest technology. Hopefully this would give us pointers for the 2020 ASM.

I would also like to take this opportunity to highlight the importance of being part of The British Pain Society. I fully acknowledge that BPS as an organisation should pay more attention to facilitate networking opportunities for its members whilst delivering a high quality scientific programme; this is the first step in that direction. I would kindly request each and every one of you to consider joining the Society so that we can make the Society stronger and enriched by its MDT. Increasing the membership numbers to encapsulate all members of the MDT dealing with pain and your support by attending the ASM are two of the sure-shot ways to address the financial concerns facing the organisation. Our aim is to mitigate the losses in 2019 and consolidate the finances by 2020; I am sure we can do that with your support. We have a strategy planned, but I would very much welcome your suggestions in this matter.

Dr Andrew Baranowski

Pain News
2018, Vol 16(4) 156–157

SAGE

In my last editorial for *Pain News*, I finished by briefly looking to the future and that future is slowly rolling out.

The British Pain Society Annual Scientific Meeting of 2019

Many of you will have seen that there has been a change in location for the 2019 Annual Scientific Meeting (ASM) from Belfast to London. The change will enable us to take the opportunity to review the structure and format of the ASM for 2019 and beyond. I like many others am disappointed that we have had to withdraw our ASM from that great city. Please see the article by Arun Bhaskar as to why the Executive Officers and Council made that difficult decision.

The Secretariat

The Secretariat, led by Jenny Nicholas, does an amazing job under difficult circumstances. They are small in number with a large workload. Dylan Taylor joined us earlier this year working to support many of the Committees and it has been a pleasure to see him getting to grips with the many activities of the Society – well done Dylan. Casey Freeman covering Dina's maternity leave was a wealth of experience; unfortunately, we were unable to keep her, as she was head hunted – well done Casey. Dina Almuli has returned from maternity leave and we are all pleased to have her return.

Review of the Secretariat

Casey's last role was to look at the structure of the Secretariat and to use her experience to make suggestions on how we could support and develop the Secretariat in the future. Ayman Eissa, in his role as Hon Secretary Elect, reviewed that report with our CEO, Jenny Nicholas, and made proposals to the Executive Officers for the future.

Separating time out for a fundraising member of the Team was identified as a priority only second to further investment in making the ASMs' secure for the future. As a consequence, keeping outcome of the review simple, we will be:

1. Looking at outsourcing parts of the 2019 ASM, particularly those elements around income generation and trade.
2. Consolidating our aims around both pro bono fundraising advice and longer term employing a member of the Secretariat to ensure we have a dedicated team member for fundraising.

Fundraising

Over the last few years, fundraising has been a priority but we have to admit that it is not something we are good at. The Society does an amazing amount of work around guidelines, consultations on government and other publications and highlighting issues around national strategy; but, it is difficult to turn that into income generation. For several years, the Executives and Council have agreed that we need a fundraiser; my problem has been defining what we need so that we do not waste money! Casey helped us to define such an individual. We have also agreed to a process around bringing in expertise to Council by experts pro bono. For a Society such as ours, this is all new ground and if you have expertise in the field, please share your advice with us.

Ciaran Wazir

Many of you will know Ciaran. He will be joining the Team to help us work with Trade at the ASM. From a financial perspective, a major problem has been maintaining Trade involvement at the ASM. We have devised different packages and incitements, but the bottom line is that they also need to have new products on the market to work with us. Slowly we are seeing these new products coming through and Ciaran will help us work with the companies to ensure all our needs are met.

The power of the masses

The independent consultant 'Google Group' as many of you may know is a group of around 650 plus members. Many are also members of The British Pain Society. This is primarily a group of doctors though there are many who are allied professionals. Over the years, they have discussed over 4846 topics (as of

Dr Andrew Baranowski

20 August 2018). On 18 July, G Baranidharan asked the Google Group 'Has anyone had in your patch, a complete stop of Lidocaine plasters for anything other than PHN? We have been asked in our area to raise this with NHS England if we are allowed to use this'. Over the next few days, Marcia Schofield suggested writing a letter, at first to *Pain News* and then it was suggested that a letter to *The Times* should be formulated. This resulted in around 100 signatures being attached to that letter and The Society writing a statement expressing our grave concerns that these patches were being restricted, which was published on our website. Well done Marcia. A copy of The British Pain Society formal statement can also be found later in this edition of *Pain News*.

Commissioning inequalities

The structure and process of commissioning services was something that was raised at the Parliamentary Reception in late October 2017. This was also an issue recently raised again by the consultant Google Group. The British Pain Society Execs feel that this is something that we need to keep our 'finger on the pulse'. In future editions of *Pain News*, we aim to have a few extracts from the Google Group and emails that I have received on this topic. There are different arguments, but at the end of the day, what we do need to push for is transparency of process to ensure it is fair.

British Pain Society and Maps of Medicine Pathways of Care

One of the greatest projects I oversaw was the development of these pathways. My greatest regret was that they were not made freely available. After several discussions, over a number of years, we are now working to having the pdf versions of these available on the British Pain Society (BPS) website. Whereas they are a bit dated, the principles are the key to commissioning equitable services.

Change

There is no doubt that the Society will have to change to meet the future needs of its members to provide equitable excellent care to those living with chronic pain. There is a lot of pressure on services and the specialists that work in them. I am working to handing over to the new Team in six months' time.

From the Honorary Secretary

Roger Knaggs

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Membership update

Overall membership numbers remain relatively stable around 1150. The major professional groups are anaesthesia (523), nursing (151), psychology (126) and physiotherapy (101).

Council elections 2019

Although it may seem some time away, I would like to highlight that the nomination process for Council elections in 2019 will begin early in the New Year. Last year, there was a very healthy number of nominations, and it was pleasing that we were able to have so many new members join the Council. This year forthcoming, there will be two seats that become vacant.

In order to ensure that multidisciplinary representation on Council remains, I encourage all non-medic members to think about colleagues who may be able to best represent their discipline or consider standing yourself. While the role does require commit to attending Council meetings regularly and participating in the decision-making process of the Society, it can be very enjoyable and rewarding. If you would like to know more about what the role involves, please do not hesitate to contact me or any current Council member.

The next few years are going to be critical for the British Pain Society and why not consider playing a part in shaping the future of pain management in the United Kingdom.

Medicinal cannabis

Over the summer there was considerable media coverage of several children with rare forms of epilepsy who had been using cannabis medicines obtained from other countries. In the last issue of *Pain News*, there was a personal perspective on the use of cannabis-containing medicines for pain written by the new editor, Raj Munglani. Since a position statement from the European Pain Federation has been published.[1] One of the key recommendations is treatment with cannabis-based medicines should only be considered as part of a multidisciplinary treatment plan and preferably as adjunct medicine if recommended first- and second-line therapies have not provided sufficient efficacy or tolerability.

Given the pace of activities, it is likely that legislative changes will have occurred before publication of *Pain News*, so it will be necessary to keep abreast of both legal changes and new commissioning guidance.

Pain News

In my last column, I was very pleased to welcome Dr Raj Munglani in his role as editor of *Pain News*; however, I was slightly surprised when my copy landed on my doorstep and was amazed at the amount of material he had been able collect in such a short space of time. Without seeing the proofs for this issue, I understand that there is now more copy that the maximum number of pages for each issue. This is a great achievement, and I hope that you will enjoy reading this issue. In order to make this a complete representation of the British Pain Society, do think about what you would like to hear about and perhaps more importantly what you would like to share with your fellow members.

I wish you a peaceful and relaxing festive season when it arrives.

Reference

1. Häuser W, Finn DP, Kalso E, et al. European Pain Federation (EFIC) position paper on appropriate use of cannabis-based medicines and medical cannabis for chronic pain management. *European Journal of Pain* 2018; 22(9): 1547–64.

Have your say and contribute to *Pain News* today

Pain News is the newsletter for members of the British Pain Society and we welcome member and non-member contributions to share your news with the wider membership and beyond.

Do you have a news item to share?

Perhaps a professional perspective, or informing practice piece?

Maybe you would you like to feature as our 'Spotlight' member?

We'd love to hear from you so drop the Editor an email today at: rajeshmunglani@gmail.com

Upcoming submission deadlines:

Issue	Copy deadline
March 2019	4th January 2019
June 2019	29th March 2019
September 2019	14th June 2019
December 2019	27th September 2019


JUNE 2018 VOLUME 16 ISSUE 2

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Credit: Studiovin

Focus on pain research day

Consent in Pain Medicine

Increasing access to psychological services (IAPT) and pain services

ISSN 2050-4497

THE BRITISH PAIN SOCIETY

EXPERTISE WHERE IT MATTERS


SEPTEMBER 2018 VOLUME 16 ISSUE 3

PAIN NEWS

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Credit: Eva-Foreman

A role for cannabis in pain?

Is there a future for pain physicians?

Consenting in pain medicine

Will we ever be able to measure pain?

ISSN 2050-4497

THE BRITISH PAIN SOCIETY

EXPERTISE WHERE IT MATTERS


DECEMBER 2018 VOLUME 16 ISSUE 4

PAIN NEWS

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THE BRITISH PAIN SOCIETY

EXPERTISE WHERE IT MATTERS

News

THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

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SAGE

Is access to pain relief a human right?

Marcia Schofield *Pain Medicine Physician*
Rajesh Munglani *Consultant in Pain Medicine*
Chloe Gamlin *Medical Student Lucy Cavendish College, Cambridge*

> *The arc of the moral universe is long, but it bends toward justice.*
>
> Martin Luther King, Jr.

This article is taken from a live debate between Dr Rajesh Munglani and Dr Marcia Schofield held at Lucy Cavendish College, Cambridge Medical Society in November 2016. No vote was taken, but lively debate followed before an audience made up of medical students and others including students and dons from various colleges from the disciplines of medicine, law, theology and philosophy.

It was followed, as all passionate debates are, in such august Cambridge college surroundings, by a banquet and we shared a cup of wine to soothe each other's ruffled feathers and committed to a continued mutual respect for each other's position.

Dr Rajesh Munglani, Consultant in Pain Medicine, St Thomas Hospital; Chloe Gamlin, Medical Student and President of the Lucy Cavendish Medical Society; Dr Marcia Schofield, Pain Physician and Alumina of Lucy Cavendish.

No, access to pain relief is not a human right – proposed by Dr Rajesh Munglani

In my view, the simplicity of the question, and the seemingly obvious answer, belie the deep complexity of two questions: what is a human right, and what is pain?

The right to be free from torture, and from cruel, inhuman and degrading treatment or punishment is seen as a fundamental human right. However, neither the Universal Declaration of Human Rights 1948[1] nor the European Human Rights Convention 1953[2] specifically elevate pain relief to the same status of a fundamental right.

Despite this, a number of transnational bodies have elevated pain relief into something approaching a right, with some going so far as to assert that it *is* indeed a right.

The World Health Organization (WHO) has long agreed on the absolute necessity of the availability of opioid analgesics. In 1961, the UN adopted the Single Convention on Narcotic Drugs, declaring the medical use of narcotic drugs indispensable for the relief of pain. Pain relief as a human right was promoted by the International Association for the Study of Pain (IASP) in 2004, and crystallised at the World Congress of Pain in Montreal in 2010. In that same year, Lohman et al.[3] stated that in his view, international human rights law meant that governments must ensure that people have access to pain relief, and as a minimum they must ensure the availability of morphine. Therefore, failure to make morphine available was a violation of the right to health, and was cruel, inhuman and degrading treatment.

But what are the implications of these seemingly impressive statements? The ability to perceive pain is built into us. Pain is not an unwanted part of the human condition – the presence of a pain system is essential to our survival. People who do not feel pain have a shorter life expectancy, because the ability to feel pain draws our attention towards a source of danger that may be causing bodily harm. But pain is far more complex than being something that provokes a reflex, such as withdrawing one's hand from a candle flame. In human beings, pain is invariably associated with feelings of distress and suffering. Is this really pain?

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.[4] This unsatisfactory definition is the result of a debate that has been going on for the last 2,500 years as to whether pain is on the one hand a sensation, like touch, or whether it is on the other hand more a feeling or emotion. The theory that pain is a feeling or an emotion was supported by Aristotle, who considered the heart to be the seat of feelings. In his theory, to experience pain is to have an emotion like pleasure. Galen, a doctor from Alexandria in around AD 150, disagreed with Aristotle, and placed pain completely within the sphere of sensation, arguing that it was like the experience of touch or temperature. As doctors we also recognise that even if the pain started out as an actual physical insult, as time goes on, it certainly becomes more emotional and self-sustaining in the brain, suggesting in my view that the Aristotelian position was correct.

This same model suggests that those patients who have suffered prior emotional trauma, distress or childhood abuse are more likely to develop chronic pain, even in the absence of physical trauma. Their deficient pain-control systems are probably not due to a primary lack of endorphin/morphine production but more likely due to an apparent deficit of other neurotransmitter systems associated with resilience of mood, such as the noradrenergic and serotonergic systems. However, despite the different pathophysiologies, the diagnosis of pain continues to be based almost exclusively around the physical paradigms; certainly the descriptors are usually in the physical realm, even for those conditions with a very probable psychogenic basis, for example, fibromyalgia (literally ‘tissue-muscle pain’).

It is extraordinarily difficult as either a doctor or other health-care prescriber to withhold pain medication when somebody is complaining of pain, whatever the cause. Their pain may not be attributable to any physical cause, but their description and experience is invariably one of physical pain.

In recent years, opiates became the pain medication of choice in such chronic-pain states. The addictive nature of opiates has been recognised for a long time, which is why opiate-based drugs have been placed under legal control. Until the early 1980s, there were only a few parts of the world where patients had access to strong opiates, but a landmark paper in 1986 by two physicians changed everything.[5] It concluded that opioid maintenance therapy can be a safe, humane treatment in those patients with intractable, non-malignant pain. There then followed the liberalisation of opioid therapy, with an over 1,000% increase in the availability of opioid-based drugs in the next two decades.

At the same time, pain relief was touted as a human right and linked with opiate availability (IASP, 2004). The failure to treat pain was seen as both clinical and legal negligence, with respected figures such as Somerville,[6] a professor of law at McGill University, arguing that the right to pain relief was in fact already enshrined in Article 5 of the Declaration of Human Rights: This states that ‘no one should be subject ... to inhuman or degrading treatment’, and although it was meant to be about the treatment of prisoners, it was now applied to patients.

None of us can feel a patient’s pain, and if the patient says that the pain was relieved every time the dose of morphine was increased, who could argue with them? Using the legal argument, doctors were warned that they could be sued for not providing enough pain relief. This led to a diktat to ‘treat to effect’; in other words, give as much of a drug as is required until pain relief is achieved. There was no upper limit given for doses of opiates. Devulder et al.[7] argued that function and quality of life improved in patients given long-term opioids.

Morpheus is the God of dreams. Morphine may help you dream for a bit, but the reality is, having swallowed the red pill and dived down into the matrix of the ‘rabbit hole’, you eventually realise you are literally dreaming. You wake, craving your next dose. Nothing has changed, and the wonderland turns into a nightmare.

But this realisation has come too late for some communities in the United States, as they have already been destroyed. In 2013, Sean Dunne made the award-winning documentary film *Oxyana* about Oceana, an old coal-mining town in West Virginia. Nestling deep in the Appalachian Mountains, Oceana is typical of an increasing number of ex-industrial communities in the developed world suffering from the effects of globalisation and the subsequent growth in local unemployment. Wyoming County, West Virginia, population 23,200, had the state’s highest rate of fatal overdoses in 2011, with Oceana the seeming epicentre of the oxycodone-addiction epidemic. Residents appear to choose to numb the pain of poverty, low self-esteem and hopelessness with liberal prescriptions of oxycodone – oxycontin – hence the name of the film.

Outcome studies were starting to sound alarms from as early as 2003. In Denmark, where 3% of the population were on strong opioids at any one time, Becker et al.[8] showed that there was no evidence that strong opioids were associated with any improvement in quality of life – in fact, just the opposite. These disturbing findings have been replicated around the world: Dillie et al.’s[9] landmark article in 2008 showed that quality of life declined as doses increased above 120 mg of morphine a day. In a review of all evidence published prior to 2010, a Cochrane review[10] showed that ‘*quality of life and functional status were* *inconclusive due to an insufficient quantity of evidence for oral administration studies and inconclusive statistical findings for transdermal and intrathecal administration studies*'. In 2018, in the largest study to date, with over 5,000 participants, Hayes et al.[11] showed that there was no difference in 12-item short-form health survey (SF-12) outcomes among chronic-pain patients who either did or did not take opioids. It is ironic that the same leading authorities who encouraged us to prescribe are now telling us to stop prescribing opioids.

It is clear that an analysis of the patients who are prescribed opiates show that the most distressed patients are the ones least likely to benefit from them. In short, mentally distressed people present with physical pain symptoms and are given opiates that do not address the real or main cause of their pain, which is actually emotional, psychological or psychiatric in cause. Morphine is not a cure for this. Liberal prescribing of morphine and other opioids has made life worse, rather than better, for millions; and their pain is still not relieved. Morphine and other opioids have killed increasing numbers of chronic-pain sufferers.

From 1999 to 2015, more than 183,000 people have died in the United States from overdoses related to prescription opioids. In 2015 alone, more than 15,000 Americans died from overdoses involving prescription opioids, while 12,000 died from complications of HIV. Incorrectly interpreting suffering as pain leads to wrong treatment, overdosage and death.

The very fact that we are able to feel both pleasure and pain in equal measure is what makes us human. But as a consequence, we can suffer. The right to the relief of suffering is something we can all agree upon. If that were the question, tonight I would be on the other side of the debate.

I would appeal to you all not to support this motion – it is the wrong question to ask. We should not be asking whether pain relief should be a human right, but instead how we as a society should promote instead the universal relief of suffering of all those who share our humanity.

Yes, access to pain relief is a human right – proposed by Dr Marcia Schofield

My honourable colleague has made some good points in his argument. But I would suggest that he is not answering the principle of the debate. The key is whether one supports the Aristotelian or Galenic interpretation of pain.

It is unfortunate that prescribing of opioids for suffering, depression and low self-esteem has been spreading, due in no small part to aggressive marketing of opioids by companies.[12] Part of the reason for this is because of the lack of pain-management education in medical school. Indeed, our own survey[13] showed that medical students get, on average, only 2 hours of pain-management education, whereas veterinary students receive 80 hours on average. But we are not discussing bad prescribing. We are discussing whether access to pain relief is a human right, as the concept is defined by the UN Convention, EU Declaration and other international conventions.

When the IASP published its Declaration in Montreal in 2004, suggesting access to pain relief is a human right, it was based on their interpretation of the UN Universal Declaration of Human Rights[1] Article 5, which states: '*No one shall be subjected to torture or to cruel, inhuman or degrading treatment* ...'. Therefore, deliberately ignoring a patient's need for pain management or failing to call for specialised help if unable to achieve pain relief may represent a violation of Article 5: '*This declaration ... recogniz[es] the intrinsic dignity of all persons and that withholding of pain treatment is profoundly wrong*'.

Article 2 of the UN convention proclaims the universality of its treaty:

> *Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth ... political, jurisdictional or international status of the country or territory to which a person belongs*.

Furthermore, the right to health is enshrined in Article 25 of the UN Convention (and reiterated in the European and the UK Conventions):

> *Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care ... and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control*.

Therefore, according to international human rights law, every country (Article 2) has a core obligation to provide pain treatment medications as part of the Article 25's right to health care; and failure to take reasonable steps to ensure that people who suffer pain have access to adequate pain treatment may result in the violation of Article 5's obligation to protect against cruel, inhuman and degrading treatment.

In 1961, governments around the world adopted the Single Convention on Narcotic Drugs.[14] In addition to addressing the control of illicit narcotics, the convention obliged countries to work towards universal access to drugs necessary to alleviate pain and suffering. Hence, much of the treatment of pain worldwide has focused on drugs in general and opioids in particular. In 1986, the WHO, recognising the delay in implementing the 1961 treaty, published the WHO Pain Ladder, which helped health-care professionals all over the world to begin to understand that there were simple steps to the treatment of pain in cancer and terminal diseases. However, this ladder was specifically designed for the pain of terminal illness with an expected limited lifespan.

Although the focus of my honourable colleague's argument is overuse of opioids in the developed world, it is worth remembering that poorer countries consume only 6% of the morphine used worldwide, even though they are home to about 50% of all cancer patients and more than 90% of HIV infections.[15] The IASP Declaration[16] further noted '*that there were severe restrictions on the availability of opioids ... critical to the management of pain*'. What the convention does not specify is how that pain should be treated. No one has a human right to ineffective and dangerous treatment.

UN Article 25 spells out the right to access medical care, including pain-relief medications, as necessary to maintain health and well-being, whatever a person's age, whatever the conditions. We know that pain is a crippling and debilitating condition that affects all aspects of an individual's life.

Which brings me to my second point: is chronic pain a disease?

The trouble is that we can't even seem to agree if pain is a symptom, a disease or merely a disorder characterised by the very pejorative term 'medically unexplained symptoms' (MUS). How does one measure an emotional experience of potential tissue damage? I would argue that from this arises a sneaking suspicion that a patient with MUS who claims to be in pain cannot be believed. If we look at it from the patient's perspective, a health-care professional who labels the patient with MUS and all it implies – lack of credibility, drug-seeking behaviour, attention-seeking or worst of all, a psychiatric disorder(!) – has already made the distinction between a 'deserving' and 'underserving' patient, immediately violating the universality principle.

The IASP definition of pain is derived from a 1964 definition by Harold Merskey, first accepted by IASP and published in 1979 in the journal *Pain*. Pain is defined as '*an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*'. We would all agree, or seem to agree, that surgery or injury or tumours are likely to cause pain and should be appropriately treated. Where the disagreement comes in is when the cause of a chronic, disabling pain cannot be seen or detected.

The IASP Declaration addresses these concerns by simply stating that chronic pain, with or without diagnosis, is highly stigmatised, and further asserts that '*there are major deficits in knowledge of health-care professionals regarding the mechanisms and management of pain*'.

If pain is a disease in its own right, then withholding treatment or access to health care is a clear violation of UN Article 25. No one would argue that surgery should take place without appropriate anaesthesia or analgesia, so how can it be right to deny the same access to pain medicines or – crucially – other treatments for patients with advanced cancer, severe neuropathic pain or who are permanently affected by crippling, painful lifelong conditions?

The International Classification of Diseases – 11th Revision (ICD-11) beta version has no less than seven different diagnosis codes for chronic pain. The authors of the ICD clearly believe that not only is pain a disease and a stimulus for seeking medical advice and attention (no matter if the pain is acute or long-term), but they attempt to differentiate between various types of pain experience.

The authors of the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-V), however, appear to disagree. They put chronic-pain disorders in a new diagnostic category called Somatic Symptom and Related Disorders, symptoms associated with 'significant distress and impairment', observing that if there is a 'somatic' or unexplained biomedical contribution in chronic pain, then the 'somatic component adds severity and complexity to depressive and anxiety disorders and results in higher severity, impairment, and refractoriness to treatments'. In other words, these patients are depressed and neurotic, and one should not attempt to treat them.

The authors of *DSM* clearly believe that chronic-pain disorder is a mental diagnosis, whereas those who wrote the ICD believe it is a disease. Many pain disorders do have a clear medical explanation for symptoms and have independent medical diagnostic criteria of their own. But some people have complex and poorly understood mechanisms that may be responsible for the onset and perpetuation of their pain state. Indeed, this year, the coroner's office has accepted myalgic encephalomyelitis (ME)/fibromyalgia as a cause of death, rather than a mode of death. So, who is right?

As little as 50 years ago, doctors were telling amputees that their phantom-limb pain was 'all in their heads' and that they just needed to buck up.[17] We now know that it's not in their heads, but it is in their brains. Neuroimaging has begun to help us understand areas that affect pain perception. Neurobiology and neuro-immunology are fast-growing fields, and yesterday's medically unexplained 'somatic' symptom is today's splanchnic viscera–visceral interaction. As we learn more about the body's immune and nervous systems with novel imaging and research techniques, more and more of these 'unexplained' phenomena reveal themselves.

If we accept that pain and chronic pain are diseases that require treatment, we must accept that the all-treaty provisions pertaining to health access, freedom from torture and degrading treatment apply equally to access to pain relief.

Inadequate access to pain management persists worldwide, especially in developing and poorer areas. In the United States, poor practice and overprescribing has led to diversion, inappropriate dose escalation, dependency and death. In Western Europe, not only overprescribing but also under-estimation of pain severity and under-treatment of pain are also common. By misunderstanding the nature of the pain experience, and the use of a unimodal strategy, pain slips down the list of health priorities until the sufferer becomes invisible – alone and suffering, degraded and tortured.

We also have innovative non-drug treatments that can help amputees and other pain sufferers lead relatively normal lives by helping them to control their pain and allowing them to get on with participating in life – but only if we acknowledge that they are entitled to them by right. And we need to train our health-care workforce accordingly.

Integrated approaches to pain have developed within the pain medicine movement and within the hospice and palliative care movements. Medicines alone may not be the answer, but they may be part of an integrated approach and, hence, should be available to everyone who needs them as a human right. By prioritising pain assessment, education on pain management and research into all of the aspects of pain, we can at least hope to do as well as our veterinary colleagues, to uphold the provisions of the UN and EU treaties and offer access to pain relief as a fundamental human right.

So, is access to pain relief a human right? The answer to this is a clear yes.

Perspectives from the audience – by Chloe Gamlin

It was my pleasure and privilege, on behalf of the Medical Society, to welcome Dr Munglani and welcome back Dr Schofield to debate at Lucy Cavendish College on a crisp November afternoon.

To my delight, having previously studied history of medicine, both speakers acknowledged the role of Aristotelian and Galenic theories in shaping medical thought. Yet for us medical students in the room, a third ancient philosopher was the key to our understanding and interpretation of pain: Socrates.

Indeed, any patient presenting to a medical student with pain will be subjected to questioning about its Site (where is it?), Onset (when did it start?), Character (sharp or dull?), Radiation (does it spread anywhere else?), Associations (do you feel sick or sweaty?), Timing (when does it start or stop?), Exacerbating (or relieving) factors and its Severity (on a scale of 1–10).

With the possible exception of the severity question, the focus, at this admittedly early stage in our medical careers, leans heavily towards the physical attributes of pain as a response to potential tissue damage. Some insight into the emotional impact of a patient's pain might be gleaned through further questioning about its severity, but arguably even this line of enquiry is designed to aid in the diagnosis and management of a physical condition.

Fortunately for us, each side of the debate addressed the inadequacy of this approach from the perspective of a fully fledged medical practitioner, and in so doing, highlighted the importance and power of modern medicine as a tool to alleviate not just pain, but human suffering.

Dr Munglani first presented the idea that pain is in equal measure a sensory and emotional experience, and the challenges that come with managing an inherently subjective condition in the traditional framework of medicalising a physical symptom. This culminated in his core argument that while physical pain ought to be managed by analgesics (including opioids), and thus it would be inhumane to withhold such treatment, often pain is a wrongful interpretation of human suffering, which analgesia alone cannot possibly address.

In response, Dr Schofield, too, discussed the challenges of measuring the subjective emotional experience of pain as potential tissue damage, once again acknowledging the complex nature of pain. She respectfully disagreed, however, that pain relief must be equated with opioid analgesics, and instead drew our attention to the idea that human rights legislation does not specify how pain should be treated. Rather, she advocated for an integrated approach which would see every country with an obligation to provide pain relief under the right to health – as opposed to a right to a potentially ineffective or dangerous prescription, as is potentially the case with opioids.

The debate concluded with a lively round of questions from the audience, spanning topics as broad as the nature of chronic versus acute pain, the legitimacy of mental versus physical illnesses and whether pain is a disease in its own right. Drs Munglani and Schofield wholeheartedly engaged with the audience, and we can but thank them for offering insights and wit as sparkling as the frosty weather.

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News

Lidocaine 5% medicated plasters for localised neuropathic pain: A position statement from the British Pain Society

THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

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The British Pain Society is a multidisciplinary, multiprofessional organisation representing people living with pain and the professionals who care for them.

Neuropathic pain is primarily a clinical description and not a diagnosis. People with neuropathic pain are a heterogeneous group in terms of underlying pathophysiology, clinical symptoms and signs they present with. Many people, for instance, following surgery or injury or after shingles, develop features of neuropathic pain. Fortunately with time, only a very small proportion (2%–5%) is likely to have persistent symptoms. In the general population, the prevalence of long-term severe disabling neuropathic pain is estimated to be less than 1%.[1]

Persistent neuropathic pain affects many dimensions of a person's life and can lead to significant suffering, loss of function, decrease in mobility and reduced work capacity, all of which contribute to decreased quality of life. In most people, pain which becomes persistent cannot be cured and instead has to be managed using an individualised approach that includes education as to the nature and expected course of the condition, medicines, injections and complex interventional procedures, physiotherapy, occupational and psychological therapies.

Current medicines available for localised neuropathic pains are very limited. Many of the oral medicines used to treat persistent neuropathic pain have potentially serious side effects, such as sedation, confusion, dizziness, visual disturbances, falls, dependence and addiction as well as effects on the cardiovascular and renal systems. Appropriate use of topical treatments (i.e. applied directly to the site of pain) for localised neuropathic pain thereby reduces or avoids the numerous side effects associated with the use of oral medicines.

Lidocaine 5% medicated plasters are one of a few topical treatments available for localised neuropathic pain. They only have a UK Marketing Authorisation for the management of persistent neuropathic pain following shingles – otherwise known as postherpetic neuralgia (PHN). However, the reason that the Marketing Authorisation was for PHN alone was simply because it was the only type of peripheral neuropathic pain studied in the registration trials. Since then, there has been considerable experience from pain specialists prescribing lidocaine 5% medicated plasters in other types of peripheral localised neuropathic pain such as post-mastectomy and post-thoracotomy pain, as well as for local scar pain, pain following nerve injury and painful diabetic neuropathy. Current international guidelines suggest that lidocaine 5% medicated plasters are an established second-line treatment for peripheral neuropathic pain.[2]

No medicine, including lidocaine 5% medicated plasters, is effective for more than a proportion of people with neuropathic pain. Like any treatment, we understand that what works for one person may not work for others. At present, there are no tests or predictive factors we can use to indicate whether lidocaine 5% medicated plasters are going to be effective for a particular individual. Pain services therefore often use short sequential trials of different/several medicines to help each person to decide which medicines work best for them.

We acknowledge that pain services have historically and indeed continue to use medicines outside their Marketing Authorisation, so-called 'off-label' use. Some populations (e.g. people under 18 and over 65 years) are often excluded or underrepresented in clinical trials and use of many medicines in these groups is 'off-label' in any case. One class of medicine for neuropathic pain, namely, tricyclic antidepressants, has been used 'off-label' for many years. For over a decade, UK pain services have carefully assessed whether lidocaine 5% medicated plasters are appropriate for people with otherwise intractable localised neuropathic pain for a wide variety of conditions before returning management of the person back to primary care where such prescriptions have been continued.

The British Pain Society supports the widest choice of effective treatment options for people with neuropathic pain. We believe that people have the right to effective medicines with minimal side effects that allow them to lead as normal and productive lives as possible. We believe that right should extend across the United Kingdom, no matter where the person is resident.

The British Pain Society endorses the National Institute for Health and Care Excellence (NICE) clinical guidance CG173 (Neuropathic pain in adults: pharmacological management in non-specialist settings) which states clearly 'Continue existing treatments for people whose neuropathic pain is already effectively managed, taking into account the need for regular clinical reviews'.

In November 2017, National Health Service (NHS) England recommended that lidocaine 5% medicated plasters should not routinely be prescribed in primary care. We suggest that if a person is referred to a specialist pain service and their expert advice is to use lidocaine 5% medicated plasters, then treatment should continue to be funded in primary care. Furthermore, people who have already been prescribed lidocaine 5% medicated plasters should be reviewed to assess efficacy. Where there is evidence of substantial benefit, people should not be disadvantaged by prescribing being discontinued.

We believe that looking after people living with persistent pain is best managed by primary care teams, with recourse to specialist pain services only when required. Indeed, prescribing of current NHS England advice specifically states 'that if, in exceptional circumstances, there is a clinical need for lidocaine 5% medicated plasters to be prescribed in primary care, this should be undertaken in a cooperation arrangement with a multi-disciplinary team and/or other healthcare professional', indicating the need for liaison between primary care and specialist services.

On behalf of the Council of the British Pain Society 02 August 2018.

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Professional perspectives

Language and pain

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Peter Wemyss-Gorman *Retired Consultant in Pain Medicine*

We have long recognised the inadequacy of language for describing the nature and intensity of pain or conveying the experience of suffering, but attempts to 'measure' pain have been largely abandoned and alternative methods of conveying pain and suffering such as art and drawing, though valuable, are of limited availability and practicality in the clinic. Some become adept at reading 'body language' and other forms of 'non-verbal communication', but words remain virtually indispensable in the intercourse between clinician and patient. These issues have frequently featured in our discussions at meetings of the Philosophy and Ethics SIG but this year's meeting was the first in which we have directly addressed the problems inherent in language as a main theme.

Language is of course a preoccupation for philosophers, and in his paper 'Speaking of Suffering', Michael Bavidge helped immeasurably to clarify our often confused thoughts on the subject. He argues that the criticisms of language are misplaced; they start in the wrong place and are the wrong sort of worry about the wrong things. 'We *express* pain and suffering, before we describe them'. Of more immediate importance and applicability to our practice is not so much the problems patients have of expressing themselves but the language which clinicians use to patients. In her powerful article, Betsan Corkhill urges us to think much more carefully about our own words: we can become so used to the medical language we've always used that we cease to consider its effect on others. Words have a powerful potential to set a person down a path of fear and catastrophisation or start them on a journey to wellness and recovery.

The article by Antony Chuter and Krithika Anil, which was submitted independently and coincidentally, has many parallels with Corkhill's. Chuter writes with the authority of a patient with unfortunate experience of the way some doctors have spoken, adding weight to the contention that this neglected area demands our prioritised attention. Rajesh Munglani's September editorial, from a more 'scientific' perspective, describes the tantalising search for biomarkers such as functional magnetic resonance imaging (fMRI) to allow clinicians to bypass the need for a common language to assess the nature and severity of someone's pain. The fact that this search has remained unrewarding after so many years suggests that while it may not be entirely futile it may be asking the wrong question in view of the entirely subjective nature of the experience of chronic pain and suffering. Thankfully, few people now continue to hold the once prevalent view that lack of objective evidence suggests that some pain is not 'genuine'. But the very failure of the search for such evidence points to the continuing necessity to look for ways to help patients find the language, however inadequate, to express their pain, and for clinicians to find words to explain the complexities of pain causation and perception which will reassure rather than alarm.

Professional perspectives

Speaking of suffering

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The problem

There is supposed to be something wrong with language about pain and suffering. David Biro[1] begins his book, *Listening to Pain*, with a discussion about the failure of language to capture the experience of pain. To illustrate the point, he draws on many sources – clinicians, patients and writers. '*Pain*', he says, '*is difficult to express. Language and pain seem as far apart as the opposite poles of an electric current. While language can capture much of the diverse range of human experience, it fails us in the case of pain*'[1] (p. 11).

His anxiety is not confined to language and its limitations. He goes on to ask '*Can we really convey our subjective experiences to another person? Can other people ever understand how we feel?*' These epistemic questions – what we can know and communicate – collapse into a final ominous metaphysical query: '*… are disconnection and isolation just facts of the human condition?*'[1] (p. 19). To be fair, he does not stop there, with a series of sceptical questions or expressions of anxieties about the human predicament. In fact, the whole book is designed '*to help sufferers recover their voice and to generate a rhetoric of pain*'[1] (p. 14). Still these criticisms of language seem strange. It is odd that we, the most communicative of animals, fail so abysmally to communicate an intrusive aspect of our experience. If these failures really are endemic to language, then the best we can do is to guess on the basis of clues and contaminated evidence what is happening on the inside of people's experience.

We need to examine these claims about the failures of language and examine their philosophical roots. Perhaps, a philosophical error underlies the anxieties about the communicative failings of language: we misread personal isolation as the privacy of experience, which leads to, and is bolstered by, a private semantics. As Humphrey Bogart says in the *Barefoot Contessa*, '*There's more to talking than just words*'. Perhaps, the criticisms of language are misplaced. They start in the wrong place: they are the wrong sort of worry about the wrong things. We *express* pain and suffering before we describe them. Through the dynamics of interpersonal expression, we share our feelings and we disclose ourselves.

Italo Calvino[2] writes:

> *There are two different drives that will never attain complete fulfilment, one because 'natural' languages always say something more than formalised languages can – natural languages always involve a certain amount of noise that impinges on the essentiality of the information – and the other because, in representing the density and continuity of the world around us, language is revealed as defective and fragmentary, always saying something less with respect to the sum of what can be experienced.*

A formalised language is a vehicle for transporting information; it is cut adrift from 'the density' of human life so that it can be programmed into a machine and used as the basis of information transfer. Natural languages, particularly expressive forms of natural languages, arise out of our engagement with the world and our responses to it. The 'noise' of natural languages is not some interference; some crackle on the line. It is the tolerance, the play that language needs to convey our presence in the world and our presence to each other. It is a consequence of the fact that we live through language. Language is not some sort of perfectly engineered tool for completing a pre-defined goal.

If we experience the dislocation of language and world (and it is a professional requirement that philosophers experience that), we come to compare what is said to what is being talked about, the word to the object, the representation to the represented. David Biro[1] comments on his own book '*Throughout this book our focus has shifted back and forth between the felt experience of pain and verbal representation of that experience*' (p. 137). If that is our focus – the contrast between experience and representations of experience in language or in any other form – then as Calvino says, the

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representation is always 'something less'.

We can describe our experiences, even raw sensations like pain. But we do so on special occasions. A clinician asks us to describe the pain: how intense is it? Place it on a scale from 1 to 10. What sort of pain is it? Where is it? Whether a description is a good or a bad description depends on the purpose for which it is designed. Descriptions are not attempts to duplicate in linguistic space the reality of the object described. One special feature of descriptions of sensations is that we get to them through the person who experiences them. Take, for example, the location of pains. Pains have a location. That is one of the features that makes pain so thing-like, more thing-like than love or resentment. We can say where the pain is – perhaps not always, but often. It is in the second joint of my middle finger. But my pain is not 6 foot from the wall and 6 inches about the table, even if the second joint of my middle finger is 6 foot from the wall and 6 inches about the table. Pains are located, but not in the way physical objects are located.

We complain about the wrong thing. The '*experience of pain and its verbal representation*' is the wrong contrast. If we think that is the problem and if we generalise it, we get a dizzying philosophical problem: how can we put anything into words? How is our experience, how is the world, speak-able at all?

Language: from public to social to interactive

Wittgenstein suggests ways out of this impasse. He starts with the impossibility of a private language. The individual cannot inaugurate a language by mental acts of attending to his or her own experience and putting names on things. Whatever we say or think has to be rooted in public criteria which anchor what we mean and the truth of what we say. If we lose the connection to the public world, then '*whatever is going to seem right to me is right. And that only means that here we can't talk about "right"*'.[3] This applies not just to talk about the world around us; it holds in relation to our own experience. Whether we are talking about tables and chairs or pains and anxieties, the meaning of what we say has to be publicly grounded.

However, that is just the start of it. It is not just that meaning, and therefore, the possibility of truth-seeking is a public affair dependent on criteria which are independent of any individual's say so. Making sense of the world is social. The individual on his or her own cannot initiate and maintain a language. Language depends on conventions; we are required to think and act in this or that way. For example, we cannot but see this as 'a chair' or see that the hands on the clock tell a particular time. But those necessities cannot be explained by pointing to a rule written up on a wall, or for that matter in our minds. The issue is, how do words on the wall shape the way we think and feel. The rules involved in any understanding of the world do not apply themselves; we have to apply them; and this involves interpretation: how do we take the rule? There's the arrow painted on the wall; but what makes it point in this direction, rather than that; or indeed in any direction. It seems we need another rule to tell us how to apply the first rule. But this in turn requires a further interpretation and so on. Wittgenstein[3] argues that the threat of an endless appeal to one rule after another shows that '*… there is a way of grasping a rule which is not an interpretation, but which is exhibited in what we call "obeying the rule" and "going against it" in actual cases*'.[3] What grounds a rule is not another rule, not a super-rule which just hangs there and forces upon us its own application. We have no *reason* which forces us to understand things in the way we do. In this sense, we '*obey the rule blindly*'.[3] 'Blindly' does not mean 'arbitrarily', as if we just opted to think this way rather than that. We cannot choose how to think, in the way we might choose to play chess or draughts and so put ourselves under the relevant rules. In the case of our fundamental ways of thinking, there is no place for us to stand to make a choice to play or not to play.

It is the actual interactive engagements with others which constitute the weight of the rule: we are called into the social world by other people. The vocative comes first; then we respond. The first *blind* steps into the meaningful world are taken in response to a call, and they are encouraged through endorsements and validations. These are not incentives or inducements – we don't bribe infants into language – but neither are they reasons – we do not argue children into language. They constitute the social underpinning that will eventually allow reasons to be given. Other people play a constitutive role in the establishing and maintaining of language and other forms of communication. The exchange of expression and response is the basis from which we go on to open up a gap between ourselves, other people and the world. Only then can we take the objective stance, report on the way things are and give our reports as reasons for action.

This is the line of thought: if we are to understand anything about the world, about other people and ourselves, we must be settled into a publicly accessible world; and not just a public, but a social environment. We are introduced by others into the world, through forms of life, culture, language and values of society. And not just a social environment, but into a community of interacting people who initiate us into, and maintain us in, an intelligible world. We are domiciled in the world before we acquire information about it. And this community is woven out of expressions and responses, not out of an exchange of information.

The magical option

In his book *The World of Silence*, Max Picard[4] comes out with a striking fantasy thought: '*Of his own accord, man could never have been able to create language out of silence. Speech is so completely different from silence that man himself would never have been able to make the leap from silence to speech*'. He is imagining a situation in which we, without resources, absolutely speechless, face a world absolutely un-talked about. He dramatises the idea that description, reporting the facts, collecting information, cannot be what we do at the interface with the world.

Virginia Woolf[5] imagines the same confrontation in relation to pain:

> *The merest schoolgirl, when she falls in love, has Shakespeare or Keats to speak her mind for her; but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry. There is nothing ready made for him. He is forced to coin words himself, and, taking his pain in one hand, and a lump of pure sound in the other (as perhaps the people of Babel did in the beginning), so to crush them together that a brand new word in the end drops out.*

This is a wonderful description of what Wittgenstein thinks can't happen. It is magical thinking to hope that a word can be precipitated out of mentally squeezing together something, anything, a pain or for that matter a carburettor, and a noise, and thereby generate a meaningful word.

Well, if it can't be done that way, how is it done? An objection might be that pain is so insistent that it forces itself upon our attention, and thereby into our language – a carburettor lies there on the shelf minding its own business, but a pain makes itself felt. Yes, but how does that attention generate meaning? How does the pain get into the conversation?

Expression

In the first place, we express our feelings, we do not describe them. This is not a remark about a linguistic distinction, relying on features of vocabulary or syntax –for example, in expression, we use emotive words and we speak in the vocative case. It is a remark about how we relate to experience, our own and other people's, and how our ways of speaking wrap round those engagements. We speak *out of* our experiences before we speak *about* them. Through expression, we manifest our fundamental alignment to other people and through them to the world. It is through the whole dynamics of expression that our minds are on show.

How can expression bear this weight? What is it about expression that allows it to carry the heft of intimate personal communication? Expressing something to somebody has a different dynamic from imparting information. Idiomatically, we use the word 'expression' to cover all sorts of utterances, including expressions of opinion or belief; but we need a distinctive notion of expression when we talk of 'expressions of feeling' or of 'self-expression'. Expression is unmediated: we don't first become aware of our experience and then, if we so choose, give expression to it. That is the point of Wittgenstein's[3] rhetoric question: '... *how can I go so far as to try to use language to get between pain and its expression?*' (§245). First expression; then information.

Expressions are *modulated*. They acquire their communicative content in part through being more or less intense or hesitant or ironic. The dynamics of expression are inseparable from its content. Expressions have a *mood*: we express ourselves enthusiastically or reluctantly or shamefully.

Expression is a type of *action*. An expression is *directed towards* someone, even if there is no one there. An expression is a *disclosure*: confessions, confidences, apologies and declarations of love or regret are expressions. They are ways of putting ourselves on the line, of putting ourselves about a bit. Expression is a way of making our presence felt. When we express and talk about our feelings, there is an *integrity* requirement. As the great singer, Tony Bennett said, the first thing a singer has to do is to *turn up*. It is through expression that we turn up. The location of expression is *entre nous*. We address each other. People have thresholds and margins; they have to be approached. The way we approach someone in pain is an integral part of understanding what their pain is like.

Here is a parable to illustrate the point. Imagine you are a townie, totally out of your comfort zone in the country. On holiday, you wander into a remote Northumbrian farmyard. You see a pile of stones. You may wonder how they came to be there but there is little to go on. Next day, you walk in and see an enormous machine. You have no idea what it is for. But you can tell from its gears and levers that it is machine: it is for something. It has intentionality built into it. The following day, the farm dog is there. A dog whisperer will know what the dog is up to. But, being a townie, you are nervous. You know there is more to a dog than meets the eye. But you don't know whether this one sees you as an intruder, a threat, a soft-touch or a new companion. On your final visit, the farmer is at the door, with his gun over his arm.

Stones, machine, animal and person – how we approach them reveals our commitment to what sort of thing they are. Our deportment is crucial; before we say a word, the negotiation has begun. We turn to other people; we appeal for companionship. We reach for ways of keeping company. We see this at its most spontaneous in the way the infant reaches for its mother. Later in life, this spontaneous turning towards and reaching for each other comes less easily and is shaped by, perhaps distorted by, the social and institutional structures within which we live. In pain and suffering, it becomes difficult; at worst, it becomes impossible. But whether it comes easily or with difficulty, at all phases of life, what we want is trust and confidence in each other; we neither need nor want certainty.

So, expression is the way we communicate our inner lives, but that does not mean that it always comes easily. But being very good at it does not mean that it always comes easily. Some difficulties are dysfunctional, shyness for example. They get in the way of communication. But some difficulties are internal to the communication itself: inhibitions, restraint and discretion are part of the content. Some things can only be said with difficulty. Wittgenstein[3] gives a nice example:

> *In this way I should like to say the words 'Oh let him come!' are charged with my desire, And words can be wrung from us, – like a cry. Words can be hard to say: such, for example, as are used to effect a renunciation, or to confess a weakness* (§546).

What we withhold and what inhibits us, as well as what we make explicit, allow us to understand and misunderstand each other. Unrestrained venting of feeling can be as uncommunicative as sullen withdrawal. Road rage is expressive not of the enraged person's feelings about the traffic incident, but of their hysteria.

Our attempts to control our expressions of pain are part of the expression of pain. They reveal the ways in which people take or try to take their experience. Even silences are sometimes deeply significant: the pauses between question and answer, reticence when chat seems natural, a generous action made without comment and dumb insolence.

In the key of suffering

The difficulties we have in speaking about suffering do not just affect individual words or phrases, or particular utterances, they can affect the whole of language, putting it in a new key. Virginia Woolf describes in her essay, 'On Illness', how our relation to language takes on a strange quality when we are ill:

> *In illness words seem to possess a mystic quality. We grasp what is beyond their surface meaning, gather instinctively this, that, and the other – a sound, a colour, here a stress, there a pause – which the poet, knowing words to be meagre in comparison with ideas, has strewn about his page to evoke, when collected, a state of mind which neither words can express nor the reason explain. Incomprehensibility has an enormous power over us in illness, more legitimately perhaps than the upright will allow. In health meaning has encroached upon sound. Our intelligence domineers over our senses. But in illness, with the police off duty, we creep beneath some obscure poem by Mallarmé or Donne, some phrase in Latin or Greek, and the words give out their scent and distil their flavour, and then, if at last we grasp the meaning, it is all the richer for having come to us sensually first, by way of the palate and the nostrils, like some queer odour.*

Being Virginia, she takes examples from fine literature, Mallarmé and Donne, but what she is describing occurs in everyday experience – for example, the sound of a mother's voice to a sick child. In illness, we become aware of the hum around words. We become aware that we gather from words more than the words. The dislocation of words and meaning leaves us in a half-life. Normal rules do not apply. We experience both a heightened sensuous awareness of the physical and an oceanic feeling adrift from ordinary life. The hectic pulsing of the fevered body merges with out-of-body experiences. At its extreme, illness engulfs us: our experience becomes incomprehensible, unsurveyable.

We should not assume that the way we talk and what we talk about always link up in the same sober way. Is there a comparison between the language of delirium and the language of dreams? Dreams are a sort of after-image of experience and the language of dreams is an after-image of language. When we recount our dreams, we are aware of them slipping away as we speak. But this is not a failure of memory in the usual sense. The difficulty is not the difficulty of recalling the objects on the conveyor belt in *The Generation Game* – the matching luggage, the steak knives and the cuddly toy. When we awake from a vivid dream, we start to narrate it, then we begin to lose confidence. We try to carry language across the divide between sleeping and waking. We give up in frustration or we cheat by forcing the well-ordered language of everyday onto the dream experience. We are unsure whether language fails because the dream slips away or the dream slips away because language won't stay stable.

We cross and re-cross thresholds as we wake and fall asleep. Normally, we move easily between these worlds. Transmigration seems to be a permanent feature of the human soul. But sometimes nightmares mark the transitions from one state of consciousness to another. Something similar happens in relation to suffering and living with pain. The bereaved, the depressed are incorporated into the world in distinctive ways. Suffering can overwhelm us. If communication becomes difficult, it is not a failure of vocabulary or an inability to find a powerful metaphor. Acquiring a language is to be taken up into a conversation, to acquire a form of life; not a means of managing a task already defined and understood. And there are many ways of living a human life and we go through many phases in the course of a lifetime. It does not seem possible to live a human life on one storey.

The moral of all this: we should look after each other and language will look after itself.

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Professional perspectives

Pain signals and other bad language

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This article discusses the language used in healthcare with a focus on pain.

Its aims are to encourage you to

- Think deeply about the language you use;
- Think about alternative options and begin changing;
- Encourage others to think about language;
- Reflect on how language and burnout may be linked;
- Challenge organisations that continue to use outdated or factually incorrect language.

We can become so used to the words we've always used and medical language that we cease to consider their effect on others.

Words can set a person down a path of fear and catastrophisation or start them on a journey to wellness and recovery.

I am convinced that for outcomes to change, the language we use needs to change. People living with pain rely on us to help them understand their symptoms. As 'patients' within the patient/clinician role, they are more vulnerable to the words we use.

They get an expectation of what their future holds from these words. These expectations have a real impact on their health, well-being and outcomes:

> *What you hear goes straight into your imagination*. (Gillian Reynolds, Radio Critic)

Language shapes ideas and changes the way we perceive our world. Those perceptions change the solutions that people choose and the outcomes achieved.

Creating expectations

It's time to think deeply about how the words we use affect people's expectations, their biology and your own. I want you to think about this not just in your spoken language but in all your communications from the letters you send to the messages left on answer phone machines.

People often bring me hospital letters to translate so it comes as no surprise that *50% of patients don't understand what their doctor has told them*.[1] Given the purpose of communication and language is to be understood, it's important we use plain English, everyday words that are factually correct. You can inadvertently distance yourself from those you treat by using complex language.

It's not just words that create expectations but the way you present them. Many letters are poorly written, have spelling or other errors that, at best give a poor first impression, at worst, create an expectation of incompetence. If your department sends out automated letters, take a look at the templates. What does the heading say? I once received an appointment for a blood test on headed paper that said HAEMATOLOGY ONCOLOGY DEPARTMENT. It scared me because oncology = cancer = scary to most people, particularly when the only discussion has been that 'you need another blood test'.

Think too about the letters you send to general practitioners (GPs) and where the(ir) copies are sent to patients. Have you told your patient everything that's in it? Do they understand? I am frequently asked to explain words that people have no idea of the meaning. Last year, my husband had heart surgery to repair a mitral valve. There were a few post-op complications. The discharge letter to the GP said he was in heart failure, something the hospital had omitted to tell us. You can imagine our shock when we read this.

Communications set the stage and create an expectation. They can improve confidence and promote a sense of safety … or not. The way we communicate has a direct impact on a person's health, well-being and outcomes. I believe it's time to start using language, and our presentation of it, not just to eliminate bad or factually incorrect language but to take it a step further – to start using words to deliberately create positive expectations; to change perceptions; to purposely promote recovery and healing and to actively promote health, well-being and active recovery. Those who use hypnosis already know the benefit of this approach and the power of words.

Words in pain

Before 2 years, I was offered the opportunity to run my own 'pain management' programme outside the National Health Service (NHS). I started by thinking about what kind of information I would like if I had ongoing pain. That led to taking a detailed look at the language I was routinely/automatically using. We'll look at this later alongside suggestions for change:

Sticks and stones may break our bones but words will never hurt us.

I think we all recognise now that words can cause significant harm and, if chosen with care, significant help. Words get into your subconscious, they permeate your thoughts, become your ideas, your story. They affect your perception, understanding, expectations and can become so routine and familiar that we stop thinking about their effect. *Words can change the very nature of pain and our understanding of it*.

The following words were said to patients or overheard by clinicians listening to colleagues.

'Now what is it that makes you feel the need to be unwell ... my dear?', said to a lady with myalgic encephalomyelitis (ME). Are those with ME/chronic fatigue/fibromyalgia more likely to hear this type of language because we don't understand their condition?

'I don't know why you're so worried. You already have a wheelchair', said to a lady with ongoing pain who had broken her ankle and was concerned it wasn't healing as it should.

'Dress for your disease ... my dear', said to a lady with rheumatoid arthritis.

'Basically, your father's head is falling off', said to the daughter of a man with severe dementia who was no longer able to hold his head up. I'm happy to say, good physio remedied this.

Then you have the more subtle such as, 'You have to stop gardening'. Again I'm happy to say this lady is now back gardening and enjoying it.

'You'll end up in a wheelchair', said to a man with newly diagnosed psoriatic arthritis. Based on this comment, he resigned from work, so he and his wife could enjoy what was left of his 'walking years'. There's a good chance that he may not end up in a wheelchair.

'Rest until it calms down'. I once met a lady who had been in bed for 40 years following a minor back injury at 18. She was still waiting for it to calm down.

'You no longer fit our criteria'. How soul destroying is this to get in a letter? Yet it's being used increasingly as services struggle.

Words have a greater effect when they come from THE expert. When the expert uses bad language it makes it is even more difficult to convince people otherwise. Just recently I was having a conversation with a lady about the benefits of movement. Her reply was 'Aaah, but that doesn't apply to me because my consultant told me I have two vertebrae out of line crushing my nerve'. *These words create powerful images in our minds*. What kind of message did she take away from that? 'If I move, it may damage my spinal cord'. 'I have to protect my spinal cord at all costs'. When she gets pain in the future will she think her vertebrae have moved again? She is in a state of constant vigilance and stress.

People change their lifestyles based on what we tell them. Words can, and do, change people's futures. I'll come back to specific language like this later.

Words of war

I'd like to focus now on the widespread use of warmongering language in society when talking about health issues. Imagine for a moment that you are a soldier going into battle against an enemy you can't see or hear – one that can creep up on you in the middle of the night or suddenly jump out at you. It thrives on making you suffer. Worst of all, it is invisible to others and you cannot describe it with words. In fact your friends are so sick of you trying to explain, they've deserted. Others think they know what it feels like, but no one really does. You feel very alone.

You set out to fight this enemy and are determined to beat it with an ever-expanding arsenal of painkilling weaponry, but the harder you fight, the harder it fights back. Pain is the enemy you live with every day ... every hour ... every moment of your life. It disables you, stabs you, crushes and pinches your nerves, burns you, shoots down your legs, blinds you with headaches so severe, it makes you sick. Even those rare moments without your enemy you have to be vigilant, waiting for it to return.

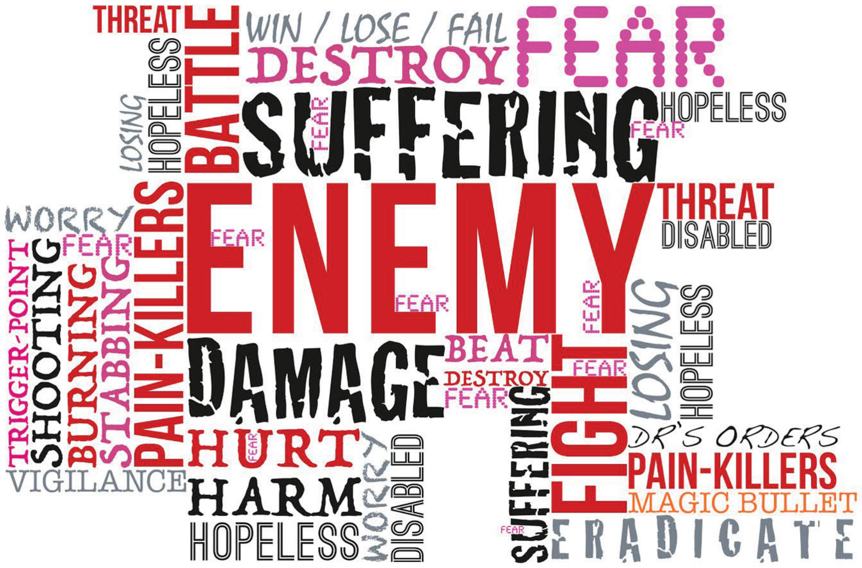
It has a nasty habit of flaring up and getting angry. It loves to visit in the middle of the night in your darkest hour when you feel most vulnerable and alone. In fact, it is so evil it makes a point of attacking you when you are at your weakest – stressed, ill, low, depressed, anxious – you have to be alert at all times – Hypervigilant. You start to predict, to anticipate when your enemy will strike and avoid those situations.

This enemy is out to damage you, degenerate you, harm you and has powerful friends it can call on to inflame your body and mind and fatigue your very being. When you have an enemy like this, you can never relax, never sleep, never have fun. Your body becomes a battleground and you lose touch with the you that is you. Nothing and nowhere feels safe. You lose hope, feel defeated, you soldier on, barely surviving, always searching for that magic bullet. *Life is so exhausting when pain is your enemy*.

Ironic battlefield

Widespread use of warmongering language is ironic given our goal is to alleviate suffering, to save lives, treat injury, help people recover and heal. The use of warmongering language prepares people to fight, run, freeze, flop. How does this encourage healing and recovery? *How can turning your body into a war zone lead to increased well-being and improved health?*

War links pain to suffering, it generates fear, worry, anxiety, hopelessness, despair. The more threatening we perceive our world to be the more we look out for threat, the more likely we are to come to catastrophic conclusions. We see less of the good things. We become



vigilant and sensitive to symptoms. War leads to chaos, destruction and uncertainty. A place where there is little safety, increased stress, tension and pain. You can't begin a journey towards recovery and healing like this.

Cohort – An ancient Roman military unit, comprising six centuries, equal to one tenth of a legion.

It is interesting that the word cohort was originally a term used to describe a large unit of soldiers, showing how ingrained warmongering language is. As researchers recruit 'cohorts' of people and are immersed in a society where there is an accepted and widespread use of warmongering language, it may unknowingly bias their thinking, narrow their focus or prevent them considering alternative options.

Do pharmaceutical companies have a vested interest in promoting warmongering words where drugs – painkillers – are seen as weapons? Viewing drugs as weapons invites us to try one more drug, a new weapon, to fight until the bitter end, try every treatment, every weapon at our disposal. This can lead to overtreatment and medicalisation. It encourages a scenario where the doctor becomes 'the commanding officer'.

An individual doesn't lose a battle with disease

It's not about winning or losing. This sets an expectation of recovery based on how hard you fight. It's not about using medicine as a battle against disease and death. If you die it doesn't mean you've failed or that you haven't fought hard enough. It becomes a battle that no one can win because we all die eventually. This can have a detrimental effect on the people we treat and clinicians. I think it contributes to clinician burnout because it can make everyone feel like failures. Always being ready to run or fight suppresses healing in patients and clinicians.

Be strong?

You have to suppress emotions when you are constantly at war. You have to appear strong, to hide any weakness – an enemy will pounce on weakness. It can mean you miss out on the things that make life worthwhile, it leaves no room for fun, play, laughter, curiosity or healing in either the person with pain or those treating them.

When we view a person's body as a battlefield it can prevent us caring for the person behind the label.

It comes as no surprise that women with breast cancer who 'ascribed negative meaning of illness with choices such as "enemy", "loss" or "punishment" had significantly higher levels of depression and anxiety and poorer quality of life than women who indicated a more positive meaning'.[2]

Words of war make good headlines, don't they? They can motivate angry people. Warmongering language is so ingrained that it's become natural to want to fight or battle disease. So ingrained it's become difficult to come up with alternatives. Moving from words of war to words of healing and recovery is difficult. Changing this language will mean changing the way society views disease, changing our views on healthcare so as to focus on health and recovery, changing medicine and pharmaceutical companies.

Healing words that focus on recovery can seem a bit 'bland' or 'airy fairy' in contrast. Yet, they should carry more power than destruction. Words of healing and recovery should carry more power than fighting and killing ... shouldn't they?

Our goal should be to enable the people we treat to use words that work for them within the context of recovery.

Another perspective

The Welsh word for pain is poen, like the latin poena meaning punishment, retribution or penalty but we have a different word for pain following exercise. 'Scrwb' (scroob) is a word that carries no danger and is often said with a shrug of the shoulders, 'It's just a bit of scrwb'. That shrug of the shoulders is really important. It attributes insignificance. Perhaps, we need to find different words for pain?

Notice that sharp fonts, shapes and certain colours are more likely to be linked to stress, anger, shouting, pain, whereas more rounded shapes are more comforting and calming.

It's difficult to change the words people use so perhaps we need to find new ways of presenting our words to change their impact.

Advertisers have understood the power of words within the context of presentation, the fonts and colours used, for a long time. I think we could learn valuable lessons from the way they influence expectations in order to purposely create different expectations to actively promote health, well-being and recovery.

We have already moved from the language of war to one of care and healing in the field of HIV. A similar process is starting to happen with type 2 diabetes. It is being recognised as a curable condition if you focus on improving health. Those who are reversing their type 2 diabetes aren't battling or fighting their disease. They are not making a battleground of their bodies. They are doing the opposite. They are focusing on improving lifestyles, focusing on improving well-being and health.

It's time to start asking do we want to kill and destroy or recover and heal and begin to create an environment of safety and compassion within which this can happen.

De-humanising words

Another problem we have is the use of de-humanising language such as 'pain patients', 'How's the back?', 'I saw a difficult knee today', 'frequent flyers', 'bed blockers', 'bed 6', 'fibro patients', 'migraineurs'.

People give themselves labels too. Many are unhelpful for aiding recovery and healing. Terms such as 'fibro warriors' or 'mesh injured patients' do little to promote health, well-being or hope. And there is hope.

The use of this type of language stops us seeing the person, encourages us to identify by disease. Used alongside automated, impersonal letters that no human sees it can send a powerful message that we don't really care about the person behind the label. Human beings need to feel connected, cared for. Nurturing compassion in our language and communications is good for everyone.

The language of pain

The language we use and the conversations we have with people can intensify and prolong their pain experience … or not. When I started looking at the language I was routinely using, my first conclusion was that if I had ongoing pain, I wouldn't want to just 'manage' it. I would want to learn how I could still live well. I called my course a 'Wellbeing for People in Pain' programme, but soon changed to 'Wellbeing for People with Pain' because if you are in pain it implies that pain is bigger than you – it's not. Pain is in you.

I wanted to focus on an individual's capacity to create health, to improve well-being. To focus on their ability to change.

Moving people from this...

To this:

Notice pain is still there. It has to be because without pain we wouldn't survive. Recovery isn't about eliminating pain. I believe everyone can make changes whatever their starting position.

The big problem with pain is that words can't describe it.

'How do you spell love?', said Piglet. 'You don't spell it, you feel it', said Pooh.

As a result, we resort to warmongering and mechanistic language (wires and gates) or isolate pain to a symptom or sign. But pain is about a lot more.

Let's think now about the type of expectations we create with the language we use. The following are examples of two different pain programmes.

The first is called a 'Pain Management Programme'. Within the introductory words the course leader says, 'We're not here to fix your pain. We will be teaching you coping skills to manage your pain, learning about self-management'. This overview covers 'learning to live with pain' and the importance of 'pacing'.

The second programme is a 'Pain Education Programme'. The course leader uses slides and images as I do. Participants enter the room to a slide that says HOPE in large letters. In this introductory session, the course leader says, 'I expect your pain to improve'. 'I expect your mobility to improve'. It takes a lot of confidence to say this type of thing doesn't it? It takes confidence, energy and most importantly a healthy practitioner.

I'm going to suggest this now:

> Pain is what we say it is within the context within which we experience pain. The language we, and our patients use, creates and can change context.

I spoke earlier about what happens if we regard pain as the enemy. Pain evolved to protect us and it can change context significantly when we start slowly and steadily introducing 'protective' language. Gently moving people way from pain as the enemy. I always find it helps to go back to evolution. I talk a lot about evolution on my programme. Pain evolved to stop us putting our hand in a hot fire or walking on a broken leg. With this as a foundation, you can introduce the idea of a system that becomes over sensitive like a car or fire alarm that goes off when it doesn't need to. In this case, we wouldn't focus our efforts on putting out the fire. We would focus them on re-setting the system. Introducing ways of calming the system down takes the focus away from a linear, biomechanical viewpoint.

X-rays and scans

The way we describe X-rays and scans can significantly influence the context within which people feel pain and what they do about it. It changes outcomes.

Words such as 'wear and tear', 'bone on bone', 'damage', 'entrapment', 'degeneration', 'unstable', 'crumbling', 'twisted', 'crushed', 'slipped disc', 'soft', 'pinched nerve', 'vertebrae out of line' are still routinely and widely used. I'm sure you could add to this list.

Why are we so surprised when people don't move?

> *They're just behaving logically based on what they've been told*. (Eve Jenner, Clinical Specialist Physio)

What would happen if instead we said something like this:

> *I can seen there are normal changes due to getting older, but these are nothing to worry about. Your joint may have become extra sensitive and feel painful but you won't do it any harm to move. In fact, moving will help to strengthen and lubricate your joints and muscles ... and you're pretty good at healing – just think back to when you last cut your finger. There is a lot of repair going on too*.

Painful words

Let's take the term 'pudendal nerve entrapment'. It's enough to make anyone's pelvic floor spasm. What kind of image does this fill your mind with? A nerve that's trapped gets stretched in all ways when you move. David Butler and Lorimer Moseley say, ‘Pinching a nerve is like trying to pick up a lychee with chopsticks’. It’s actually difficult, they’re slippery, slidey, elastic. Yes they can become very sensitive to movement but rarely, truly crushed, entrapped or pinched. *People who improve from sciatica often do so without any change in their magnetic resonance imaging (MRI) findings*.

Let’s take a further look now at some of the words routinely used in the world of pain.

‘Self-management’ – The term implies limitation to me. Would we get further if we started talking about ‘self-nurture’, ‘self-nourishment’. It suggests growth and healing.

‘Goal setting’ – You may be surprised to see this on my list of potentially problematic terms.

I’m talking about blinkered goal setting. You can become so focused on reaching the end goal that you miss out on life – all those little things that make life good and special. *You can stop enjoying the process and that process is your life*. I prefer to use flexible goal setting as a means of setting direction while also focusing on increasing enjoyment of life now. One lady on my programme said, ‘I’ve realised I don’t have to be miserable. I can have fun’.

It’s about learning to go with the flow of life but having your direction mapped out, recognising that life events, unforeseen circumstances and opportunities can change that direction, *focusing on flexibility because nothing in life is linear. Pain, well-being, life itself, none of these are linear events*. Within this less-driven viewpoint, you can better cultivate compassion for yourself and others.

‘Pacing’ – What does ‘pacing’ say to you? To me it says ‘limiting’ and I certainly wouldn’t want to pace my life forever. It would be a depressing thought. What about using the term ‘activity planning’ instead?

I’ve opted for ‘baselining’. It’s a term I got from project management in business. *Finding your baseline of activity from where you can begin to improve*. A baseline is a point of reference. It involves making a plan to set your direction (goals) while taking into account all your available resources. This can include financial, social, your support networks or knowledge, so enabling your plan to ‘fit’ your specific needs, into real life. That’s what I love about it. You agree to stick to this baseline and keep at it, regularly checking the viability of your plan in the recognition that circumstances may, and do, change. Does it still fit in with real life?

When circumstances change, the baseline can be reset. That’s OK. It’s about finding a steady platform or foundation from where you can begin to live again. *It changes the focus from one of symptoms limiting life to one of moving forward*.

‘Let pain be your guide’ – When I trained as a physio, we learned to say ‘let pain be your guide’. We now know that if someone stops every time they feel pain, we’re training people to move less. We’re training their brains to make more pain with less activity. We were unwittingly training them to be less mobile.

‘Chronic pain’ – It’s good to see a move away from the term ‘chronic pain’ because it means different things to different people and can mean ‘intense’ to some. But have you thought about the replacements – ‘long-term’ or ‘persistent’. What do these ‘say’ to you? If I had to choose, I would use long-term because ‘persistent’ says to me, going on and on and on and on without a break.

I prefer to use the term ‘ongoing pain’ because it offers a small chink of hope because there is hope.

‘Exercise’ – is another word that causes problems. Words can get caught up in pain maps and trigger pain. Exercise is one of these. You can see people visibly tense when they hear it. *The word alone can trigger pain*.

I’m pleased to see the Chartered Society of Physiotherapy’s recent campaign to stop using the word exercise and instead talk about increasing levels of ‘activity’. *‘Activity’ is a much safer word isn’t it? It has more chance of fitting into real life too*.

Before I talk about ‘pain signals’, ‘pain receptors’, ‘fibres’ and ‘centres’, I’d like to introduce you to the complex conversation (see below).

And take a moment to talk about simplicity versus complexity.

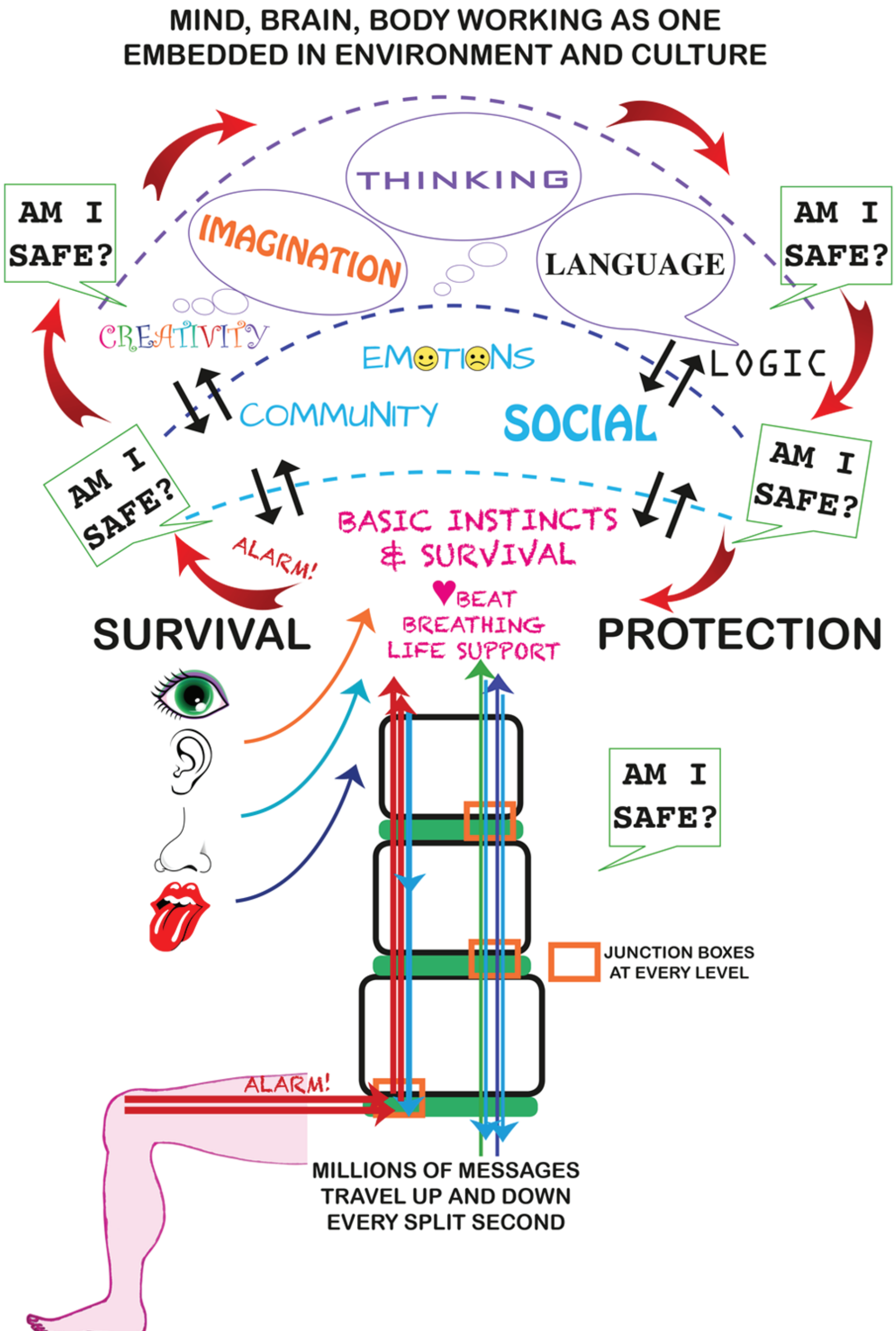
Complexity gives hope

Sometimes in an attempt to explain pain, we can over simplify it. *I’m a firm believer that those living with ongoing pain need to understand the complexity of pain*. When they ‘get’ this they understand why one approach or pill can’t ‘fix’ the issue. It helps to move them from a linear, biomechanical viewpoint to an understanding that pain is made, or not, as the result of everything going on within you, around you, your culture and past experience. *Everything goes into the mix of this conversation* including what Lorimer Moseley calls, ‘All the things you know but that you don’t know that you know’.

Even words can bias this conversation towards making pain ... or not. We can make the complexity work for us. *The fact that everything goes into the mix of this conversation gives us many avenues in to change the conversation. The complexity gives hope*. There is always something you CAN do to improve the situation. Something you can make changes in. Understanding this complexity means you begin to understand that pain isn’t an accurate measure of what’s going on in the body.

It’s not a signal

This takes me to the issue of ‘pain signals’. I am reminded of a quote,



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Anyone who talks about pain signals is talking neurobollocks. (Dr Mick Thacker)

These nerves aren't carrying pain in some sort of package of pain. As far back as 1986, Patrick Wall and Steve McMahon said, 'The labelling of nociceptors as pain fibres was not an admirable simplification but an unfortunate trivialisation'.[3] That was 32 years ago!

Talking of pain as a signal reduces it to simple mechanics. *Understanding that nociception or alarm signals are NOT pain is at the core of understanding pain*.

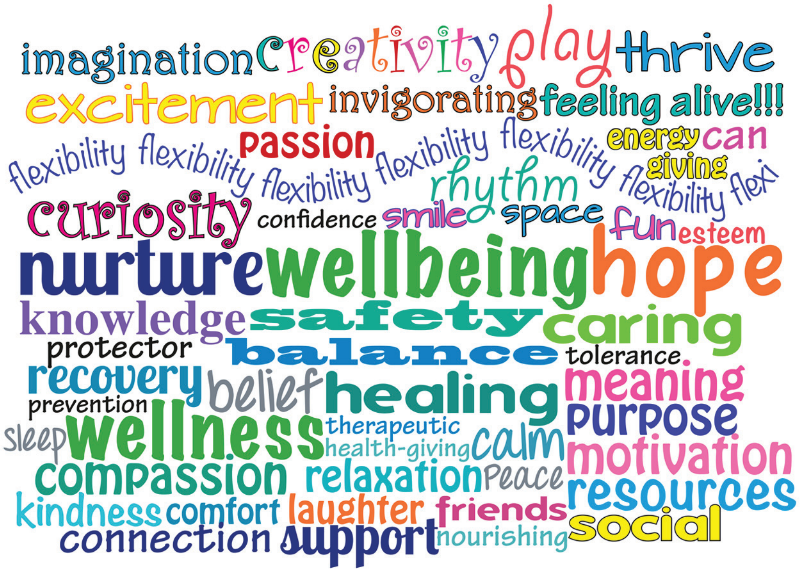
Understanding that pain, the feeling, the experience and the injury or condition are separate issues which are at the very core of understanding pain.

Pain is a conscious experience. Nociception is an unconscious process. They are different. Nociception is happening all the time in the background and is never felt. It is only part of the complex conversation. Pain is the 'felt' experience that emerges from a mix of numerous inputs, different contextual, attentional, emotional and cognitive states.

Nociception is still present in people under general anaesthetic, whereas pain is not. If you don't feel pain, it doesn't exist, whereas nociception does. *It's hugely powerful to realise that when you're not feeling pain it doesn't exist*. If nociception resulted in pain every time, we would all be in pain every moment of every day. So it is really important not to use the term pain signals and vital that the people we treat get consistent, factually correct information.

Brain scans and X-rays don't show pain. A scan can't show a feeling, an experience. In fact, they probably don't mean much at all unless you know that person's social background, past history, current state of mind, culture, home environment, level of knowledge. They might mean a bit more then.

So there are no pain signals, pain pathways or pain fibres. When you look at this conversation, it also becomes clear that there is no pain centre either. The issues that contribute to this conversation will be different for everyone, so you begin to get an understanding of how each person's pain is unique. You can also talk about those downward signals. These are of increasing interest in current research. *The fact that our thoughts, beliefs, experiences, environment and state of mind can change these downward*



signals to modulate those alarm signals is hugely powerful. It gives hope.

Instead of using words of war, we can talk about making changes to this conversation, to bias it towards not making pain. A model like this can help you to use alternative language (see Image). Focusing on well-being enables people to look forward.

Life's a journey

We can talk about going on a journey of change. I'm aware that some people don't like the metaphor of 'going on a journey' but it works in so many ways. It focuses on where you are going. You can talk about potholes, pits, signposts and occasional roadblocks along the way. Sometimes there is a need to take a different direction. Your goals set your direction but you can choose to take an alternative, more scenic route if you wish. Winnie-the-Pooh says, 'Life's a journey to be experienced, not a problem to be solved'. There are no winners, losers or failures on a journey. Some will carry heavier burdens while others get fatigued more easily but that's all OK. The clinician moves from being the commanding officer to a trusted guide exploring different avenues and directions. Importantly, it provides an opportunity for the traveller to travel unaided only calling on guidance when the road gets rough.

In war, you are dependent on a good commander, whereas a traveller can undertake a journey by themselves with perhaps the occasional input from a guide. *They're not dependent on the clinical guide and, as they learn from experiences along the way, there is potential to become less so. And that's what we want to achieve isn't it?*

> *The best medicine entails not only minimising the use of medicine but making medicine redundant.*[4]

Pictures and quotes

Don't be afraid to use powerful images in your programmes. They can say a lot more than words. I use an image of a person standing on a tall post situated on top of the tallest building in Hong Kong to illustrate how our thoughts influence our biology, our physiology. We visualise balancing there, feeling the wind buffeting us because we are so high up. We feel our bodies sway slightly as we watch the tiny cars below moving along the crowded streets. We feel our heart rate and anxiety levels rising as we visualise this scenario.

Then, we focus on an idyllic beach with its blue sky and gently lapping waves and we feel an instant change in the way our bodies respond. In these scenarios, our bodies are responding to our thoughts about these images – and they're just images. The experience is far more powerful than any words.

I also use popular quotes – they're easy to read. People like and remember them:

> *When a flower doesn't bloom, fix the environment in which it grows, not the flower.* (Alexander den Heijer)

> *You won't have any ladybirds in your garden if you don't have aphids.*

Gardener's question time

Winnie-the-Pooh is a source of great quotes:

> *'Supposing a tree fell down, Pooh, when we are underneath it' said Piglet. 'Supposing it didn't' said Pooh after careful thought. Piglet was comforted*.

> *It's more fun to talk with someone who doesn't use long difficult words, but rather, short easy words*. (Winnie-the-Pooh)

It's quite fitting that such safe, wise little characters were created at a time when AA Milne was suffering from post-traumatic stress disorder (PTSD) and the trauma of World War I.

Burnout and words

Focusing on improving well-being has a lot of benefits for the patient and you, the clinician.

It opens lots of avenues in which you can help the people you treat. Changing our language changes the context within which a person experiences pain and the context of our consultations. *Helping those you treat to understand the complexity of pain and its emergent nature means there is always something they can do to improve and always something you can do to guide them*.

The use of warmongering language means you are fighting a battle you can never win. It can lead to mental defeat in you and those you treat. Add this lack of achievement to the pressures the system poses on you and you could well be accelerating your path to burnout. *Moving from 'I can't make a difference' to 'I can make a difference' is good for your health too*.

> *Be careful how you are talking to yourself, because you are listening*. (Lisa Hayes)

Think too about how you talk to yourself. Do you talk to yourself as you would talk to a friend you care for? Do you nurture you? It matters because everything goes into the mix of life, health and well-being. You are listening to your own self-chat.

It's time to start cultivating compassion and self-nurturing for everyone, including ourselves. *Just think if speaking kindly to plants helps them grow, imagine what speaking kindly to humans can do?* And if you think you can't make a difference you absolutely can. As the Dalai Lama once said, 'If you think you're too small to make an impact. Try sleeping on a mosquito'.

> *The highest form of the art of war is to wage no war at all.*[5]

About Betsan Corkhill

I am a Wellbeing Coach specialising in working with people with long-term conditions, particularly ongoing pain. I have a clinical background in physiotherapy spending many years helping those with long-term medical issues.

I left physiotherapy in 2002 having become frustrated at the 'system' I found myself in. I was working in the community and was expected to treat people with multiple cormorbidities of all ages in a few visits. Many had the capacity to improve significantly given time and ongoing guidance. I felt they should be offered the opportunity.

I am a passionate advocate for a whole-person approach to health, from managing day-to-day stress and life's inevitable challenges through to managing ill-health. My many years as a physiotherapist have enabled me to combine my clinical knowledge with coaching to help individuals navigate our fragmented health and social care services, as well as to improve their health and wellbeing.

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Sticks and stones and words: synchronising everyday language and professional language in the health domain

THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

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SAGE

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Credit: Marrio31

Language is a tool that performs a wide variety of functions in different domains of social life. One such domain is the communication of the experience of pain. The experience of pain can be miserable to the point that some may describe that their pain is beyond language. However, being unable to describe pain has usually been found in relationships between those who have pain and those who do not. Among those experiencing similar pain, people have found that communicating their pain is suddenly much easier.[1] The difference here is the empathetic factor; the ability of the listener to understand the thoughts and feelings of the speaker. When someone talks about their pain to others, be it physical or emotional, the person is confiding in another by revealing their vulnerability. This creates an interpersonal connection between the speaker and the listener. The listener often can experience second-hand pain, which further cements the connection. This connection serves as social and emotional support that can help improve care. Empathy is a critical factor for effective pain communication and to build a positive relationship between the speaker and the listener.

Pain is largely associated with mental health, where the impact of pain on daily life can cause extreme emotional distress and undermine one's own confidence in themselves. Pain communication can help relieve some of this distress, and thus, it is important to have empathy when talking about pain. While it is nice to think that most people who are not in pain are empathetic, such as researchers or health professionals, it is not always the case. Sometimes the language that we use to talk about pain can lack this empathy without even realising it. Let us take the example of the term 'catastrophising'; this term is regularly used to describe the event when someone is feeling overwhelmingly helpless about their pain. This is used regularly in the literature, and 'catastrophising' can be defined with the term 'exaggeration' or some form of the word.[2–4] Catastrophising is a serious phenomenon that severely influences the experience of pain and is taken seriously by health professionals and researchers.

However, this term may do harm unknowingly. 'Exaggerating' (used in the definition of 'catastrophising') may be used to indicate a serious pain-related event in the health domain, but 'exaggerating' in everyday life is usually used negatively, that is, to indicate that someone is knowingly overstating a situation to seek attention. This link between the health domain and everyday life can significantly affect the communication of pain, which can influence the care for pain. Considering this link, 'catastrophising' in itself implies the person is knowingly exaggerating their pain. This, of course, is a terrible way to think about it because to the person in pain, it is not an exaggeration.

While carers or health professionals may understand that this is not simply exaggerating, it still may negatively affect the way they treat the pain because of the inherent definition of 'catastrophising'. Even if the care for pain is unaffected, the person in pain themselves may think that they really are exaggerating (in the everyday sense of the word), which may have detrimental effects on their mental health. One individual living with chronic pain states that '*"Catastrophising" is so dismissive and potentially a devastating label for a clinician or anyone working in pain to use. When I hear that word, I feel instantly misunderstood, disbelieved, patronised and either angry or tearful or a mixture of both*'. In addition, he also reports a nurse telling him he was 'blowing it out of proportion'. This is something that no one should ever say to someone in such pain; however, this may be an incidence of 'leakage', where the semantics from the everyday definition of 'catastrophising' is passing into the professional environment by the professional themselves. Even with training to be compassionate, and even with training to be sensitive, a leakage like this may happen more often than we know and may do more damage than we know.

However, what word should we use instead of 'catastrophising'? What other word can encapsulate the helpless distress that the individual in pain is going through? There isn't an immediate solution with a neat label, and the health domain likes to create terms to capture and condense complicated phenomenon. This allows for easier communication not only for those working in the health domain but also to patients, as some patients may feel reassured with a label to describe their experience. However, this makes it vulnerable to wide interpretation. There may be those reading this article who think this is being overly sensitive, but we need to consider the patient in all aspects of care, including communication. After all, the patient is at the heart of the health domain. However, while difficult, this is something that we can work on and develop for future practice. Some already avoid the term 'exaggerating' to define catastrophising, taking great steps to come to a resolution.[5,6]

'Catastrophising' may not be the only term where the link between the health domain language and everyday language has a negative effect in the care of pain. This is said because too often many people with chronic pain report that those around them are not really listening to them or they feel that others do not believe their pain experience. Initial research may find many more similar terms that are taken seriously in the health domain but are used negatively in everyday life. However, it also may be that the problem isn't as wide-spread as this article is making it out to be, but we can only know for certain once steps are taken to examine this.

Even more so, the language disparity can be seen in the way pain is reported by professionals compared to patients. Patients tend to use rich and vivid language to describe their pain; they use metaphors of 'boiling water poured on my skin' or 'something crawling inside me'. Some patients even describe their pain as a separate entity that they are fighting against, that there is a battle going on between the two and the patient desperately wants to win.[1]

However, this is not what is usually seen when professionals report pain for either diagnostic, therapeutic or research purposes. Usually, pain is described as increasing or decreasing with relatively simple descriptions of the quality of pain (temperature, stinging, stabbing, etc.). This type of pain narrative in the health domain seems detached and ignores how patients are actually describing their pain.

This may be one of the reasons why patients often feel that they are not believed when they communicate their pain. This is incredibly damaging not just to the feelings of the person in pain but also to the relationship between the person and their health professional. People can become insecure and close-up during their appointments if this relationship if damaged, thereby degrading the care they could have been receiving. Empathy is clearly needed. However, this article is not trying to vilify health professionals. Most professionals receive the required empathy training and really do put their sweat, blood and tears to get the right care for their patients. This article is saying that despite this effort, patients still feel disconnected with those who provide their care. Training may need to include the professional and everyday dimensions of pain communication to give greater support during care.

The literature consistently suggests that a positive, strong support network is a key factor that contributes to the treatment and management of pain.[7,8] However, there needs to be more attention towards the language used in this support network, as this has an influence over the way both patients and their loved ones perceive their pain. It may even influence the professionals' view of pain. Language is a tool that is heavily influential, to the point that many take it for granted. Synchronising everyday language and professional language, and synchronising the way patients communicate their pain and how professionals report pain may serve to bolster the relationship between the two, thereby alleviating feelings of disbelief and allowing patients to be more accepting of their pain.

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Professional perspectives

Consent in Pain Medicine part 3: law and implications for practice – the practicalities of consent in patients with chronic pain

THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

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SAGE

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A quack physician probing a man's head for lumps and making incisions ostensibly to remove 'stones'. L'Operation Inutile Teniers, David, 1610–1690. Paris: Pierre François Basan. National Library of Medicine in the Public Domain. http://resource.nlm.nih.gov/101392973

> It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has. (William Osler)

> The art of medicine consists in amusing the patient while nature cures the disease. (Voltaire)

> Whenever a doctor cannot do good, he must be kept from doing harm. (Hippocrates)

> The doctor sees all the weakness of mankind; the lawyer all the wickedness ... (Arthur Schopenhauer)

Introduction

In Parts 1 and 2 of this series (*Pain News June and September 2018*), we discussed how the role of the doctor has changed in relation to a patient being offered pain management options. In this part, we discuss the detailed implications of the change in law in relation to specific pain management scenarios.

The mechanisms, treatment and prognosis for chronic pain

Chronic pain is usually incurable and affects the patients, their significant others and society in many ways. In view of the complex and biopsychosocial nature of chronic pain and impact, treatment often necessitates use of a blend of different approaches.

Despite the advances in our understanding of the mechanisms underlying pain and in the availability of technically advanced diagnostic procedures, the past decade has not seen the development of novel evidence-based therapeutic methods, but rather changing trends in applications and practices within the available clinical armamentarium.

In Pain Clinics various management options are offered including spinal interventions, pharmacological and physical methods and psychological techniques including pain management programmes. Generally, there is variable and usually only a modest impact of available treatments on psychological and physical aspects of chronic pain and usually the pain does not change much as we or the patient would like it to.

Hence, chronic pain management should include a comprehensive dialogue with the patient about the realistic expectations of possible (modest) outcome from any given treatment just as much as acceptance of the likely enduring nature of chronic pain.

These more realistic outcomes of treatment have now to be explicitly discussed with the patient now that the extra dimension of patient autonomy over treatment must be considered.

From the consent and legal perspective, the patient is now ultimately in charge of what clinical treatment they would choose. The doctor's role is now of an advisor setting out the range of reasonable clinical treatment options and the patient will have the right to make the ultimate decision about whether to go ahead with a range of reasonable procedures or indeed none.

This change in the law has necessitated a significant change in the process of consent and in consequence clinical consultations must undergo a radical transformation. The process of consent is now patient centred and those aspects which are important to the patient, which critically now include non-medical factors, must also be considered.

Patient information leaflets

Thus, the implication is that information offered to patients including patient information leaflets during the consent process will have to change significantly. In the past, patient information leaflets have often contained the implicit assumption that the (appropriate) procedure has already been decided upon (by the doctor) and all that was now required was for the (medical) risks and benefits of such a procedure to be explained.

The process of consent

The consenting process post Montgomery[1] must include all the reasonable treatment options *including the option of not doing anything at all*. This latter issue becomes more important to convey in clinical situations where our clinical interventions may only be modestly effective at best and probably only in the short to medium terms, and with even more uncertain outcomes of treatment in the long term.

Therefore, we as health care professionals have to be explicit about the natural history of the (usually intractable pain) condition and the uncertainty of the risks and benefits of any treatment including those which may be associated with rare but devastating complications.

It also goes without saying that there is likely to be a (wide) range of medical opinions/options about the possible therapies and their relative complications/implications. The complexities and uncertainties of medical treatment have now to be clearly spelt out and applied to the specific circumstance in the context of priorities of the patient. This has been decided by the Court (and the General Medical Council (GMC)) on the basis that any reasonable patient would want to know about these before consenting to the treatment. A record should (and in our view, *must*) be made to indicate that such a discussion took place.

There is no doubt that the clinical consultation, and in particular the consenting process, is going to take far longer than previously. There will be significant resource implications for this approach, but in our view that will be balanced by the likely fewer treatments that will be performed once patients realise that the medical optimism about a favourite treatment will not invariably be translated into a good patient outcome.

A written record should be made of this process and as indicated, in our view, it is mandatory that such consenting needs to be accurately reflected in the records. This document needs to include the treatment options discussed and the reasons why we are advising a particular pain management option out of all that are available and whether it is going to make any long-term difference to the patient in the context of natural history of the condition in that particular individual.

The preceding paragraphs form a summary of what has been discussed previously based on the developing case law following the Supreme Court decision in Montgomery.

What follows are the details of management options which should be discussed, with particular emphasis on the type of information that should be provided to patients about pain interventions and pharmacological treatments post Montgomery.

Interventional pain management techniques

Preamble

Interventional pain medicine involves the application of various techniques that can be used to diagnose or locate an individual's source of pain or provide therapeutic pain relief.

There has been a perception among some (and fortunately a rapidly decreasing minority of) Pain Medicine clinicians that all chronic pain can be satisfactorily treated by such methods in the long term. This is unlikely to be true because of multiplicity of various pain mechanisms even within an individual and the known poor efficacy of available treatments.

The desperation on the part of the patients suffering in chronic pain, combined with the (usual, inevitable) therapeutic optimism of treating physicians utilising their favourite pain relief techniques (often with little evidence base), may lead to retrospective accusations of futile and unnecessary treatment by lawyers, especially when things go badly wrong. This situation depressingly and recurringly forms the backdrop to many of the clinical negligence cases many of the authors have been involved in.

General principles of consent and GMC guidance 2008

As mentioned previously, Montgomery gave legal weight to the GMC guidance that was already in place. Prior to this, the Courts applied the Bolam test which focused on what a reasonable doctor might say rather than what a reasonable patient might wish to know. The test now is whether the doctor has taken reasonable care to ensure that a patient is aware of any material risks involved in any recommended treatment and of any reasonable alternative or variant treatments. A material risk is one which, in the circumstances of a particular case, a reasonable person in the patient's position would be likely to attach significance to or which the doctor should reasonably be aware that the patient would be likely to attach significance to. A small risk may be regarded as significant, depending on its potential impact on the patient.

Currently, the doctor's advisory role involves dialogue, the aim of which is to ensure that the patient understands the seriousness of their condition and the anticipated benefits and risks of the proposed treatment and any reasonable alternative, so that they are then able to make an informed decision. This role will only be performed effectively if the information provided to the patient is comprehensible to that particular patient. The doctor's duty cannot possibly be fulfilled by bombarding the patient with reams of technical information and then demanding their signature on a consent form. The GMC guideline 'Consent: patients and doctors making decisions together' in 2008 highlights the following issues:[2]

- The condition and treatment options and likely outcomes must be discussed with a patient.
- The patient's right to make decisions about their care must be respected. This may *require time to obtain further information* (including possibly a second opinion) and to consult with others including family.
- There must be a discussion if this treatment might result in a serious adverse outcome, even if the likelihood is very small. Serious includes medium/long-term pain, long-term effect on employment and social or personal life. Patients must be told about less serious complications if they occur frequently.
- A clinician will need to be satisfied that they have informed consent before they provide any treatment. This will involve providing clear and accurate information to patients in a way that they can understand and focused on individual situations and the risk to the patient.
- Experience shows that the Courts often believe patients who say they were rushed into a hasty signing of a consent form, and as anyone who has used the NHS can testify, unhurried conversations are not the norm. Written consent should be obtained but this is just the endpoint of the consent process. *Obtaining informed consent is a process of discussion and joint decision-making. In our view, it has to be explicitly demonstrated as such*.

Consent in specific situations

Cervical transforaminal injections and other spinal injections and the role of particulate steroid–mediated neurological injury

Cervical transforaminal injections have been associated with cases of death and serious complications[3] and such injections are currently not being practised in some pain units. In other UK units that continue to offer these injections, it is recognised that it is likely that particulate steroid injections are the main (but not the only) cause of such serious neurological complications.

Part of the difficulty is that there is considerable variation in practice on use of the type of steroid preparations and approaches for neuraxial use as well as many disciplines who offer these injections.[4] The British Pain Society and the Faculty of Pain Medicine of the Royal College of Anaesthetists published a summary for clinicians to inform decision-making in this area.[5]

There have been many reported catastrophic neurological complications with transforaminal injections in the cervical region as well as in other parts of the spine with particulate steroids.[6,7] According to the current evidence, the likely mechanism of such injury is due to the unintended intravascular injection of the particulate steroid causing direct vascular ischaemia of the spinal cord.[8] Particulate steroid–induced aggregation of red blood cells may also be a relevant mechanism.[9] It is accepted that the risk of such catastrophic neurological complication is likely to be much lower in more caudad regions with non-transforaminal routes of injection but the risk is not zero.

There has been one recent case report of non-particulate steroid administered via a transforaminal epidural lumbar route being associated with ischaemic neurological injury. This suggests that other poorly understood mechanisms may also be at play.[10] Some preservative formulations used in steroid preparations may be neurotoxic and the use of steroid preparation for epidural use is off-label.

Other types of injuries may also lead to neurological complications including direct neurotoxicity of drugs and neural injury and vasospasm secondary to needle trauma. There is conflicting evidence that particulate corticosteroid preparations have better efficacy than non-particulate preparations in the short term.

It is difficult to give an accurate assessment of the risk as only a proportion of serious complications are reported in the literature. In addition, there are no long-term data to indicate the efficacy of any steroid preparation.[11,12] This becomes relevant in the context of the (usually intractable) natural history of the pain condition and how one consents for current practice.

Based on current evolving evidence and mindful of the requirement for fully informed consent that is relevant to the patient, the position of the BPS and FFPMRCA working group at the time of writing can be summarised as follows:

- Particulate steroids *must not* be used for transforaminal cervical epidural injections on the basis of the risk of rare but catastrophic complications. While definitive recommendations were not given for the choice of soluble or particulate steroid for injections in interlaminar cervical epidurals, clinicians should be aware that serious neurological complication can still occur.
- While definitive recommendations were not given for the choice of soluble or particulate steroid for injections in epidurals undertaken in any areas of the spine (thoracic, lumbar and caudal), clinicians should be aware that serious neurological complication can occur with any route of administration particularly if there is a history of previous spinal surgery.
- The doctor must follow current GMC guidance on consent and record the discussion process. The discussion should preferably occur on an occasion prior to the procedure as well as at the time of the procedure to allow time for reflection and should include discussion and documentation regarding indications, efficacy and safety, including the possible use of particulate steroids and alternative treatments including no treatment.

NICE Clinical Guideline 59 on management of low back pain and radicular pain

NICE Clinical Guideline 59 on management of low back pain and radicular pain[13] suggests the consideration of facet joint radiofrequency for back pain and supports epidural injections only for acute and severe sciatica. There is significant variation in the published evidence base for the use of epidurals[14] and facet denervation,[15,16] and the strength of recommendation depends on which review one reads. The duration of action of any spinal procedure is likely to be limited.

Again, this uncertainty of efficacy does have major implications for consent and subsequent clinical practice and in the context of evidence of efficacy, risks and natural history of sciatica and low back pain. In the current UK practice, there has been a major shift noted in reduced commissioning of repeated spinal injections and indeed in some areas no spinal injections are commissioned at all.

Spinal cord stimulation

Spinal cord stimulation involves the implantation of electrodes in the spinal column near the dorsal column to modulate pain processing, resulting in the inhibition of nociceptive signals. The use of this technique in carefully selected patients with refractory neuropathic pain (complex regional pain syndrome (CRPS) and failed back surgery syndrome) has been shown to reduce pain, improve quality of life, reduce analgesic consumption and allow some patients to return to work and has been supported by National Institute for Health and Care Excellence.[17]

Several studies evaluating the efficacy of spinal cord stimulation for failed back syndrome[18] report good improvements in pain and quality of life, but they needed more ongoing input from the neuromodulation service (hardware issues, lead or battery replacement).[19] Studies on CRPS concluded that there is evidence for improvement in pain over long-term follow-up, but function may not necessarily improve[20] and up to 35%–40% patients will have less than 30% pain relief.[21]

One randomised controlled trial (RCT) reported significant differences for pain, but not for function. Recent RCT evidence for spinal cord stimulation has been mixed; the SENZA RCT by Kapural et al.[22] in Neurosurgery 2016 demonstrated large effect size, but another RCT study published by De Andres[23] in Pain Medicine showed much lower level of benefit over 12-month follow-up period. This conflicting evidence and variation in published treatment outcomes create significant challenge to practitioners offering this treatment. This has significant implications for informed consent with this treatment as to which evidence should be relied upon in informing the patient about the range of possible outcomes.

This becomes more important from a consent perspective in the context of the natural history of the progression of chronic pain and its impact. A study by Hayek et al.[24] showed an explant rate of 24% over 45 months. In a multinational chart review study of 955 spinal cord stimulator (SCS) implants, performed from 2010 to 2013 and followed until mid-2016, it was found that the rate of unanticipated explants was 8.0% per year of follow-up in a cohort of subjects known to suffer from complex chronic pain. The most frequent reason given, inadequate pain relief, was given in 4.2% of implants per year of follow-up. The survival curve showed a total rate of explant for inadequate pain relief of 19% at 5 years after implant and nearly the same rate of explant for other reasons (hardware replacement due to technical issue). So, in the longer term SCS treatment may have 8.0% explant rate per annum[25] (mostly due to diminished efficacy, but also related to complications), and need for reoperation to troubleshoot hardware issues (infection, lead migration, hardware malfunction) and the risk of serious neurological and life-threatening complications, though fortunately rare, needs a thorough discussion with the patient. Of course, patients often consider it worthwhile to proceed with implantation of SCS considering the nature of the pain.[26] However, it is important that the information given to the patient should be presented in a way that really informs them and so enables them to make realistic decisions and choices about their management options.

Neuroablative pain interventions

Spinal neurolytic blocks[27] and neurolytic sympathetic blocks, for example, coeliac plexus block and cervical cordotomy, can all have significant beneficial clinical effect on pain but also have rare but serious risks including death. However, one needs to consider the likely trajectory of these pains in relation to disease progression and life expectancy. Multiple specialists may need to be involved. Prior discussions often need to be had with Palliative Medicine and Clinical Oncology and any other parent specialty treating the cancer.

Neurolytic blocks are usually effective for 2–4 months and can be repeated in the event of recurrence of pain. Informed consent, explaining the side effects of these neuroablative techniques including numbness or dysaesthesia, is a key when considering spinal neurolytic or any other neuroablative block. Unexpected complications can occur even with meticulous conduct of the procedure and this needs to be discussed and understood by the recipient of this treatment. Strength of recommendation for these types of treatments is weak, but the effect is often considered worthwhile and indeed may transform residual quality of life based on case reports from the literature.[28]

Cordotomy for cancer-related pain has been described in the literature from the early 1900s, initially as an open surgical technique, but from the 1960s as a percutaneous technique. The technique has been further refined with the evolution of technology involving X-ray imaging facilities and radiofrequency machines, allowing a reliable heat lesion in the spinothalamic tract. There is limited high-quality evidence[29] but it seems to be helpful for the well-selected patient with over 80% undergoing this technique reporting significant improvement in pain and reduction in analgesic consumption.[30] There are small but significant serious risks reported as well as new neurological deficit, mirror pain and serious catastrophe including death. So this probably very effective pain-relieving technique requires a detailed clinical assessment and documentation of the assessment and consent process (e.g. initial assessment in joint clinic, explanation of the procedure, offer of alternatives including no intervention, and a written leaflet to take home, reassessment and consent and reconfirmation of consent again on the day of procedure) so as to meet the current standards for consenting.

We emphasise again that simply performing an interventional technique to the correct standard will still be associated with side effects or complications in a proportion of individuals. This is relevant as there have been successful legal claims despite non-negligent performance of surgery. A patient would have reasonable grounds to initiate a legal claim if relevant information was available to the clinician, but was not shared with the patient, which could have affected the patient's decision as to treatment. That would arise if the patient would have attached significance to the risk so that, if they were in possession of the full information, they would not have elected to undergo the non-negligently performed procedure and so would not have been exposed to the associated risks or complications. Thus, the negligence or breach of duty giving rise to the claim is in the area of consent rather than relating to the manner of performance of the procedure.

Medicines

Recommending or prescribing medicines is perhaps one of the most common activities undertaken by pain services. Before considering the information that should be discussed with a patient in that process, it is worth first reviewing the different types of medicine and the information available for patients.

Licensed medicines

Before a medicine can be marketed in the United Kingdom, it requires Marketing Authorisation (MA; previously the product licence), which means that a medicine has been approved by a regulatory body for use in humans and is licensed for specific indications and patient populations. According to the Human Medicine Regulations 2012, the manufacturer must provide a package information leaflet in accordance with the summary of the product characteristics for the medicine. Regulation 26 specifies the information that must be included, but this is a very extensive list including name, intended effects and indication, side effects and specific storage instructions. However, in order to comply with this legislation, the leaflet may not be particularly 'user friendly' for patients or their carers.

'Off-label' or 'off-license' use of medicines

'Off-label' or 'off-license' describes the use of a licensed medicine beyond the specifications of its MA (e.g. for an unlicensed indication, or in doses, preparations, patient population or route of administration not covered by the MA). Hence, information provided in the package information leaflet will not be relevant for these groups of people.

'Off-label' use is widespread and considered clinically acceptable, particularly in specialties such as paediatrics, pain medicine and palliative care, with surveys in the latter suggesting that up to one quarter of all prescriptions come into this category.[31,32]

Mixing of two or more licensed medicines prior to administration is (technically) considered to produce a new, unlicensed preparation.[33] Common examples of this include the mixing of a local anaesthetic with a depot corticosteroid prior to injection and the mixing of two or more medicines in a syringe for administration by continuous infusion.

Unlicensed medicine

There is no simple definition of an unlicensed medicine. Essentially, it is a drug which does not have MA for medicinal use in humans.

It is important that prescribers (or those authorising treatment on their behalf) provide sufficient information to patients about the expected benefits and potential risks of using a medicine beyond or without MA (undesirable effects, drug interactions, etc.) to enable them to make an informed decision.

The GMC Good practice in prescribing and managing medicines and devices (2013) recommends when prescribing an unlicensed medicine,

> (a) You must be satisfied that there is sufficient evidence or experience of using the medicine to demonstrate its safety and efficacy;
> (b) You must take responsibility for prescribing the medicine and for overseeing the patient's care, monitoring and any follow-up treatment, or ensure that arrangements are made for another suitable doctor to do so;
> (c) You must make a clear, accurate and legible record of all medicines prescribed and, where you are not following common practice, your reasons for prescribing an unlicensed medicine.

In addition, you must give patients (or their parents or carers) sufficient information about the medicines you propose to prescribe to allow them to make an informed decision.

The patient will have certain expectations about the medicine that are likely to be untrue, including the following:

- The medicine is likely to work in providing complete relief from their pain;
- The risks associated with the prescription are insubstantial or simply risk free;
- The medicine may cure the patient of their pain rather than just palliate it.

All these expectations are likely to be unachievable and erroneous.

The questions that clinicians must help the patient to consider should include the following:

- Why is the medicine being prescribed?
- What are the chances of the medicine being effective on me?
- What are the likely side effects and what complications and harms need to be considered in both the short and long terms? This will include the effect on lifestyle including ability to drive.
- For how long will the medicine be prescribed and what is the review process for assessing whether the aims are being achieved?
- Will the medicine change the outcome of my (pain) condition?
- What happens if I don't take the medicine?

Efficacy of pain medicines

While some analgesic medicines can be beneficial for acute pain, in general they are of much less benefit for chronic pain and often do not change the outcome. In the words of a seminal viewpoint published in the BMJ,[34]

> *Expect analgesic failure: pursue analgesic success.*

In determining whether to consider a particular medicine for an individual patient, there needs to be careful consideration of the likely benefit and possible harms, often quantified as the number needed to treat (NNT) and number needed to harm (NNH), respectively.

In the following sections, we explore how prescriptions for specific pain medicines should now be addressed in light of changing standards of consent.

Opioids

Despite the long time that opioids have been available, there remains much that we simply do not yet know. The aims of opioid therapy should be to relieve pain and improve physical function and quality of life. However, there is little evidence of any of these aims being achieved in the long term in any types of chronic pain.

There are now numerous randomised control trials and systematic reviews that conclude that opioids may reduce pain for some patients in the short and medium terms (usually less than 12 weeks) for a number of chronic pain conditions. However, until early 2018, there was no study of opioid therapy versus no opioid therapy evaluating long-term (>1 year) outcomes related to pain, function, quality of life, opioid abuse or addiction.[35]

In a recently published 12-month study, opioids provided no benefit over non-opioid medications for improving pain-related function in people with chronic back pain or hip or knee osteoarthritis.[36] There is also a critical lack of evidence regarding the effects, both benefits and harms, of high opioid doses (oral morphine equivalent > 200 mg/day).[37] Patients with psychological illness and substance abuse problems are more likely to receive chronic opioid therapy (adverse selection) and at higher doses than people without those risk factors.[38] Perversely, these are just the groups who are unlikely to benefit from such therapy.

In a review of 14 relevant Cochrane Reviews, there were a significantly increased risk of experiencing an adverse event with opioids compared to placebo (risk ratio (RR): 1.42, 95% confidence interval (CI): 1.22–1.66) and a significantly increased risk of experiencing a serious adverse event (RR: 2.75, 95% CI: 2.06–3.67). Furthermore, significantly increased risk ratios for a number of specific adverse events, such as constipation, dizziness, drowsiness, fatigue, hot flushes, increased sweating, nausea, pruritus and vomiting, were reported.[39]

Other side effects and harms are less well suited to being studied in randomised controlled studies. At present, there is no '*strong' evidence* and only fair-quality observational studies suggest that long-term opioid therapy for chronic pain is associated with increased risk for overdose, opioid abuse, fractures, myocardial infarction and markers of sexual dysfunction.[40]

It remains illegal in England and Wales to drive when taking prescription medicines if a medicine impairs a person's ability to drive. In 2015, a new offence was created which refers to driving with a specified controlled drug in the body in excess of a specified limit. The drugs include licensed medicines, including morphine and methadone but not other opioids. The specified limits are generally above the normal therapeutic range so most patients prescribed these drugs are unlikely to be driving with a concentration of a specified drug in their body above the specified limit.

A patient on high-dose morphine (around 200 mg/24 hours) could be as impaired as someone with blood alcohol around the level above which it is illegal to drive. Patients should be aware that during the period following dose adjustment (either increasing or decreasing) they may be particularly vulnerable to impairment. Prescribers of opioid medicines must be aware of the likely impairing effects of the drugs and must advise patients accordingly. Although this legislation has impact on patients taking morphine, prescribers should be aware that equi-analgesic doses of other opioids are likely to be equivalently impairing.

The new offence has a statutory 'medical defence' to protect patients who may test positive for certain specified drugs taken in accordance with the advice of a healthcare professional or the patient information leaflet that accompanies the medicine. It remains the responsibility of all drivers, including patients, to consider whether they believe their driving may be impaired on every occasion when they drive. A patient also drinking or taking other sedative drugs could be impaired at a lower morphine dose. Discussions in relation to drugs and driving must be clearly documented in the medical notes and a copy given to the patient. Prescribers should also advise patients of the potentially distracting effects of pain, and other comorbidities such as fatigue and poor sleep in relation to driving and working with machinery:

> *Drivers who tested positive for morphine were between 8 and 32 times more likely to be injured or responsible for a road traffic collision compared with those who did not have a positive test result.*[40]

Historically, it was assumed that the incidence of addiction when opioids were taken for pain was extremely low. However, this was based on a flawed four-sentence letter that was published in the New England Journal of Medicine[41] that has been retracted very recently. It is difficult to provide a precise figure for the incidence of addiction as studies have used varying definitions. In a systematic review, rates of misuse varied between 21% and 29% (95% CI: 13%–38%). Rates of addiction averaged between 8% and 12% (95% CI: 3%–17%).[42]

In December 2017, the Centers for Disease Control and Prevention (CDC) reported that life expectancy in the United States had dropped for the second consecutive year to 78.6 years and they attributed the primary cause to be the increase in deaths due to opioid overdoses.[43]

Antidepressants

Although antidepressant use is relatively ubiquitous, safety concerns continue to be raised and they may not be as innocuous as they seem. In a recent meta-analysis of 17 studies comparing people using antidepressants to those on placebo, people taking antidepressants were 33% more likely to die during the study period and 14% more likely to have a heart attack, stroke or other cardiovascular event. People who already had cardiovascular disease, however, were at no higher risk if they took an antidepressant. The type of antidepressant did not seem to make a difference.[44] Serotonin syndrome, particularly in combination with tramadol or other opioids, has been reported in case reports.[45]

Gabapentinoids

Over recent years, the prescribing of gabapentin and pregabalin has increased dramatically. Anticonvulsant medications such as the gabapentinoids can cause sedation, cognitive impairment and visual disturbance and are associated with a significantly increased risk of road accidents.[46]

Gabapentin and pregabalin can cause substantial weight gain for a relatively small proportion of people; however, the mechanisms by which this occurs remain unclear.[47]

There is preclinical evidence[48] that gabapentinoids gabapentin and pregabalin may reverse opioid tolerance and increase the respiratory depressant effects of opioids and clinical evidence to support this.[49] Last year, the Medicines and Healthcare products Regulatory Agency (MHRA) highlighted the risk of respiratory depression with gabapentin, with or without concomitant use of opioids,[50] and the combination may be associated with increased mortality.[51]

Case reports and case series have reported changes in mood, depression and suicidal ideation after commencing pregabalin for neuropathic pain.[52,53]

Potent binding at the calcium channel results in a reduction in the release of excitatory neurotransmitters. Furthermore, gabapentinoids are thought to possess gamma-aminobutyric acid (GABA)-mimetic properties while possibly presenting with direct/indirect effects on the dopaminergic ‘reward’ system. Concerns regarding the potential for misuse and abuse of gabapentinoids have been highlighted for several years. Overall, pregabalin is characterised by higher potency, quicker absorption rates and greater bioavailability levels than gabapentin, and hence associated with greater potential for misuse.[54]

Consent and pain management options

Considering the evidence for risk/benefit ratio (see above) with opioids and other drugs for chronic pain (gabapentinoids and antidepressants), the pain clinician may be left with limited management options.

Treating the cause of pain often leads to good long-term outcome in many conditions, for example, microvascular decompression for trigeminal neuralgia and surgical microdiscectomy for acute sciatica.

However, most patients in routine Pain Clinic setting do not have these clear-cut options and require further management/help/support. This causes uncertainty regarding future management options in the current clinical and medicolegal context.

Examples of what would previously have been considered reasonable clinical management regardless but now been considered examples of poor consent and open to criticism

For example, a patient with severe acute exacerbation of neck and arm pain with magnetic resonance imaging (MRI) scan showing a moderate disc bulge undergoes a seemingly uneventful cervical epidural steroid injection but complains bitterly of pain afterwards. Even if there is no evidence that the clinical management or procedure would be considered substandard, and indeed that particular treatment pathway would have been offered by many Pain Consultants, would the Consultant be liable for unfavourable result?

Another scenario from an anaesthetic perspective could be a patient offered a brachial plexus block as an adjunct for, say, a surgical procedure on the shoulder. The regional block by an experienced doctor seemingly proceeds uneventfully with careful ultrasound and nerve stimulator guidance. However afterwards, the patient complains of bitter pain and yet there is no evidence of any substandard clinical decision-making (*i.e. the same procedure would have been offered by many anaesthetic consultants faced with the same situation*). Is the consultant liable for an unfavourable result even though the performance of the interventional procedure is not substandard in any way?

In these clinical scenarios, the decision as to whether there has been *a breach of duty* by the doctor will depend on the information offered to patients during the consenting process. In particular, we recognise that with any medical intervention, even that which is technically perfect, there is always risk of new adverse symptoms or complications.

In the two scenarios above, the patient having suffered an unfortunate complication because of the injection may well complain,

> *yes the injection did help me at the time but you didn’t tell me that the long term outcome would probably be the same for my neck pain (or shoulder surgery) even if I didn’t have the injection. In fact, I now have this extra (long term) pain because of the nerve injury you caused. If I had been told of the (lack of) prospects of long term benefit and the risks inherent in the procedure I would not have agree to have the injection, and I would not now have this extra pain.*

It is now up to a patient to make that informed choice if they wish to undergo that injection with the probability of short-term pain relief and a shortened attack of neck pain or extra perioperative pain relief during shoulder surgery. But now, in addition a patient must have explained and so must explicitly accept and consent to the concomitant risk of serious complications *knowing that such interventional procedures are not going to make a long-term difference to the outcome of, say, neck pain or shoulder surgery and could have longer term adverse effects*.

This is why we are of the opinion; if more time is taken to explain these matters, many fewer procedures are likely to be done.

Summary: time for a change

Pain Doctors do need urgently to review their consenting process. This will include provision for explaining the clinical indications and explaining the evidence of the benefit from the offered treatment (or from the range of treatment options) in the context of the natural history of the condition treated.

In view of the current legal position, the published low-level evidence for the efficacy of pain interventions (and spinal interventions in particular) in the context of the natural history of chronic pain may in some cases beg the question: why do the interventions at all? The current position on consent post Montgomery and the GMC guidance 'Consent: patients and doctors making decisions together' may mean that many patients may elect for more conservative measures.

The therapeutic options will need to be discussed in more detail, and more frequently, and the patient's agreement to treatment needs to be reached by the patient in close liaison with their treating physician in an explicit and transparent manner which can be scrutinised in detail in retrospect.

The current legal position leaves the door wide open for various consent claims retrospectively, currently and for the foreseeable future. Clinicians in response need to be prepared to mitigate this risk by changing their current practice. This will mean, longer consultation times, avoiding simply consenting on the day of procedure and, we submit, will mean fewer procedures.

We are left with no choice but to profoundly change our approach as to how we offer various management options to our patients. But this is surely a good thing.

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A personal view

THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

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SAGE

A day in the life: a working doctor's struggles with the NHS hierarchy, prescribing limitations, impending community pain clinics and human nature

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It's Friday. I've driven to work in 18 minutes, which isn't bad, but I'd have been quicker if that idiot hadn't cut out in front of me and then driven along the country lanes at 25 miles per hour. Why do they do that? Do they really not see two tonnes of Birmingham's finest hurtling down the road? Do they assume that a 30-year-old Land Rover is going to be slower than them? Maybe they're simply selfish. A lot of people are – and that's sad.

I park in the Consultants' car park. We're not supposed to call it that any more – it's the *senior staff car park*. To suggest that having a huge IQ, getting stellar A levels, working through a 6-year degree, 10 years as a junior doctor, three post-graduate exams and years of experience in making life-and-death decisions might just make one more qualified than a manager is *elitist*. Of course it is. As a manager once told me: she has a right to be involved in patient care too. Being a clinician doesn't give me a monopoly on delivering *care*.

I walk through the car park. It occurs to me that the queue of people wanting managerial care for their aneurysms is a bloody small one. It also puzzles me that none of these intelligent, kind, caring people can manage to get one car into one parking space. For Heaven's sake.

I arrive in the outpatient clinic. I notice some rather over-weight and sad-looking people sitting on National Health Service (NHS) chairs in a row. Some of them have crutches. I do hope that none of them are waiting to see me. Surely, today will bring me a super-model with a brilliant smile, no whiff of ashtrays or body odour and a well-localised pain that I can blast with RF: I shall be her hero and before we know it I'll be all over *Forbes* and hosting my own intelligent talk-show on Radio 4.

I enter into the clinic room. My colleague has left me a bucket of strong coffee and I glug greedily as I wait for the computer to boot up. I log on and the PC wheezes into life as I peruse the clinic list. We have two new patients: one of them sounds familiar and is probably a re-referral. That's good: I can spend more time on the patient I've never met before. Then there are eight follow-up patients. Oh dear! I recognise most of the names and none of them are going to be quick. At the end, we have quick transfer from the private sector (counts as a new patient but takes 10 minutes) and an urgent cancer referral – which could take anything from 10 minutes to an hour or more.

The computer is awake. At last, I log in, now, to the pain record system, then the hospital record system, and finally, the clinical information system. Three more user names, three more passwords, a slow PC and an even slower network connection. What more could a busy doctor ask for?

I read the first referral letter. 'Dear Doctor, This lady has ME and her back pain is growing worse *despite* strong pain-killers. Please see and advise'.

Really? That and a summary of her general practitioner's (GP) record is a 'referral' to a consultant these days? Lord, I am old and growing short-tempered.

The first consultation gets under way. Of course, she has seen the spinal team and their assurance that 'there are no targets for surgery' has somehow morphed into 'All my discs are out and I need surgery: but the consultant says the operation will paralyse me and could kill me'. Not to worry, she knows the diagnosis *and the aetiology* – she has multiple disc prolapses, caused by heavy lifting. All I have to do is to give her stronger pain-killers … that's why she's here. The GP has started her on morphine patches but even 75 µg of fentanyl isn't touching it any more.

We have 30 minutes. It takes an hour to obtain a coherent history, perform a thorough examination, chase up the imaging (some of which is on a different system in another hospital) and try to explain, well, everything. All of those misconceptions tackled. All of the many 5 minutes shaved off her previous medical encounters to be paid for. At the end of it, I think we're getting somewhere. She agrees to start weaning down her fentanyl. She will see the psychologist and the physio. She will try the TENS, and she will be no more disappointed that it stops working when it is turned off than she is angry that her lights stop providing illumination when they no longer have an electrical supply.

By now, it's gone 10. I'm officially 30 minutes behind, and I've only seen one patient. I swig the remains of my coffee bucket. Fortunately, I don't mind cold coffee: I drink the stuff mainly for the caffeine and sugar anyway.

I pause to wonder about the last lady's treatment plan. It sounds great on paper: Physio, Psychology, TENS, back to me for a review … but how long will all of that take? Four months to get to see the pain physiotherapist? Six months for the nurse-led TENS clinic? Ten months for the clinical psychologist? We are drowning and now a new threat looms: the Community Pain Service.

Here, as in many parts of the Country, the local commissioners have decided to try to save money/increase efficiency/expand access (call it what you will) by setting up a rival pain service. Our managers, knowing nothing of clinical medicine and less of chronic pain (but, of course, still having every bit as much right to *care*) have decided to start reducing the staff in the pain clinic. They're doing this because the commissioners say that 20%, no 40%, no 60% (no-one can agree) of our referrals will be seen and treated by the new service. Under a mechanism called TUPE, some of our psychologists, our nurses and our physiotherapists will go and work for the commercial organisation running the rival clinic. They have been told that they have no option. We (the doctors) haven't been asked. It will occur. So, what's going to happen to the waiting times for all of the appointments that my patient needs? Will she get her next appointment this year? It seems very unlikely.

And, what's going to happen to people like her who, in future, get sent to the streamlined commercial system? Will they really get an hour with an experienced senior clinician?

The situation makes me angry because I really do support the idea of community pain clinics. The more resources we have to help people with chronic pain, the better. But, I want to work *with them* – not in competition against them – and I don't want to see my struggling pain service impoverished in order to get the new services established, I want the new services to have new funding. Otherwise, it's not increased expenditure on chronic pain. It's doing it less well and allowing a private enterprise to take a cut of the action.

Patient two

He looks familiar. I remember him: he's the guy who builds model steam engines for a hobby. I think I did RF … yes, the notes (when the computer finally responds) show that I denervated his left L4/5 and L5/S1 facets 3 years ago. I haven't seen him, myself, since. The nurse-led follow-up says that at 4 months, he was off his analgesics and was able to care for his wife again.

The story unfolds: after a year, his back began to niggle again, but he was coping. After 2 years he was needing strong opioids once more. His GP saw that I'd said '… if his symptoms come back, please re-refer and we'll list him for repeat treatment…' but the GP's letter to me went off to a triage centre. And he was seen in a 'choose-and-book' clinic in a private hospital. He had a steroid injection, which helped for 8 weeks, and eventually, the retired NHS consultant who ran the choose-and-book clinic recommended referral back to us, for RF.

Clinically, he's just as he was pre-RF. He's now on MST and laxatives, but otherwise, it's simple facet pain again. He thought that today's appointment was for treatment because I'd said that we'd repeat if his symptoms came back the same. I told him that we're going to be lucky to get him down to the procedure room within 6 months, and he looks broken: defeated. He tries to get a grip of

A day in the life: a working doctor's struggles with the NHS hierarchy, prescribing limitations, impending community pain clinics and human nature

his emotions but a tear runs down his cheek.

The model railway? Not for over a year. With his back, it's all that he can do to lift and carry his wife who is now a complete invalid. No: she will not go into a nursing home. She doesn't want it, and he is duty-bound to care for her because they love one another. Perhaps he could dip into their savings and pay me to perform the RF more quickly as a private patient? Just so that he can keep things going at home?

I love money as much as the next man, but I have my limits. I telephone my secretary: Monday is over-booked. And the Monday following. The Monday after that? We have four RF cases? Well, now we have five. It's not possible? Fine: we'll do the impossible. Add him on for repeat RF, please, and we'll muddle through.

As he leaves the room we shake hands. 'See you in a fortnight, but do remember: the greatest risk of these procedures is disappointment: it might not work as well as it did the last time'.

'Oh, I have faith in you doctor. You're the only one who's helped me'.

What an accolade: but what a burden. It's all riding on me, my Radiographer, and a couple of 16-guage needles.

The clinic winds on. We're now well over an hour behind. Of course, all of the people who have been waiting, making snarky comments to the nurses, don't mind a bit. Quite understand. Such a busy doctor! Lots of people to see. They are, of course, entitled to spend 20 minutes talking about themselves in their 15-minute slots because they've been kept waiting. That's only fair.

Around 11:30, a small miracle happens. Two patients haven't turned up. One of the follow-up people simply popped in to say that she's still alive, still coping and would like to see me again next year … if we're both spared. I'm only a few minutes behind schedule.

The next patient is a man who has been having steroid injections around his right L4/5 facet joint since Adam was a boy. I inherited him from a predecessor who took him on while I was still enamoured of intensive care unit (ICU) and thought that dopexamine and Swan-Ganz catheters could save everyone. Don't judge me: we all believed in Father Christmas once upon a time.

I've taken him down to the procedure room to do diagnostic medial branch blocks twice – and had a positive response both times. I've done RF, twice, and it simply doesn't help him. Is it the steroid? Is it the intention to treat? Does he have odd medial branches? Have I missed my targets twice? I simply don't know.

He gets between 9 and 11 months of relief from the injections and is content to see me once a year for a repeat. Frankly, the cost to the NHS must be negligible. Five minutes of my time, a single flash from the fluoroscope, 10 shillings' worth of drugs and he's back to the waiting area to get dressed. Why this appointment? Well, NHS England says that his treatment shouldn't be funded anymore. I want to try to explain to him that as long as I can continue with his annual injections, I shall, even if we have to dress the injection up as something else. But, there may come a time when even my ingenuity fails to bamboozle the managers (who, of course, have every bit as much right to *care* as any doctor). And what do we do then?

He's in his 94th year. He turns up, always, in neatly-pressed trousers, clean shirt, tie and blazer. How in the name of all that is right am I to tell this man that he can no longer have his annual treatment? That the health economists have decided that his pain relief is not worthwhile for the few pounds that it adds to my procedure list? But yes: you can have hundreds of pounds of encouragement from a community physio and a nurse who has been on a course. It may do you damn' all good, but something has been done and it's your tough luck that it doesn't work as well as a quick shot of Kenalog. You were at Arnhem? That must have been nice: to have a holiday in Holland. Did you do much while you were there?

I'll keep going with the L4/5 facet injections for as long as I can.

The clinic continues. One of the 'DNA' patients has turned up. She was reliant on hospital transport, and they arrived here 90 minutes late. I say that I will see her, but that I should really see the patients who arrived on-time first. The transport people are not happy: do I think that I can keep them waiting all day? I forget, sometimes, that I'm only a consultant, and that my time is less valuable than everyone else's. Of course I'll simply do the impossible: what else do I get paid for?

Then, it's a girl (I say girl: she's nearly 40, but younger than me) with arm and chest-wall pain. I've been treating her for several years now. She had surgery, chemo- and radio-therapy for an aggressive tumour in her breast. It seems to have worked, but she now has neuropathic pain. Lignocaine patches make things bearable for her. Will her GP prescribe for her? Of course not. He says he 'isn't allowed'. We know that he *can* prescribe if he wishes, but he may then have to defend his actions to the commissioners and that would be too much to ask. So, I prescribe the patches instead. And I'll see her every 3 months and prescribe a carrier-bag full of lignocaine plasters until something or someone stops us.

I should not wish chronic pain upon anyone. But, if the high-flying evidence-based here today and promoted tomorrow managers who have taken control of the NHS could have it for a while, a short while, a few months perhaps, might we not see a more benign countenance shining forth on our patients?

It's time for the last two patients. Thank Heaven that the 'private transfer' patient is straightforward. She is simply here to agree with the treatment plan that we discussed when her medical insurance was active, and she saw me at the private hospital. The appointments are made and she goes off clutching an advice sheet.

The last patient, however, seems to have a combination of mechanical back pain, nerve-root involvement from his secondaries, distress and opioid-induced hyperalgesia. The next clinic should have started 10 minutes ago? Well, is there a room where we can continue? OK, we'll move to the treatment room and carry on there while my colleague starts his outpatient clinic in here.

As I leave the outpatient department at 3 in the afternoon, to start dictating my letters, I wonder how on Earth is the new community service going to cope with any of these patients? I would be the first to admit that, for many of them, medicine doesn't have a treatment. The problem is that simply saying 'we cannot help you' is no more use than telling them that they have 'a slipped disc' or 'a bit of arthritis in the neck'. The full, true, explanation takes a lot of time to convey and that's really why I'm here.

I worry that the future holds a plan that doesn't involve me, or people like me, and how, then, will we help our patients to control the biological elements of their pain while helping them to address the psychological and social elements of the problem?

The drive home is pleasing. Another Mr Selfish tries to pull out in front, but I have Blondie on the stereo and 25 tonne of hardened steel rolls on no ordinary wheel. He thinks the better of it before I can demonstrate the principles of momentum on his car; and my Land Rover then has a clear run home. If only NHS policymakers were so easy to brush aside.

Professional perspectives

A tale of two tribes

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THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS

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SAGE

Credit: Robru

In the beginning, in 1948, were the Consultants and general practitioners (GPs). Many were passionate about the NHS and worked round the clock to make it work, and between them they ran the NHS, with little interference from anyone except Matron. Patients were very grateful for treatment and the Consultant was God.

Then, at the end of the 1980s, Satan tempted politicians with the notion that Consultants weren't all that good at running the service and should stick to what they did best, that is, doctoring (patients, not statistics, of course!). An army of professional managers were recruited to take over NHS management, Consultants were largely confined to being doctors, and darkness was upon the face of the earth, where it has remained pretty much ever since.

To be fair, attempts were made to encourage doctors to get involved in management, and some Consultants were happy to moonlight on the 'Dark Side' and became Clinical Directors, or even Medical Directors. I remember an early implementer of this approach whose management style was too muscular even for the taste of the true managers, let alone the other Consultants, and he eventually went back to being the excellent clinician he had always been. Others have been much better at keeping their balance with a foot either side of the void, but not many have left clinical practice and totally embraced the Dark Side, and so it was that professional managers came to run the NHS. This was quite a double bind for Consultants. Few of them really wanted to spend their time doing management, but almost all resented the newcomers who were sent to relieve them of this chore. The result was 27 years, and counting, of tribal warfare. So why did it become so tribal?

Probably because tribes have always existed in the NHS. Obstetricians and midwives spring readily to mind. As a houseman in the early 1980s, the ward nurses at my teaching hospital told me they were taught as students that doctors would all dis them and treat them as serfs, so it was important to get firmly on top of that with the newly qualified ones. Thus, it was de rigueur to make life awkward for them and to drop them in it with their Consultants. So why did I, as a houseman, get let into the secret? Well, that was about tribes as well; they were all women, and so was I. I believe career managers might have got away with making colleagues, not adversaries, out of Consultants in the early stages, had so many of them not been unfrocked nurses (I speak metaphorically, of course), and so from the wrong tribe.

Maybe, 70 years after the NHS was set up, it's a good time to cogitate on the whole issue of hospital management. My personal opinion is that two things, above all, have caused the NHS a lot of grief, and neither were the fault of managers. The first was the growing realisation that demand for the service was increasing at a frightening rate and that the NHS could easily swallow the entire GDP if allowed. A belief evolved across the political spectrum that the public weren't willing to pay more taxes to ensure that the NHS could grow to meet the increased demand and that even thinking about increasing taxes was a vote loser, so the NHS was starved of cash.

The second factor was that politicians across the political spectrum felt that the best way to improve the NHS was to set performance targets against which they could measure it. They seemed unaware, first, that targets have unforeseen perverse outcomes and, second, that sick patients and targets don't always mix well. Much of this could have been dealt with had they asked, and listened to, some jobbing clinicians or even hospital managers, but no self-respecting politician was going to do that.

So, from the word go, the new breed of managers were being asked to implement some pretty dumb stuff in with some changes that were wholly sensible. Human nature being what it is, especially among Consultants, they focused on the more stupid aspects of this, blamed the managers and ignored the fact that many of the changes were for the better. Was it so great when the Consultants ran the system? Have the professional managers wrecked the service? For example, how long does a patient really want to wait for an operation? Most patients would prefer 3 months to a year wait, which is what it used to take to get cataract or joint replacement surgery. Was it so much fun to be brought in at 2 pm for a clinic, along with everyone else, and then be seen at 5 pm? Several days in bed post-knee replacement surgery on a passive knee waggler, anyone?

There have been some really good management achievements which were resisted by many Consultants but have greatly improved patient care. On the down side, QOF points appear to have had little impact on outcomes in primary care, and the 4-hour wait in A/E has been a triumph of populism over common sense. I would wholeheartedly support the critics who point out how much in NHS resources has been ploughed into the management of targets that were always stupid, but for that we have to blame politicians, not managers.

I worked for many years with a hospital chaplain who used to tell us that most people are trying to do what they think are the right things for the right reasons. I believe that to be true of both the management and Consultant tribes.

I have met many managers who were passionate about the NHS and worked their guts out for it, although I have also met some who were self-serving idiots and/or downright bastards. Similarly, I have met many Consultants who were passionate about the NHS and their patients, and who worked their guts out for them, but I have also met some who were self-serving idiots and/or downright bastards.

The stupid thing is that if you get either side talking about the NHS in general, the majority care a lot about the NHS, but neither tribe can bring itself to trust the other. What both sides need to get their heads around, in my humble opinion, is that patients are more important than tribes and it's time to recognise each other's strengths and get a whole lot more collaborative. Managers need to seek advice from clinicians, and clinicians have got to stop bristling every time managers have a cunning plan. It's about mutual respect and maybe even the odd visit to the pub together. Is that really such a big ask?

Informing practice

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EXPERTISE WHERE IT MATTERS

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SAGE

Ketamine – (Some) Americans reach consensus on Pain Medicine's Marmite

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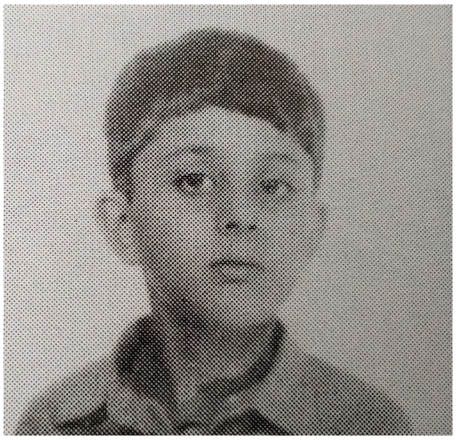


In July 2018, the American Society of Regional Anesthesia and Pain Medicine, the American Academy of Pain Medicine and the American Society of Anesthesiologists published the Consensus Guidelines on the Use of Intravenous Ketamine Infusions for both Acute Pain Management and Chronic Pain Management.[1,2]

These documents have an impressive pedigree and contain a comprehensive summary of the current evidence base and knowledge (up to January 2018) underpinning the unlicensed use of ketamine in pain.

Anyone familiar with the off-label prescribing of ketamine, or indeed anyone contemplating prescribing it for the first time, would do well to read the guidance and the references, bearing in mind the caveat at the start of these documents which states that

> *The opinions or assertions contained herein are the private views of the authors and are not to be construed as official or as reflecting the views of the US Department of the Army or the Department of Defense. Importantly this document has neither been presented to nor approved by either the American Society of Anesthesiologists Board of Directors or the House of Delegates, nor is it an official or approved statement or policy of the Society. Variances from the recommendations contained in the document may be acceptable based on the judgment of the responsible anesthesiologist.*

So why did this guidance, written with an American audience and population in mind, come about?

Well, what has become clear in the last few years is the dramatic increase in research and publications concerning ketamine, a drug that has been clinically available for almost 50 years.

This has also been accompanied by a rise in clinical use, a situation which at one recent symposium on its use was considered to be a situation analogous to the 'Wild West',[2,3] due to reports of its use in private pain and psychiatric clinics across the United States.

There are accounts of some centres providing 'cash only' intravenous (IV) ketamine infusions to patients coming in with a variety of pain and psychiatric disorders, with one letter writer alleging that 'ketamine clinics or ketamine wellness centres already offer ketamine as outpatient treatment with unscientific and dangerous methods' and going on to state: ' To overcome the lack of regulation, consensus statements and their dissemination are of utmost importance'.[4]

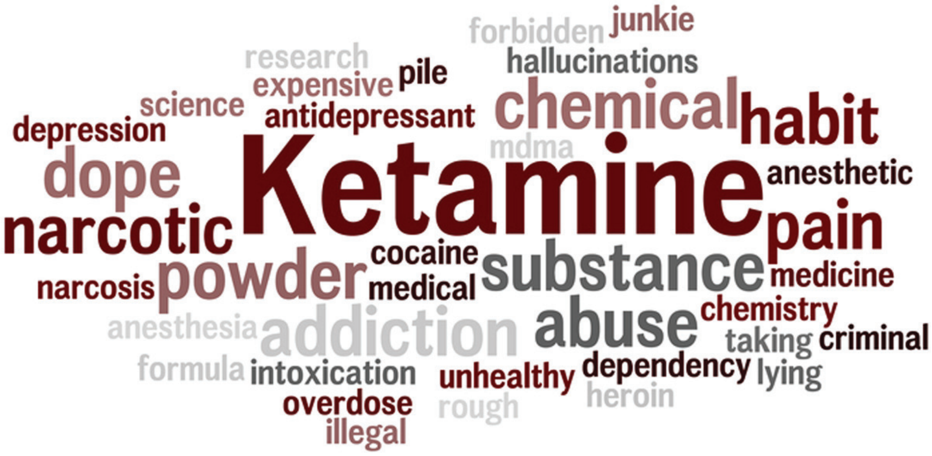
Close observers of the 'Ketamine scene' will already be aware that the American psychiatrists were quicker off the mark with their consensus statement, which was published in April 2017.[5]

As stated by the authors of the latest guidance,

> *The objectives of this consensus statement are to provide an overview on the literature supporting ketamine for chronic pain, depression, and post-traumatic stress disorder (PTSD); determine appropriate patient selection for the use of ketamine infusions to treat acute and chronic pain; establish a framework for standardization of use during intravenous (IV) infusions; and establish safety parameters regarding monitoring, personnel, and dosing, which can be used for the treatment of chronic pain and psychiatric disorders*.

So where does this guidance leave jobbing UK (pain) clinicians? That ketamine has a pharmacological effect is not in doubt. The evidence supports that there is a clinically relevant effect and where Acute Pain Services in hospitals have existing protocols which have stood the test of time and have not resulted in too much post-operative cognitive dysfunction, little will need changing.

What is less clear, particularly for patients with chronic pain, is the dose and route that should be pursued. While



the guidance suggests that regular IV infusion treatment every 1–2 months is reasonable (Grade C evidence), I am not personally aware, in an austerity era NHS, of any Pain Centre in the United Kingdom which is offering this as a service, or indeed has the desire to do so. I would be delighted to hear from anyone who is managing to achieve this and how they have managed to do so.

Just thinking about it practically, I can foresee that with regular infusions, eventually we would need to enlist the help of members of the 'Tricky Vein Society' as the ease of venous access is likely to diminish with each successive administration. The American guidance does state that

> *Considering the costs and resources involved with IV infusions, it is reasonable to try a follow-up intranasal ketamine, oral ketamine, or oral dextromethorphan treatment regimen in lieu of serial treatments (grade B recommendation, low level of certainty for oral preparations, moderate level of certainty for intranasal ketamine).*

I am aware of at least one other centre that uses the approach of an initial IV infusion of ketamine followed up by oral use if the IV infusion was found to be of benefit.

For UK prescribers of oral ketamine, the situation has not been helped by the National Institute for Health and Care Excellence (NICE) evidence summary on oral ketamine from 2014, which was less than lukewarm about the drug, or the rescheduling of ketamine to a Class 2 drug.[6] This reclassification has increased sixfold the prescribing workload for busy clinicians, as prescriptions now have to be written on a monthly basis, whereas previously a single 6-month prescription sufficed.

There are many unanswered questions regarding the role of sub-anaesthetic doses of ketamine in medical practice, but we are possibly coming to the stage where with enough resources we could try and answer some of them.

A UK company (Neurocentrx Pharma Ltd) has been producing ketamine capsules for some small-scale studies, so in theory these capsules could be used for future randomised controlled trials (RCTs; although as the potential indications are not licensed, they are unable to advertise this drug to health care practitioners).

A good place to start would be to ask patients already on a stabilised dose of ketamine (say for more than 2 years) if they would be prepared to get involved with studies which involve finding out whether they could tell the difference between active placebo capsules and capsules containing the real drug. The American guidance also has concerns that oral ketamine has significant abuse potential and has a high street value. The guidance suggests that for patients with a history of abuse or who are at high risk of abuse, the risks of prescribing it chronically in a community-based setting should be weighed against the potential benefits, and proper surveillance, similar to what is done for patients on chronic opioid therapy, should be used.

This creates a sense of cognitive dissonance in the United Kingdom, because currently the MRC is conducting the KARE study, a multi-site project running in both the South West of England and London. This is a clinical trial exploring the combined use of psychological therapy and a low dose of ketamine as a possible treatment for alcoholism.[7]

With respect to surveillance of patients on an established dose of ketamine, again, with resource, it may be possible to assay patient ketamine and norketamine blood concentrations when patient bloods are taken, in order to monitor for hepatic or renal dysfunction. This could simultaneously help to establish whether or not diversion was taking place and also establish what drug concentrations appear to provide therapeutic benefit.

Finally, the idea of a 'Ketamine Register' has been mooted in both the JAMA consensus guidance and the ASRA guidance. The rationale is that while placebo-controlled clinical trials gauge efficacy in small, well-selected populations, registries can provide a better measure of effectiveness in large populations treated under real-life conditions, and may provide important information regarding who is likely to benefit from a specific treatment. In the absence of large, randomised studies, the establishment of ketamine treatment–based registries can help guide treatment decisions. This is probably reasonable and a useful starting point. A modified version of the data collection tool that Grande and colleagues at the University of Washington have used to carry out their chart review of 400 patients who have been taking Ultra-Low Dose Oral Ketamine for Chronic Pain (personal communication) could be the basis of such a register.

Like Marmite, you either love it or hate it, but regardless, the use of ketamine in Pain Practice is likely to stay with us for a while.

Acknowledgements

Over the years, I have attended meetings and had lunches/dinners sponsored by a range of pharmaceutical firms and equipment manufacturers. My work on Ketamine is frequently referenced in the book 'Ketamine for Depression' written by Dr Stephen J Hyde.

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The British Pain Society is nothing without you, its members, and we appreciate your continuing involvement and support. We recognise that, for many members, in recent years, the decision to pay the membership fee for a non-compulsory professional society has been more challenging so we will continue to look closely at our fees and we will take care to limit any increases. We hope that you will continue to encourage your colleagues to joins us.

May we also remind you that The British Pain Society is a registered charity and we welcome funds received from legacies and through sponsorship. As we know from the numbers who have joined fun runs at previous ASMs, many of our members are actively engaged in sporting activities. So, if you are signing up for any marathons, half-marathons, triathlons, swims or tiddlywinks contests, please consider nominating The Society as your chosen charity.

Thank you for supporting the BPS!

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SAGE

Pain in survivors of torture – the complexities of assessment

Juliet Cohen *Head of Doctors at Freedom from Torture*

Credit: The Crimson Monkey.

Introduction

This essay will examine the following issues:

1. What is torture?
2. Assessment of pain in survivors of torture
3. Risk assessment
4. Examination and investigation
5. Effective treatment

The incidence of chronic pain in survivors of torture is high, but varies based on the country of origin and type of torture methods. A literature review by Williams and Amris[1] found a range of 39%–93%. Estimates of the prevalence of torture vary widely in different populations, but a recent US meta-analysis suggests up to 44% of asylum seekers may be survivors of torture.[2] In a typical inner city practice in the United Kingdom, it is estimated that this could represent four times as many patients as have lung cancer. Post-traumatic stress disorder is commonly found to be a co-morbid condition with chronic pain in this patient group.

What is torture?

Torture has been described as the act of killing a person without their dying. It is an attempt to destroy a person's physical and psychological integrity.

The United Nations Convention Against Torture (UNCAT) internationally agreed definition of torture is this:

> *Torture means any act by* ***which severe pain or suffering****, whether physical or mental*, ***is intentionally inflicted*** *on a person* ***for such purposes*** *as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a* public official *or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions*.[3]

It therefore requires the three cumulative elements of intentional infliction of severe pain or suffering by or with the knowledge or acquiescence of a public official. Similar clinical effects, however, are seen in survivors of other forms of serious harm where the victim has been in the control of the perpetrator, such as trafficking for servitude or prostitution, domestic violence, or where the persecution is by the community rather than a state official, such as can occur in countries where homosexuality is not tolerated.

The particular types of torture suffered by an individual may be difficult for them to describe, but understanding what has occurred is critical if a full assessment of the impact of the torture is to be made. Torture may be physical, psychological, sexual or environmental but to an extent these divisions are artificial, for example, nearly all forms of torture have a significant psychological impact and sexual or environmental torture will include both physical and psychological elements. Environmental torture includes extremes of temperature, sensory deprivation or extreme noise, constant light or constant darkness.

Physical torture may be as follows:

- Blunt force – punch, kick, forced impact with walls, floor or furniture, beating with weapons – baton, stick, gun butt, whip;
- Sharp force – knife, blade, bayonet, machete;
- Burn – molten plastic, cigarette, heated metal object, chemicals, for example, acid;
- Crush injuries – roller, pliers, weights;
- Penetrating injuries – gunshot wound, shrapnel, puncture wounds.

Physical torture methods that may leave little or no physical evidence afterwards include asphyxia, beating on the soles of the feet (falaka), electric shocks and prolonged restraint in suspension or stress positions. Most blunt force trauma causes bruising and abrasions that usually heal without lasting physical evidence, but while scars may be absent, chronic pain may still be a consequence.

Sexual torture begins with forcing a person to be naked and may include all forms of sexual assault by touching, digital penetration or by penetration with an object and rape – oral, vaginal or anal.

Psychological torture includes the following:

- Solitary confinement;
- Deprivation of food or water;
- Forced administration of drugs;
- Forced to witness or participate in torture of others;
- Forced to transgress religious, cultural, sexual boundaries or to betray others;
- Mock execution, threats of death or harm to family members;
- Verbal abuse;
- Forced to perform humiliating acts.

Assessment of pain in survivors of torture

Assessment requires a holistic approach and the ability to facilitate the disclosure of highly traumatic experiences, since without an understanding of what has happened to the patient, it will not be possible to effectively treat their pain.

Facilitating disclosure requires the following:

- Communication skills;
- Development of a trusting relationship;
- Gender sensitivity;
- Cultural awareness.

Patients may choose not to disclose some or all of their torture experiences for a long time and some will never disclose everything that happened to them. Torture often includes an element of sexual torture, and this can be one of the most difficult experiences to disclose to another person. It is recognised that disclosure of sexual assault in the criminal context is often long-delayed – a UK study found that around 89% of rapes go unreported to the police and 38% of adult victims of serious sexual assault tell no one about their experience.[4]

Trust and rapport may be more difficult to establish due to torture damaging a person's view of the behaviour of other people. For survivors of torture, the difficulty in disclosing may be due to the shame, fear and avoidance symptoms generated by the torture, and possibly to medical complicity in the torture itself, making it difficult to trust another medical professional. A patient may benefit from seeing a healthcare professional of the same gender as themselves but this cannot be assumed, and they should be offered the choice where possible – a male survivor of sexual torture may prefer to be examined by a woman, for example.

Many experiences of torture involve sexual violence, forced transgressions of sexual orientation, of gender identity and of cultural norms and forced betrayal of others. Describing what happened evokes the highly distressing emotions experienced at the time and intrusive recall of trauma memories and can trigger flashbacks. Advice written by a survivor on how to help survivors of torture can be found at https://www.bmj.com/content/355/bmj.i5019

Avoidance, a common finding with PTSD patients, is the seeking to avoid these distressing symptoms by avoiding their triggers and may affect help-seeking behaviour and also limit both attendance at appointments and the extent of any disclosure.

If the person is distressed or appears distracted by their memories:

- It may be helpful to use a phrase which helps the person come back to the here and now.
- Speak in a low, calm voice 'Look around and see that you are safe now, we are here to help you'.
- Asking them to touch the chair they are sitting on or to press their feet onto the floor can also help to ground them, as a physical reminder of their present location.

To help a person to feel in control:

- Be careful about interrupting them as this may remind them of the pressure of interrogation;
- Explain why you are asking particular questions;
- Ask the person 'what would be helpful for you to feel comfortable?';
- Remind them 'nothing here will happen without your consent'.

To understand the mechanism of injury, and therefore the likely clinical consequences, it is important to ask open questions, particularly of the 'how' and 'what' type, and to explore the history as fully as possible by asking, for example, 'and what happened next ...?' Enquire what is meant by euphemisms such as 'they did what they wished to do' and overly general replies such as 'I was beaten', by asking for specific details of how the beating was done and whether or not the person was restrained, and in what position, during the beating.

Interpreters

The majority of torture survivors seen in the United Kingdom will not speak English as a first language, so the assistance of a professional interpreter to facilitate communication is a critical first step. The gender of both healthcare professional and interpreter may be important and the patient should be asked if they have a preference in this. Family members or friends should never be used as interpreters except on an emergency basis, as confidentiality cannot be assured without the use of a professional.

Psychological effects of torture can be devastating. They may include debility, dependency, dread, disorientation, helplessness, hopelessness, shame, depersonalisation, loss of trust in the world and in authority figures, and destruction of self, family relationships and community.

The resulting psychological symptoms include difficulty falling asleep and staying asleep, nightmares, intrusive recall, flashbacks, anxiety, low mood, loss of appetite, anger and irritability, sadness, guilt and shame, numbness and avoidant behaviour and can lead to self-harm and drug misuse.

Experiences of torture may not have happened in isolation from other life events, so survivors may also have suffered bereavement, witnessed harm to others or the deaths of others, been victims of trafficking and slavery and lost their home, their family, their expected future life.

Other health conditions will affect the survivor's pain state and may have been exacerbated by their journey. They may have suffered a prolonged period during their journey to the United Kingdom without access to medical care, or a lengthy detention in poor conditions. Malnutrition, tropical infections and other undiagnosed conditions should be considered.

Once in the United Kingdom, they may be having difficulty adjusting to living in a different culture and living with uncertainty about their future in the United Kingdom. They may be in fear of being returned to their country of origin, suffering dislocation from family and community support, loss of meaningful activity, poverty and homelessness and may be vulnerable to exploitation.

The effects of torture need to be carefully distinguished from other health conditions in order to treat effectively. While it may perhaps seem that some of these symptoms are not really the province of the pain specialist, it is unlikely that good pain control will be achieved if the 'clamour' of other symptoms is disregarded and conditions left untreated – this is part of taking a holistic approach. 'Stress' may evidently cause or exacerbate many of the below symptoms – it may be specifically linked to the psychological response to experiences of torture or to other aspects of their current life. Survivors of torture may have had difficulty in communicating all their symptoms and health concerns to their GP in the short appointments available, especially if an interpreter is not used, so the findings from a full assessment can be invaluable to them (Table 1).

Table 1. Relationship between medical symptoms and torture methods.

Common symptoms	Torture cause
Headache	Head injury, neck injury, insomnia
'Funny turns'	Seizures due to head injury, pseudo-seizures, panic attacks
Poor vision	Forced solar gazing, vitamin deficiency
Shortness of breath/chest pain	Rib or thoracic spine injury, panic attack, TB secondary to detention in poor conditions
Gastritis	Prolonged hunger, hunger strike, oral rape causing repeated vomiting, Helicobacter pylori infection following detention in poor conditions
Abdominal pain	Pelvic infection or untreated sexually transmitted infection after rape
Constipation or rectal bleeding	Secondary constipation, haemorrhoids, anal fissure or unhealed anal injury following anal rape or assault, untreated sexually transmitted infection
Dysmenorrhoea	Sexually transmitted infection, unexplained post-rape symptom
Joint pains, back pain	Restraint positions in torture, suspension positions, forced labour, repeated blunt trauma in beatings
Foot pain	Beating on the sole of the feet – also known as falaka
Dry itchy skin	Detention conditions, malnutrition, infestation
Vulvovaginitis	Compulsive washing post rape
Urinary dysfunction	Untreated sexually transmitted infection, damage to urethra during rape, beating or electric shock; renal damage from beating
Sexual dysfunction, infertility	Sexual torture resulting in impotence, dyspareunia, vaginismus
Nocturnal enuresis	Nightmares especially reliving involuntary urination during torture, damage to urogenital tract from torture

Risk assessment

The assessment of risk of harm to the patient themselves or harm to or from others must be part of the holistic assessment. PTSD and depression are common in survivors of torture and carry an increased risk of suicide and self-harming behaviour in themselves, but even without a specific psychiatric diagnosis, survivors of torture may experience profound feelings of helplessness, isolation and despair that can trigger acts of self-harm. External stressors such as their uncertain position in the United Kingdom, being made homeless, fear of being detained for immigration purposes or their application for asylum being refused may also tip the balance.

Angry outbursts are not uncommon as a feature of PTSD and other conditions, and so assessment risk of harm to others is also important if this behaviour is identified. Harm from others is a further concern and may come from within the family, the community or others involved in exploitation and abuse.

Confidentiality concerns, particularly about disclosure of sexual violence, are critical here and the healthcare professional should be mindful of the risk of domestic violence or honour-based violence, and check explicitly about consent to share information and whether or not it is safe for letters containing confidential information to be sent to the home address.

Examination and investigation

The physical examination may be stressful and difficult for a survivor of torture. They may be highly apprehensive about being touched, about exposing their body and about their limbs being moved for them by the examiner. Explain carefully the purpose of each element of the examination before proceeding. For those who have been subjected to forced nakedness and other sexual torture, it may be preferable to expose only one part of their body at a time for examination, keeping as much of their body covered as possible so that they feel less vulnerable. Ask rather than assume – a chaperone may be welcomed, or alternatively may feel like too great an intrusion.

The examination itself may reveal injuries that have not previously been disclosed, as movement limitations and scars become apparent. Behaviours such as self-harming, self-neglect and compulsive washing (often with harsh chemicals such as disinfectant) may only become clear at this stage.

Investigations should be carefully explained to the survivor to assess if they can manage them: machines with wires, such as for an ECG, EEG or EMG recording, may evoke memories of electric shock torture; being in the dark or in a confined space such as an MRI scanner may evoke memories of solitary confinement in a small space; and memories of medical complicity in acts of torture may also be evoked. If a full history has already been taken, the healthcare professional will be better able to acknowledge and mitigate the survivor's anxieties.

Effective treatment

For treatment to be effective, communication and compliance are key. Good communication depends on information being given in a language that can be understood, so the use of a professional interpreter, if needed, is required throughout, not just for the initial assessment. If written information is provided, it should ideally be in a language the patient understands and literacy in that language should be checked, or a strategy to manage this difficulty should be discussed and planned. Many appointments are missed or wasted because patients have been unable to read letters about follow-up, have not attended to have the tests required or have not followed treatment plans. Many difficulties will be solved by taking simple steps, such as asking the interpreter to write down in the patient's language key information about what tablets to take, for which symptoms and at what times.

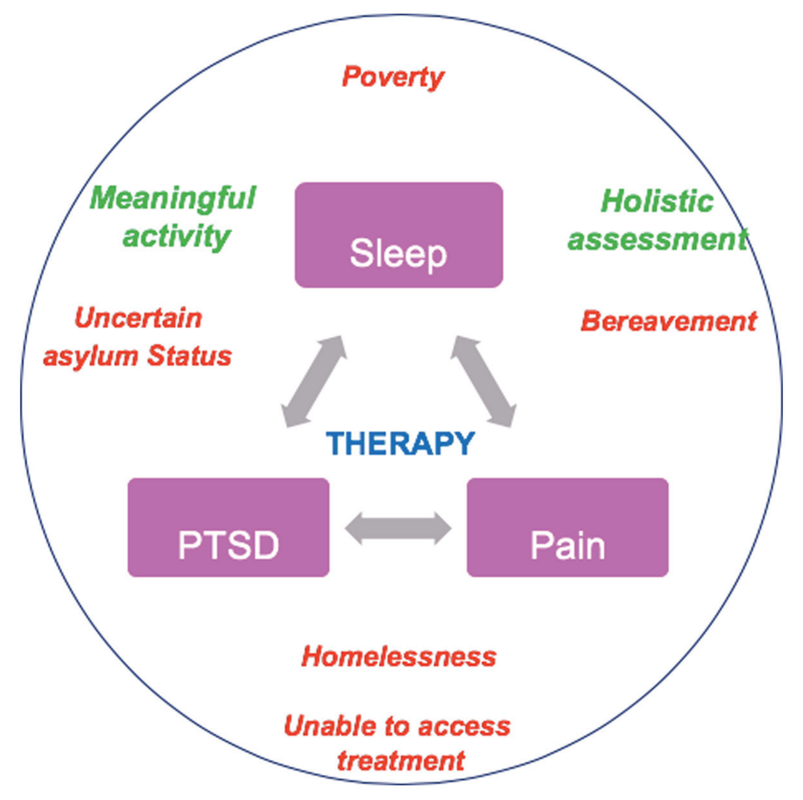
Difficulties with cognition should also be considered. Patients who have had a head injury, trauma experiences, PTSD or depression may have significant impairment of memory and concentration. Both short-term and long-term memory may be affected, and again this will impact on compliance with medication and attendance at appointments. Written reminders and a system such as text alerts for appointments can be very helpful to overcome this.

Other difficulties with compliance may be caused by the patient's living situation, with unexpected changes of address or being detained without notice by immigration authorities, leading to missed letters of appointments. Asylum seekers have only very limited allowance for all their living needs and if they do not have an exemption certificate such as HC2, they are unlikely to be able to afford prescription charges. Travel to appointments may also be too costly for them. Welfare advice and support in these areas can make all the difference to the success of treatment.

A person's cultural background is of relevance in understanding their prior perceptions about medical treatment, including non-Western therapies and spiritual beliefs.

Evaluation of their average daily activity can shed valuable light on whether or not they will be able to follow treatment advice. If, for example, they are too scared to go out alone as they are in fear of being followed, they are unlikely to take up advice about regular exercise. The clinician should ask about the patient's understanding of the meaning of their pain and other symptoms – if for example they believe that continued pain equates to damage, or they are afraid to provoke

Figure 1. Key internal and external factors that may affect response to therapy for torture



the pain due to being reminded of their torture, it will not be possible to advise exercise until a shared understanding of these meanings is achieved.

In deciding treatment options, the benefit of a full holistic assessment is that the interface of physical and psychological causes of the pain problem, as well as the exacerbating or perpetuating factors such as anxiety about return to further torture, will be better understood by both patient and healthcare professional. The utilisation of multiple modes of treatment including physical and psychological therapies, and a multi-disciplinary team approach, is essential. This diagram below summarises the key internal and external factors that may affect response to therapy for torture (Figure 1).

In summary, good pain management in survivors of torture depends on awareness of the health consequences of torture, a holistic approach with full assessment and appropriate investigation and above all, on excellent communication.

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Understanding the referral and selection for spinal cord stimulation on the NHS: navigating a way through the commissioning confusion

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In 2008, the National Institute for Health and Care Excellence (NICE)[1] published Technology Appraisal 159. It started with a Health Technology Appraisal by Sheffield University with health economic modelling and then consideration by the NICE committee including health economists, clinical experts, patients, academic societies and National Health Service (NHS) bodies. The result was a mandatory recommendation, as it is for all Technology Appraisals, that spinal cord stimulation (SCS) is available to NHS patients for chronic pain of neuropathic origin which was rated as greater than 5/10 for at least 6 months despite appropriate conventional management. This is after a multidisciplinary assessment by a chronic pain team experienced in both chronic pain and SCS assessment, the need for a successful trial of the procedure (undefined) and for provision of ongoing support for the patient who undergoes implantation.

So did we move from amber to green light as regards SCS provision on the NHS?

NICE is a policy advising body; it has no actual powers to *force* the NHS to implement. However, in 'Standards for better health' (issued July 2014), it states that

> *The Secretary of State has directed that the NHS provides funding and resources for medicines and treatments that have been recommended by NICE technology appraisals normally within 3 months from the date that NICE publishes the guidance. Core standard C5 states that healthcare organisations should ensure they conform to NICE Technology Appraisals.*

So you would think that progress would have been made towards full implementation of the guidance to those patients who would benefit from SCS.

Since 2008, the NICE guidance has not changed but the uptake of SCS has only increased (depending on the data and measures used) by about 20%.[2] There are two main reasons for this.

1. Failure of clarity of NHS commissioning

In 2012, the Secretary of State for Health, Andrew Lansley, abolished primary care trusts (PCTs) and strategic health authorities (SHAs) and created clinical commissioning groups (CCGs) and a national body known as NHS England (NHSE).[3]

NHSE would provide specialised care, including 'specialised pain management'. The trouble was that this had not been defined. Incidentally, a new service specification for a Specialised Pain Service (SPS) will be approved soon; at the time of writing, it is out for public consultation.

It is from 2012 that the confusion began. There were multiple historic documents that pre-dated NICE TA 159 that describe SCS as a 'Specialised procedure' and, like most interventional pain procedures, as 'Low clinical value'.

It is estimated that 5,000 new patients per year have persistent post-operative pain after spinal surgery.[2] Add to this figure the patients with other indications such as chronic radiculopathy, complex regional pain syndrome and other refractory neuropathies, then a possible 10,000 new patients suitable for SCS are generated each year. With a history of low SCS implementation, there is a high prevalence of unmet need. SCS is only given to 5% of the population who might benefit from it. Today, over 1,000 new patients within the United Kingdom are treated annually. A fully implemented Technology Appraisal, like that for implantable defibrillators, might mean that 10–20,000 new patients are treated annually.[3] Clearly, this cannot be corrected overnight, but it gives the reader an idea of the sort of future we should aspire to. The answer is not to expect over-stretched specialised centres to manage this. It is the unmet need and the fact that it has a NICE Technology Appraisal that means that SCS should be commissioned at CCG level as routine and therefore theoretically be widely available.

The problem is that NHS England cannot tell CCGs what to do. Do you remember? That was when we were told that local people and doctors will '*decide the local healthcare needs*' with their £80 billion of the then healthcare budget.

Despite TA 159, which mandates the commissioning of SCS, CCGs set about pruning their budgets and realised they could at a stroke remove SCS from their responsibilities. Many fine services, for example, Russells Hall, Dudley, have been de-commissioned.

Our own service at Basildon and Thurrock University Hospitals NHSFT was to be decommissioned by the local CCGs but it became an example to NHSE, whereby we eventually resolved the issue, once I brought together NHSE policymakers with NHSE regional implementation, CCGs and the Hospital Trust CEO. We now have a fully supported SCS service again.

What changed were two things. Probably the most important was a decision that NHS England would be responsible via NHS supply chain for being the National Procurer for the devices and would absorb the costs of the device, as long as NICE TA 159 recommendations are followed.

Second, I had uncovered a wilful misunderstanding of the available written guidance and had managed to get it into the sight of those who matter.

So we still have two different commissioning limbs; however, CCGs should know that they should implement TA 159. As Trusts combine as part of sustainability and transformation plans (STPs), there should be opportunities for large sustainable SCS service units to evolve. Each unit will be providing SCS to more than 50 or more new SCS patients per year.

2. Failure of clear clinical signposting for referral and selection

When I talk with referrers, I learn just how daunting it is to select and counsel a patient and make that referral.

- Where and to whom do you refer?
- What are the waiting times to be seen for assessment?
- What are the waiting times before trial/implantation?
- What if, after all that, the patient is unsuitable for SCS implantation?
  - Can you accept that the SCS service team may not wish to take your patient on?
- How do you counsel a patient who may be referred to either an in-patient open neurosurgical procedure or a day case minimally invasive procedure? These are both quite different patient experiences.

So not only is there variation in the selection and implementation processes of SCS, there has also been a growth in the variety of SCS technology, with differing claims being made by one manufacturer over another. It is important to try and keep your feet on the ground. It isn't really up to the referrer to determine the type of device. The critical issue is what type of patient to refer.

The NHS will routinely fund SCS for patients who have refractory neuropathic pain (also for ischaemic, if part of a research study). The commonest indication is back and leg pain. About 80% have had previous spinal surgery for radicular pain (Failed Back Surgery Syndrome) and about 20% have not had surgery but have chronic radiculopathy. The next commonest is Complex Regional Pain Syndrome, then other neuropathic pain including post traumatic/surgical neuropathy and painful diabetic polyneuropathy.

I think it is important to stress that, although these are the classic indications, it does not mean that all will do well with SCS. We are all steadily understanding that there are sub-types of each diagnostic group that respond better to one treatment or another. So, for example, SCS is not a treatment for CRPS but rather a treatment of a sub-type of CRPS. Defining these sub-types is in my opinion the next phase in our evolution of treating this syndrome. For example, diabetes mellitus diagnosis has now evolved from two sub-types to five, each with different disease trajectories and different treatments.

So how can we get some clarity here?

I think the solution to understanding both who to refer and who an SCS service should select to implant depends on a multi-dimensional understanding of pain. I think the four domains of pain assessment are important here:

- Physical, pathological process, response to other appropriate treatments;
- Psychological;
- Social;
- Behavioural.

Recently, I have drawn together a multidisciplinary group of European SCS experts with expertise in SCS selection, treatment and management, drawn from interventional pain, neurosurgery, psychology, nursing and physiotherapy. We aim to use Delphi methodology to try to create consensus about criteria that are likely to generate good and poor SCS clinical outcomes. We will each put forward various terms that described the selection criteria in each of the domains mentioned above of five of our own patients who went on to have good outcomes, and five patients who had poor outcomes, and then rank them according to Delphi methodology.[i] I hope we will be reporting in 2019.[4]

Most experienced SCS experts will have a clear if implicit understanding of which patients are likely to experience good outcomes and those who are more likely to have bad outcomes. We need to agree on the extremes and then think about those patients in whom we are less certain of the outcome in the middle.

Our aim is to produce a scoring system, which we will validate prospectively, to be used by referrers. Our next goal is to help with selection processes within the SCS service, to direct those where there is uncertainty to a prolonged trial and, where there is certainty, to an on-table trial with full implant.

Currently, a UK prospective randomised controlled trial is ongoing to look at whether a more prolonged trial period offers any value to long-term outcomes. Furthermore, a recent UK health economic model suggests that, contrary to collective belief, a prolonged trial with later implant strategy is more expensive than an on-table trial-only strategy, providing there is thorough MDT assessment and a greater than 75% trial to permanent implant ratio.[5]

Advice for the referrer

Physical, pathological process, response to other appropriate treatments

SCS is likely to perform at its best in an individual when there is a clear organic/somatic reason for the neuropathic pain.

> Example 1 – the patient has had sciatica and a microdiscectomy with temporary resolution for 3 months before typical neuropathic features return. The patient may have sensory or motor dysfunction, no recurrent spinal stenosis and perhaps evidence of scar tissue on MRI. Pain may be temporarily reduced by precision transforaminal injection of steroid or even pulsed radiofrequency. Do remember patients are likely to interpret this temporary benefit from your intervention as a success and often assume that you might repeat it forever, not knowing that it is likely to only be temporary and you need to consider whether there is likely to be a more successful alternative proved by NICE. You might repeat your intervention, but is it really a satisfactory way to continue thereafter?
>
> Example 2 – patient has back and bilateral leg pain with early disc degeneration but without significant foraminal or central spinal stenosis. Patient responds temporarily to transforaminal root steroid injections and experiences some modest improvement with gabapentinoids but puts on weight as a consequence of the known side effects.
>
> Example 3 – a patient who had a hip replacement but due to branches of sciatic nerve is suffering a perioperative traction injury and has developed neuropathic pain in the lower limb.
>
> Example 4 – a woman who has had endometriosis ablation surgery on multiple occasions: owing to sacral plexus surgical injury she has developed well defined neuropathic pain in the buttock, leg and vagina.

SCS is not usually helpful where the pain is widespread and fluctuating from one area to another, which often suggests a non-neuropathic somatic mechanism.

Colleagues often ask me about post amputation pain. Generally, my advice is that if the neuropathic stump pain component is dominant, then SCS offers a good outcome. In my experience, if the phantom limb (PLP) component is dominant, SCS has a poorer outcome or perhaps a lower frequency of good outcome.

How we define outcome is of course a debate on its own – too much for this small article.

Finally, consider the physical status of the patient. Significant co-morbidity that smothers any potential improvement in health-related quality of life with SCS is not the patient to refer or to select.

Psychological

There are many patients who cannot accept having an implant, let alone an active device that has to be managed by re-charging and adjusted by programming from time to time. This should be clear at referral stage.

It is important to discuss anxieties about the procedure and explain potential risks and, if unacceptable to the patient, it may mean that referral is pointless. On the other hand, some referrers, in an effort to consent well with the patient, may over emphasise the problems with the assessment process, procedure and complications. As ever, the skill of creating the right balance between potential benefits and risks is paramount.

Patients with borderline personality disorders, psychiatric co-morbidity, somatoform disorder and catastrophic illness thinking styles all tend to do poorly during SCS selection process and are usually managed without SCS.

In our experience, depression that pre-existed the pain condition seems to have little impact upon the outcome, providing that it is well managed.

In addition, depression is also a feature of chronic pain. Indeed, we often see the anti-depressant effects of a successful SCS outcome. However, the quality of the outcome is better when there is less evidence of ongoing depression.

As with any pain intervention there are psychological features that we associate with a good outcome, such as a strong internal locus of control and effective coping strategies; those who use pacing, exercise and distraction rather than reaching for more medication.

We are seeing more and more patients with opioid mis-use problems. This has to be distinguished from those who have been escalated onto excessive opioids and other drugs and have never been taught psychological pain coping skills. If patients know that there is the potential of a pain reducing procedure such as SCS, we usually start the opioid weaning process during assessment and try and reduce the levels to more acceptable doses or none, prior to the SCS procedure.

Social

Patients who are supported appropriately by a network of family and friends and employer and work colleagues are likely to have a good outcome.

SCS is a complex therapy inasmuch as they need several visits over the years for re-programming and attention to their SCS. Adequate and sustainable transport arrangements are essential.

Behavioural

Secondary behavioural gain is always a factor to consider. This can be financial, whereby continued financial provision or payout is contingent upon the continued demonstration of disability that the chronic pain causes, or it can be emotional or social, whereby the benefits of empathy can be maintained.

The green, amber and red system for patient selection and team working

Every SCS centre will have its own style of SCS assessment. All are agreed that with complex patients a multidisciplinary team is key. Some prefer to provide this through a mini PMP approach; others, like us, prefer to do this via a series of 1:1 consultations. Each patient will be placed upon the pathway by the SCS implanting consultant with a strict understanding that neither the patient nor the team have committed to SCS therapy.

Each patient will see the neuromodulation nurse first to start the SCS and pain education process. This might be the time to do a drug review, if there is still more to be done.

Then the patient will see the psychologist who also manages our PMP.

Every week we have a team meeting to discuss those we have seen, and decide if we are to give them a green light (arrange for SCS trial), amber light (e.g. see neuromodulation physiotherapist for challenge to low activity or pacing advice) or red light (the MDT has sufficient concerns not to progress the patient on to SCS). Usually, the patient has placed himself or herself on the red light, but if not, it can be a source of angst and may require a second opinion from another SCS provider.

Concluding remarks

1. SCS is a nationally recognised core NHS treatment in the management of selected patients with refractory neuropathic pain.
2. I believe that we are only treating 5% of those who would benefit annually.
3. The NHS has been contradictory about SCS services where NHSE policymakers and NICE encourage service implementation, but NHS England regional implementation and CCGs appear to be doing all that they can to frustrate its availability.
4. Other confusing and ambiguous referral decision factors concerning who, where, when and for what indications blight patient access to SCS. It can be overcome by creating STP level SCS services, or commissioning with neighbouring SCS services, and referral to NHS England specialised services only if required.
5. The clinical pathway can be better agreed between each SCS service centre and referrers.
6. The National Neuromodulation Registry is now live and participation is growing. I believe NHS England will insist upon its use. This will improve our understanding about patient access, therapy durability, outcomes and service quality.

Note

i. The Delphi method is used to ascertain expert opinion and build consensus through a series of ‘rounds’ of structured questioning with feedback at each stage. The technique enables a wide range of expertise on a particular issue to be collated and is ideally suited to electronic group communication when participants are widely geographically dispersed. Participants retain anonymity throughout the Delphi process to minimise the influence of identity in their responses.

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Informing practice

Is my pain physical or mental?

Hannah Laidley *Foundation Doctor, Northampton General Hospital*

THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS
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SAGE

This essay won second prize in the 2018 Royal Society of Medicine Andrew Lawson Prize for an essay on a pain-related subject by a Medical Student.

This is the question that many patients in pain ask of their doctor, in the hope that by finding the answer they can find the cure. Observing any patient with chronic pain will reveal that mental health will have an effect on their pain, and vice versa. We therefore ask ourselves how much pain intensity is due to mental illness, and whether treating that aspect will have any effect on the life of a chronic pain patient.

Dichotomous model of pain

Medical school education focuses on the study of pathology and how the analysis of the symptoms helps a doctor to confirm a diagnosis. For example, if one has central abdominal pain that migrates into the right iliac fossa and becomes sharper in nature, one would suspect appendicitis. But this model only works well in acute pain. In chronic pain, the physical and mental world lose their Cartesian dichotomy and blend into a more complex and usually indivisible entity.

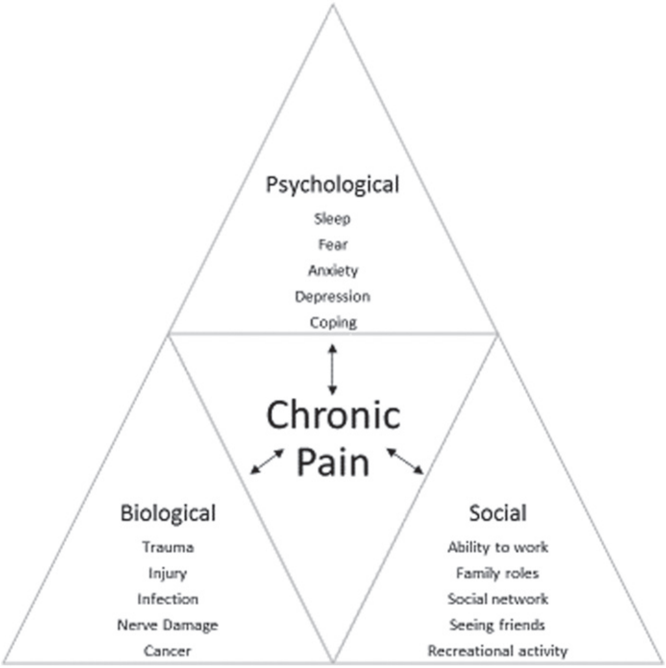
However, physicians and patients continue to assume that an underlying pathology is a necessary and sufficient cause of pain[1] and, in many cases, the numerous investigations and tests will reveal no significant physical diagnosis. In reality, sometimes conventional analgesics might not make them pain free which also may suggest a non-physical cause.

Does it matter if doctors (and patients) maintain this dualistic way of thinking? Unfortunately, the evidence suggests this is not only inaccurate but also causes harm to some individuals. Women are more likely to be given psychological explanations for their pain than men, they receive analgesia less often and when they are prescribed pain relief it is less effective.[2] Societal views, gender and culture hugely influence the way people think about pain and how easily they can access services. For example, participants in a study where cold pressure was applied to the forearm to measure pain sensitivity showed a low pain threshold if they scored high on femininity. But when the condition was changed so that men and women were given the same tolerance expectation beforehand ('the typical man/woman lasts 30 seconds') these gender differences disappeared.[2]

Biopsychosocial model of pain

A holistic approach is increasingly being adopted by health care professionals for patients with chronic conditions. Studies have looked at pain interference as a measure of how much pain hinders the social, cognitive, emotional, physical and recreational activities of patients. One such study showed that having to take time off work caused patients to feel a loss of role, and this was made worse by their relatives reinforcing a belief that going back to work might cause further injury.[3] Half of patients reported that their condition had prevented them from attending family or social events, and due to the unpredictable timing of pain, they had difficulty making social plans.[3] A high proportion of relatives of chronic pain patients also stopped taking part in social activities and suffered sadness or anxiety.

Figure 1.



Looking at the model in Figure 1 it is clear to see how the impact of chronic pain on a patient's life could cause them to become isolated, stop coping and to fall into mental health problems.[4]

Does chronic pain cause mental ill health?

Few would dispute the relationship between chronic pain and mental health, but it is not clear if there is a predictable causal relationship and which way the arrows in the model should point. The evidence so far suggests that treating depression in those with comorbid depression and chronic pain has only a modest positive effect on pain interference, and the response alters with the ethnicity of the patient.[5] Furthermore, there was no difference between pain severity for those with minimally adequate and inadequate treatment of depression. This may suggest that depression doesn't cause chronic pain since treating the depression doesn't resolve the pain.

It could also be that chronic physical pain causes mental ill health with secondary sleep disturbance and other psychological burdens such as anxiety and depression. Poor sleep has been shown to heighten pain awareness while elevated anxiety symptoms cause hypervigilance and attention to pain – both fuelling a vicious sleep disturbance – pain cycle.[6]

What is the chronological relationship between pain and mental health?

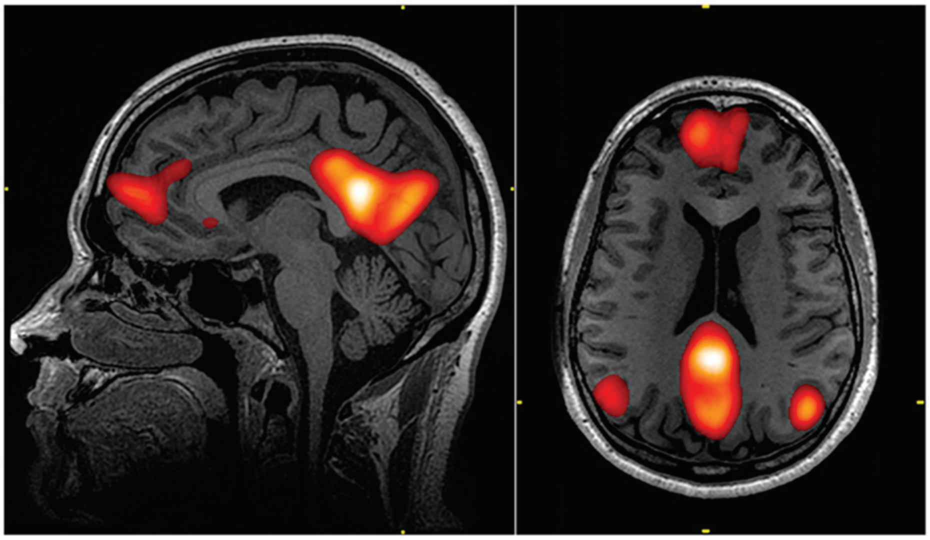
Mental health disorders have been shown to correlate with subsequent pain. A study of adolescents in 19 countries found that all mental disorders (as per *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; DSM IV) were positively associated with a subsequent diagnosis of back and/or neck pain, and there was a clear dose–response relationship between the number of mental disorders and subsequent pain.[7] Early onset mental disorders were stronger predictors of future pain if there was co-occurrence of chronic pain and mental disorders. The mental disorders were likely to precede the onset of chronic pain but not vice versa. On a shorter timescale, pre-operative anxiety has been shown to correlate with postoperative pain.[8] Expectation of pain, past memories, social environment and physical activity have all been shown to predict the post-surgical pain response and whether it would become persistent.

'Total pain'

Dame Cicely Saunders defined the concept of total pain as suffering that encompasses all of a person's physical, psychological, social, spiritual and practical difficulties, and this definition was the impetus for development of the palliative care/hospice movement.[9] It placed greater emphasis on the patient's narrative and highlighted the importance of listening to and understanding a patient's experience. Saunders describes chronic pain as 'not just an event, or a series of events ... but rather a situation in which the patient is, as it were, held captive'.[9] This is an important concept because it allows patient and physician to realise and accept that all of a person's mental health, physical perceptions, previous experiences, social support and spiritual needs are interlinked and need to be addressed as a whole. While this has started to be embedded in palliative and oncology care, it is yet to be translated into the routine management of all patients with chronic pain.

There are numerous experimental and clinical models demonstrating the interlinking of the aspects of total pain. For example, treatments for chronic pain may simultaneously alleviate depression.

Tricyclic antidepressants used for neuropathic pain and deep brain stimulation is effective both in resistant depression and chronic pain. During a 57-week Norwegian programme on 'Learning to cope' for patients with chronic pain, there was a correlation between change in pain scores and change in Hospital Anxiety and Depression Scale (HADS) score,[10] a correlation which was stronger in women.



Magnetic resonance imaging of areas of the brain in the DMN. Image taken from Wikipedia and is in the public domain.[18]

The presence of chronic pain results in physiological and psychological maladaptive processes that influence subsequent pain perception and pain-related behaviour.[11]

Resilience is how well a person can adapt to events in their life and is needed to cope with physical and psychological pain, especially if that pain is chronic. Catastrophising and lack of task persistence are indicators of poor resilience and are unhelpful in chronic pain. The patient may engage in catastrophising and believe that they need rest and to avoid activity for fear of exacerbating their injury (kinesiophobia).

This kinesiophobia can make rehabilitation impossible, even if the initial physical injury or physical pain has resolved.

They may habitually seek help and fail to persist in completion of tasks, leading to less functional ability over time. One study found that catastrophising is associated with greater pain and poorer mental health, while task persistence is associated with less pain and better mental health.[12] In the same study, pain intensity predicted only 41% of the variance in pain interference (how well a person can adapt to their pain and continue with normal life), while resilience accounted for 31%, after controlling for pain intensity. Similarly, pain intensity explained 9% of variance in quality of mental health and resilience predicted 43%.[12]

The brain as the integrator of the total pain model

There is a poorly defined relationship between the physical, psychological, social and spiritual experiences of pain and mental health that can be observed in population studies. However, a unifying theory might be proposed for this relationship taking place in the brain. Functional magnetic resonance imaging (fMRI) and diffusion tensor magnetic resonance imaging studies have identified multiple areas of the brain that show changes in chronic pain patients, but two in particular stand out – the medial prefrontal cortex (MPFC) and the default mode network (DMN), the latter being a network of interacting brain regions.

Spontaneous increases in intensity of chronic back pain coincide with activity in the MPFC.[13,14] However, this activity is not replicated if an alternative pain stimulus is applied (thermal stimulus). This area receives inputs from the posterior thalamus, ventral striatum and amygdala which are areas involved in emotion, cognition and motivation. Activation of this area may therefore occur in emotional states and persistent pain but not in acute pain. This could be because chronic pain elicits a more emotional reaction or because patients who already have high levels of activity in the MPFC due to presence of an emotional state may be more prone to chronic pain.

Furthermore, there was decreased grey-matter density in the right ventral MPFC and right nucleus accumbens in patients with chronic complex regional pain syndrome, and white matter connectivity between these regions was disrupted.[14] The degree of loss of connectivity could also predict heightened anxiety in these patients, and patients with complex regional pain syndrome performed poorly on emotional decision-making tasks, perhaps because their MPFC was not intact.

The DMN is a group of cortical regions known to be active at rest, which have been shown to be disrupted in autism, Alzheimer's disease, attention-deficit hyperactivity disorder, depression and schizophrenia.[15]

fMRI showed that while chronic back pain patients performed equally well on visual attention tasks as controls, they had reduced deactivation in areas of the DMN including the MPFC, amygdala and posterior cingulate precuneus.[15] The brains of patients with chronic pain could have less time at rest because of the occurrence of spontaneous pain and the resulting hypervigilance, thus showing changes in the DMN.[11] These changes could cause sleep disturbance, decision-making abnormalities, anxiety and depression. Areas of the brain that are affected in mental health are also disrupted in chronic pain, providing a plausible anatomical reason for the link between physical and mental pain.

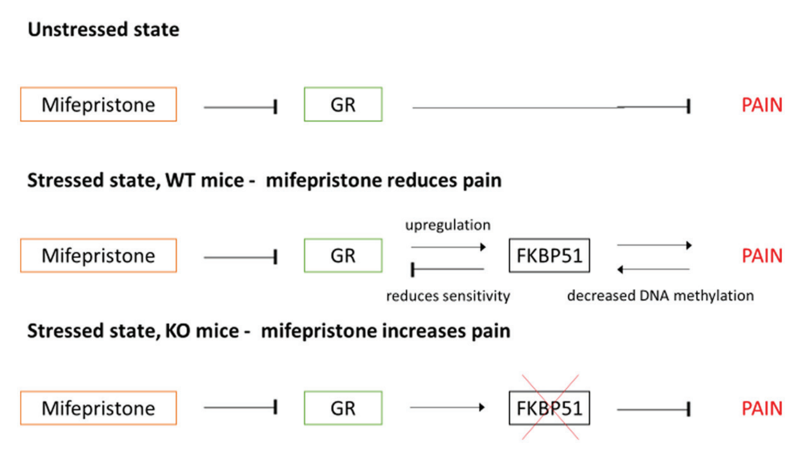


Figure 2. Relationship between FKBP51 and glucocorticoid receptor. WT: wild type; KO: knock out; GR: glucocorticoid receptor

Molecular pathways and therapeutic targets

Some individuals may have genetic traits that make them more prone to both chronic pain and mental ill health. A triggering event may be responsible for this susceptibility or act alongside it to result in pain or mental disorders. It has been noted that a prior experience of pain correlates with development of chronic pain, for example, severe herpetic neuralgia predicts development of postherpetic neuralgia.[8] Similarly, painful life experiences may make one prone to chronic pain. It has been shown that patients with genetic variants in the *FKBP51* gene are more likely to develop post-traumatic stress disorder (PTSD) after a childhood trauma.[16] This demonstrates how life experience interacts with pain and mental health through epigenetic signalling.

FKBP51 has been proposed to interact with glucocorticoid receptor signalling during pain or stress. The production of the glucocorticoid receptor (GR) is upregulated in mouse models of neuropathic pain, and use of GR antagonists suppresses both mechanical allodynia and thermal hyperalgesia.[17] Glucocorticoids usually relieve pain but in chronic pain the GR switches from an anti-inflammatory to pro-inflammatory state after exposure to a stressor. This switch is possibly mediated by upregulation of FKBP51 by the GR (Figure 2). Experiments with knockout mice (*FKBP51* deleted) and GR inhibitor mifepristone show this effect.

FKBP51 deletion in mice did not compromise detection of acute pain mice but reduced hypersensitivity in models of chronic mechanical and neuropathic pain, suggesting a role in chronic but not acute pain.[16] SAFit2, a specific FKBP51 inhibitor, was originally produced to treat stress-related psychiatric disorders and has been shown to improve stress-coping behaviour in mice. When administered intrathecally 3 days after injury (when hypersensitivity was maximal), SAFit2 reduced severity of pain.[16] Inhibition of FKBP51 could be the basis for future drugs to treat chronic pain and has been shown to affect mental health and interact with life experiences.

Conclusion

There are likely to be strong causal and mutually enhancing relationships between mental health, chronic pain and life events as evidenced by research over the past 20 years. The dichotomous model of chronic pain as either physical or mental is unhelpful. The complexity of this relationship is likely to lead to uncertainty about causation. It has been shown that good coping strategies improve both pain and mental distress, thus reducing the functional impairment of these individuals. This could have wide reaching effects, from post-surgical pain, oncology and terminal illness pain to the very common back and neck pain that affects a huge proportion of adults around the world. Not only would teaching people resilience relieve them of pain, it might prevent it from developing chronically, and new therapeutic targets have been identified which could provide options for people with treatment-resistant chronic pain.

Note

i. By John Graner, Neuroimaging Department, National Intrepid Center of Excellence, Walter Reed National Military Medical Center, 8901 Wisconsin Avenue, Bethesda, MD 20,889, USA. – http://www.frontiersin.org/Neurotrauma/10.3389/fneur.2013.00016/full; Public Domain, https://commons.wikimedia.org/w/index.php?curid=25872800

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End stuff

Metaphorising my pain

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THE BRITISH PAIN SOCIETY
EXPERTISE WHERE IT MATTERS
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SAGE

Marine fog rolls in Half Moon Bay, California by Jacek Walicki (edited by Chalger). This image is licensed under the CC BY-SA 3.0 license.[1]

My chronic neuropathic pain is a
physical reality,
not a product of my imagination.
It is the result of a spinal injury
sustained during a ‘simple biopsy’
of a spinal cord tumor,
detected through an MRI.
The operation was performed
by an eager neurosurgeon in 2004.
When I woke from the anesthesia,
I could hardly breathe;
I felt like a tight band was around
my lower chest wall.
I also couldn’t move my legs,
and they were extremely sensitive
to touch.
Since then, the pain has expanded
and intensified.
A typical dreadful day starts
when I am woken up by pain all
over my body.
Hot, coarse sand grains are
pulsating
inside my calves and thighs;
fine nails are drilling into my feet
and buttocks;
sharp knives are plunging into my
back;
needles are pricking my chest;
mallets are pounding incessantly
on my arms;
warm, fine sand grains are
swimming
inside my palms and puffed-up
fingers!
It was another night with bad
sleeping posture.
My back must have glided off the
three standing pillows
propping up my back,
curving my spine into a bow
and pressing part of it against
the air-filled pressure-reduction
mattress,
igniting pain all over my body.
My head must have dropped
forward off the pillow,
compressing my cervical nerves
and kindling pain in my arms and
fingers.
By the time I finish my four-hour
morning routine
of sitting up, lying down,
being hoisted onto a shower
commode
to toilet and shower,
being hoisted back into bed,
being turned left and right
several times for grooming,
and finally being hoisted down into
my motorized wheelchair for
the day,
I am usually in agonizing pain.

Lake Cerknica, by why 137 from Trieste, Italy, uploaded by Sporti. This image is licensed under the CC BY 2.0 license.[2]

My feet feel like they're on a tray of warm stones.
My calves seem to be wrapped with coarse sandpaper.
The small, air-filled cells of my Roho cushion are
pebbles under my buttocks.
My backrest is a stone-studded board.
The escalation continues with increasing power
over the next 24 hours and beyond.
No escape!
Except meeting the pain upfront.
Just sit upright,
keep my spine straight,
sit still,
breathe in and out very slowly,
guide the qi to the pain areas,
be mindful of it.
I sink into the pain –
identifying it,
recognizing it,
analyzing its nature,
quality, patterns,
locations, and triggers,
so that I can learn to prevent it
from spiraling into another
almost unbearable episode.

First published in Pulse – voices from the heart of medicine (pulsevoices.org). Publishing personal accounts of illness and healing, fostering the humanistic practice of medicine, and encouraging healthcare advocacy, Ed Paul Gross MD, in their monthly More Voices series: 'In Pain', on 09 October 2017 (https://pulsevoices.org/index.php/pulse-more-voices/more-voices-2,017/in-pain/1175-metaphorizing-my-pain) and later reproduced in the author's website (https://invisiblepuppeteer.wordpress.com/). What is presented here is a rearranged version with approval and permission from both the author and the first publisher. Kit would be pleased to receive comments at her website: she would be delighted and grateful to receive your feedback and comments. She is writing about how she manages her chronic neuropathic pain and disability on the website.

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