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PAIN NEWS

A PUBLICATION OF THE BRITISH PAIN SOCIETY



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Wind Song and Harmony

A biological basis of CRPS and Fibromyalgia

The BPS National Awareness Campaign

Empathy

How much pain is painful?

History of the Philosophy and Ethics SIG

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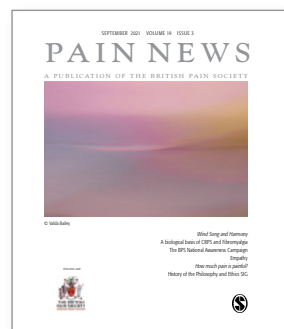
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To prescribe or not to prescribe medical cannabis – that is the question?

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The Pharmacist Pietro Longhi 1752 Style: Rococo. Location: Galleria dell'Accademia, Venice, Italy. In the public domain.

Introduction

Cannabis has been known for its medicinal potential since the 19th century, where cannabis tinctures were employed for the treatment of pain and nausea in both the United Kingdom and United States.^{1,2} In recent years, the prescribing of Cannabis Based Medicinal Products (CBPM) has been allowed by many healthcare systems across the globe including the United Kingdom. However, despite prescribing of medicinal cannabis being allowed, there still seems to be a reluctance and concerns in prescribing CBPM to patients in the United Kingdom. This article discusses the number of barriers, which have been highlighted and have inhibited healthcare practitioners from prescribing medical cannabis as follows:

1. Evidence base – data are still not clear-cut for some indications and clinicians still need convincing to prescribe it
2. Cost – approved medical cannabis is very expensive compared to other therapeutic alternatives
3. Liability – clinicians have concerns if patients experience adverse effects (such as addiction) that they could be liable to prosecution
4. Diversion – prescriptions issued to a patient could end up being diverted to other users, that is, enter illicit supply chain.

Background

The main genus cannabis is *cannabis sativa* L., which comprises two subspecies (*sativa* and *indica*) and thousands of chemovars or chemical varieties.^{1–4} *Cannabis sativa* L. contains about 120 phytocannabinoids. Δ^9 -tetrahydrocannabinol (Δ^9 -THC) and cannabidiol (CBD) are the most studied phytocannabinoids. Δ^9 -THC produces psychoactive and other physiological effects such as effects on pain and appetite through weak partial agonism of the cannabinoid receptors CB1 and CB2.⁵ In contrast, CBD produces antipsychotic anxiolytic effects through negative allosteric modulation of the CB1 receptor as well as other receptor and non-receptor effects.^{6,7} CBD does not produce any psychoactive effects.⁸ The main chemovars are Δ^9 -THC predominant, CBD predominant, and mixtures of both Δ^9 -THC and CBD.⁹ Cannabis is a Class B controlled drug (CD) (Part II Schedule 2 of the Misuse of Drugs Act 1971) and a Schedule 1 (under the Misuse of Drugs Regulations 2001).¹⁰ Under this legislation, it is illegal to possess, supply, produce, import/ export or cultivate cannabis without a Home Office licence as it has no medical use. In contrast, CBPM are classed as Schedule 2 CD (under the Misuse of Drugs Regulations 2001).¹⁰

Cannabis was deemed to be without any medical use, and hence included in the Single Convention on Narcotic Drugs in 1961, which limited its availability and use.¹¹ However, in the early

1990s, following the discovery of endogenous cannabinoids and the endocannabinoid system, cannabis re-gained interest in its medicinal use.¹² Cannabis extracts such as concentrated resin, hash oil, edibles, vapes, dabs and distillates have also gained considerable popularity over the last two decades.⁸ Due to technological advances, the potency of cannabis has almost quadrupled over the last decade. In addition, the impact of the Covid-19 pandemic and associated financial/economic strains has led to increased unregulated home-growing which, in turn, increased the potency range and versatility of the final cannabis products, thus posing considerable health risks.⁸

The case for cannabis-based medicinal products

A distinction must be made for cannabis-based medicinal products (CBPM), which are regulated and standardised plant-based or synthetic medical products with a marketing authorisation/product licence issued by a relevant competent authority.¹³ The amendment of Regulation 2 of the Misuse of Drugs Regulations 2001 defined CBPM as preparations or products that contain ‘cannabis, cannabis resin, cannabidiol or a cannabidiol derivative’, ‘produced for medicinal use in humans’ and are ‘medicinal products’ or preparations that have undergone clinical trials to evaluate their safety, efficacy, effectiveness, and potential harms in line with the Medicines for Human Use (Clinical Trials) Regulations (2004).¹⁴ These products contain synthetic Δ^9 -THC, plant-based combinations of Δ^9 -THC/CBD, or plant-based CBD. Licenced products in the United Kingdom include Epidiolex 100mg/ml oral solution (CBD), which is used as an adjunct treatment (with clobazam) of seizures associated with Lennox-Gastaut syndrome (LGS) or Dravet syndrome (DS) for patients over the age of 2 years old.¹⁵ In addition, Sativex 1:1 ratio of Δ^9 -THC: CBD is used to improve symptoms of moderate to severe spasticity resulting from multiple sclerosis (MS) in patients who have not responded to other therapies.¹⁶ Nabilone (synthetic cannabinoid) is also licenced in the United Kingdom, for people over the age of 18, as a treatment for chemotherapy-induced intractable nausea and vomiting.¹⁷

Substantive and convincing evidence have yet to be gathered to evaluate the risk/ benefit of CBPM, as a last resort treatment when conventional treatments fail, as anti-emetics post-administration of chemotherapy, appetite-enhancers, relievers of neuropathic pain, agents used to improve symptoms of spasticity in MS, relievers of chronic non-cancer pain, palliative agents in cancer pain, and antiepileptics in intractable treatment-resistant childhood epilepsy.^{13,17} Non-randomised controlled clinical trial data reported modest health benefits of CBPM in anxiety disorders, for example, post-traumatic stress, depressive and sleep disorders; other types of

chronic pain; degenerative neurological conditions; and inflammatory bowel diseases, for example, Crohn’s disease.¹³

With the exception of Nabilone, Sativex and non-controlled CBD products, prescribing of CBPM in the United Kingdom is subject to Regulation 16A of the Misuse of Drugs Regulations 2001, where the CBPM must be prescribed under the directions of a specialist medical practitioner and must be either ‘a special medicinal product’, ‘an investigational medicinal product’ or ‘a medicinal product with a marketing authorisation’.¹⁴ Subsequent prescriptions may be issued by another prescriber (e.g. a general practitioner) under a ‘shared care agreement’, whereby, counselling, and regular monitoring of adverse reactions and response to treatment are undertaken.¹⁷

Cannabis use disorders (CUD) affects a large proportion of cannabis users, yet its impact on public health is still unknown.^{18,19} As with all medicinal products, the intake of medical cannabis is not without harm. For example, while there is evidence on the benefits for Nabilone in relieving chemotherapy-induced nausea and vomiting, it can cause dizziness and xerostomia. Short-term adverse effects of CBPM include dose-dependent cognitive decline,^{20,21} drowsiness, disorientation, nausea, euphoria, confusion and sleepiness.²² Despite limited evidence on the long-term adverse effects of CBPM, researchers have reported dizziness, fatigue, headache, increased appetite, somnolence, cannabis dependence, CUD, impaired executive cognitive functions.²³

The relationship between health-related quality of life (HRQoL) and the use of cannabis as a whole or any of its phytocannabinoids is not fully understood.²⁴ In addition, evidence related to its long-term effects with respect to risk of dependence and psychological disorders is lacking.¹⁷ Despite the lack of evidence on the long-term effects of CBPM, there are data from recreational use of cannabis. Cannabis smoking has been associated with myocardial infarction and strokes in younger users, as well as chronic bronchitis.^{25,26} Semple et al.,²⁷ in their systematic review, have demonstrated that cannabis is ‘an independent risk factor’ for the development of psychosis and schizophrenia in vulnerable populations such as the young and those with a prior relevant mental history and including individuals with a genetic vulnerability to schizophrenia. Gobbi et al.²⁸ in their systematic review and meta-analysis, have identified a high risk of depression, anxiety and suicidality in young people.

Despite the issuing of the National Institute for Health and Care Excellence (NICE) guidance (2019) on the prescribing of CBPM, numerous challenges still exist, limiting the number of patients accessing treatment with Cannabis-based products for medicinal use (CBPM).

To prescribe or not to prescribe medical cannabis – that is the question?

Studies have shown that doctors are not confident prescribing CBPM and little or no educative support was/ or is included in their training.²⁹ Doctors may not always be aware of the content or adverse effects of particular chemovars (or varieties of cannabis with different relative concentrations of active compounds) at the point of prescribing. Another reason for the lack of prescribing of CBPM is cost-effectiveness. For example, in chronic non-cancer pain, the current evidence is limited in supporting the generic use of CBPM in such patients. Based on the NICE guidance, prescribers have to consider a variety of patient factors such as history of cannabis use, history of illicit substance use, medical and psychiatric history, drug and condition interactions with CBPM, pregnancy and breastfeeding, patient age, effects on neuropsychological, cognitive and brain development in young people, sedative effects, risk of dependence, impact on ability to drive or operate machinery, duration of treatment, indication, route of administration, licencing status of the product, travel with a CBPM, counselling considerations such as not to share the CBPM with anyone and use the CBPM as prescribed.¹⁷

While it is possible to produce standardised doses of synthetic cannabis products under Good Manufacturing Practice (GMP) and produce products which can meet regulatory requirements and enable their use as investigational medicinal products,^{30,31} data on CBPM from clinical trials is insufficient and hence, is not generalisable. Unlicensed products have sometimes been offered for free to patients for compassionate treatment, for example, for cancer pain.^{32,33} The use of unlicensed products can pose significant risks of liability on prescribers.

Most patients prefer herbal cannabis to gain additional health outcomes from the plant as a whole (described as ‘entourage effect’) rather than an extract of it.^{13,34} This is supported by the facts that the total pharmacological effect of a chemovar is equivalent to the combined effects of all the phytocannabinoids including different concentrations of Δ^9 -THC, CBD, terpenoids and other.^{7,35} Flexible regulatory systems generally apply with established herbal medicines as opposed to pharmaceuticals. This is based on assumptions that the herbal product is well-established and was not associated with any reported serious adverse effects. As such, in clinical trials, it is not essential to demonstrate efficacy and effectiveness of the herbal product, but in contrast, it is essential to determine its consistency and dose uniformity.³⁶ This practice poses different types of risks including interactions of phytochemicals with regular medicines, thus requiring close monitoring of potential adverse effects. It is not possible to apply those flexibilities on herbal medicines, which are also controlled substances as in the case of cannabis.¹³ In addition, herbal medicines may typically be prescribed or

recommended as add-on therapies to conventional medicines. The latter may be challenging to propose with CBPM due to high potential of drug interactions with high-risk medicines such as antiepileptics and contraceptives.

Another challenge relates to the extraction and manufacturing processes of the herbal material. It may be technically impossible to isolate Δ^9 -THC from CBD due to the sharing of the same precursor cannabigerolic acid (CBGA) and biosynthetic pathways,³⁷ hence resulting in CBD products with possible traces of Δ^9 -THC, and hence, caution needs to be exercised by prescribers. There are risks of dependence, diversion and misuse of CBPM,³⁸ and possible negative impact on developing brains, possibly leading to the development of addictive behaviours and adding to the prescribing challenges, thus increasing clinicians’ concerns as they could be liable to prosecution.

Cannabis prescribing in the United Kingdom: the clinical reality

The greatest potential demand for CBPM comes from those patients who suffer from chronic pain. It is the experience of one of the authors (RM) that those who seem to benefit (certainly) in the short term, particularly in those who also suffer from concurrent anxiety and yet almost paradoxically those who seem not to do well in the long term, are those with known concurrent mental health issues.

Routine prescribing of CBPM in the United Kingdom is almost non-existent due to the guidelines produced by the Faculty of Pain Medicine³⁹ and the British Pain Society⁴⁰ and Royal College of Physicians in response to the NICE guidelines.⁴¹ Effectively these guidelines discourage routine prescribing of CBPM for chronic pain. The conclusions of these guidelines have been primarily based on papers which show that more patients are likely to show no or adverse effects compared to those few who may benefit.⁴²

Furthermore, currently, most of the prescriptions emanate via private clinics from highly selected patients from whom a carefully collected cohort data suggest a subset of chronic pain patients do well with CBPM,⁴³ especially those who have more widespread pains. So currently the challenge is to carefully assess the long-term results and wider applicability of these cohort studies to the general population of chronic pain sufferers.

The immediate challenge is therefore balancing any possible risks and lack of efficacy in the general population of chronic pain patients against those of a small cohort who apparently show significant benefit, and how to select those patients.

To prescribe or not to prescribe medical cannabis – that is the question?

Like in so much of pain medicine, patient selection is the key, based on integrating the multiple patient variables to successfully determine how we can maximise potential patient benefit and reduce potential harm. Currently, we simply do not have the data.

What is needed is to develop a holistic approach and flexible legislative models for the provision of CBPM, enabling early access to patients who need it. But we are not alone, we need to be open and learn from other countries such as Canada,⁴⁴ where regulated medical and recreational cannabis are legally supplied under well-designed controls that focus on prevention and treatment and specifically with limited access to children and young people (who may be at more risk of harm), and reduce demand for the illicit market product which have higher levels of THC, which is more likely to be associated with harm.⁴⁵

More funding is needed to conduct research and restore services, including age-appropriate evidence-based services, for the treatment of CUD as per Dame Black report.⁴⁰ Pragmatic practice should be considered if medical cannabis is to be prescribed. These include using the lowest effective dose with a patient-specific maximum daily dose, titrate dose, use CBD concomitantly with $\Delta 9$ -THC to counteract $\Delta 9$ -THC's adverse effects, prescribe appropriate formulations (e.g. long-acting preparations in long-term conditions), monitor patients closely, use storage boxes, and ask patients to keep a diary of adverse effects and response to treatment.⁹

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Jenny Nicholas



Autumn will soon be upon us, and as lockdown has lifted and life around us slowly adapts to a new normal, we take some time for a little reflection and a new look at what we know about pain and its treatment/management.

- Our Editor, Raj Munglani, along with colleagues Amira Guirguis and Luigi G Martini open the issue with a discussion on **'To prescribe or not to prescribe medical**

cannabis – that is the question' which looks at the barriers which have inhibited healthcare practitioners from prescribing medical cannabis to date in the United Kingdom.

- Andreas Goebel, Zsuzsanna Helyes, Camilla Svensson and David Andersson share with us **'New insights into the increasing evidence for the role of "bio" in the biopsychosocial model: results from Complex Regional Pain Syndrome and Fibromyalgia Syndrome'**.
- **Relational empathy: engaging with suffering** by David Jeffery talks about a relational empathy-based approach to patient-centred care.

- Margaret Dunham discusses **older people, the ICD-11 and NICE**.
- **How much pain is painful?** Timothy Nash, Amy Bennett and Ben Thompson discuss a study which attempted to quantify what levels of pain and interference with function were generally considered commensurate with normal or near-normal functioning.

We have also introduced in this issue some further artistic, thought-provoking pieces which we hope you will enjoy ...

- **Windsong and Harmony** by Valda Bailey.

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

Have your say

We would welcome your view and letters on any of the topics we have covered in this, or previous issues of *Pain News*.

We also welcome articles, so if you have a story to share, please contact us at newsletter@britishpainsociety.org. We would be delighted to hear from you!

President's message

Arun Bhaskar



Dr William Campbell

Dear Friends
I trust this finds you well.

I sit down to write this message with a tinge of guilt as I had a few reminders from our Editor-in-Chief, Dr Munglani, who despite undergoing a total knee replacement was delivering this edition of *Pain News* and would be having his other knee done in a few days. Thank you, Raj, for your ongoing support for the British Pain Society (BPS), and I join hundreds of your friends and colleagues to wish you a speedy recovery and I am sure you would be sharing your journey from a patient's perspective to enrich our experiences as professionals in pain management.

The Scientific Programme Committee and Kenes had their first meeting, and steps are underway to have a hybrid meeting in the summer of 2022 in London. After several months of having meetings on a virtual platform, be it Zoom or other bespoke software with avatars, there is an increasing appetite to restore face-to-face meetings, and we are indeed planning for just that; however, those who want to avail the programme on a virtual format will be able to do that too. You will be hearing more about this in the coming weeks. It is my hope that you will consider attending the Annual Scientific Meeting (ASM) and supporting the BPS as your support is needed at this crucial juncture where we had to take some hard decisions to ensure that the BPS continues to function as a truly multidisciplinary Society.

The Executive and the Council recommended extending the terms of office for another year due to the extraordinary circumstances due to the COVID-19 pandemic, and this has been discussed with our charity advisers for their advice. There have been some changes in the Council membership following this decision. Prof. Sam Ahmedzai and Dr Peter Brook have indicated that they would not be extending their terms due to personal commitments. Dr Amanda Williams has also stepped down from her co-opted role from the Council. I would like to extend my gratitude for all their hard work and support to the Society over the years, and this is very much appreciated. Dr Amelia Swift has taken over as the Chair of the Education Committee and has some exciting ideas to use the virtual platform to reach a wider audience. The membership will be informed of further developments in due course.

I would like to share the happy news and congratulate Mrs Victoria Abbott-Fleming, Chair of The Patient Voice Committee (TPVC), on receiving an MBE in the Queens Honours List for her services to supporting patients and raising awareness of complex regional pain syndrome (CRPS). Some of you would know that her blossoming career as a barrister had been cut short due to development of sepsis and CRPS and had to undergo above-knee amputations to both her lower limbs. Victoria overcame all the difficulties to be a true champion for those living with chronic pain, and I am sure she will steer

TPVC to greater heights in the years to come. Congratulations Victoria.

On another note, the Council has recommended two names for Honorary Membership of the BPS, and this will be announced during the AGM to be held later in the year. The project on multidisciplinary working and the development of non-surgical pathway for the management of osteoarthritis pain are well underway, and I would like to thank Dr Amelia Swift, Mr Jonathan Bell and Prof. Richard Langford for their support and hard work in driving this forward. There has been a lot of work being done to interact more closely with the Faculty of Pain Medicine and the Royal College of General Practitioners to ensure that pain is on the agenda when pathways and National Health Service (NHS) strategies are being rolled out. The National Spinal Pathway and 'Getting it Right First Time' (GIRFT) are looking at collaborating with pain services to deliver high-quality care.

COVID-19 continues to influence how we work, and most services are busy dealing with the substantial backlog of patients who had been shielding, and along with the effect of COVID-19 on the workforce, this has been putting a lot of pressure on service delivery.

I wish you all the very best in keeping your services going and would also like to take this opportunity to remind you again of the importance of looking after yourselves and each other to overcome these trying times. I am optimistic that in the coming months we shall be looking forward to getting back together despite the probability of having another peak in COVID-19 cases as evidenced by developments around the world. I am hoping to see you in person in the not-too-distant future.

Thank you
Arun

New insights into the increasing evidence for the role of ‘bio’ in the biopsychosocial model: results from Complex Regional Pain Syndrome and Fibromyalgia Syndrome

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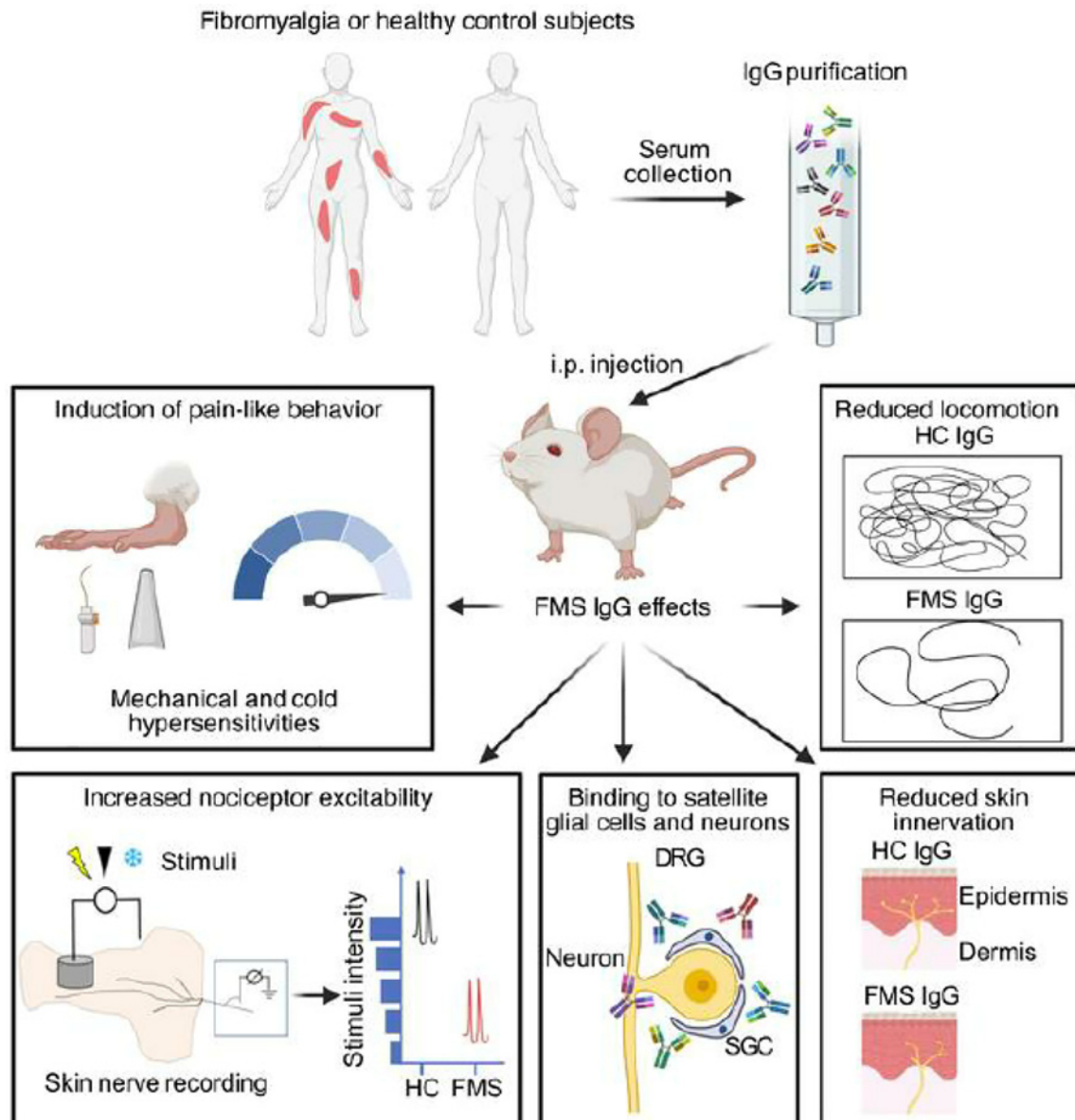
Over the past 2 years, the results of our own research have shed new light on the biological causes of two important chronic pain conditions, complex regional pain syndrome (CRPS) and fibromyalgia syndrome (FMS). CRPS is an uncommon chronic pain that typically affects a distal limb after trauma, whereas FMS is a common widespread pain condition. Both CRPS and FMS mainly affect women (ratios 3-4/1). The conditions can severely depress patients' qualities of lives. Unfortunately, there is no effective drug therapy available that can reduce pain for more than just a few weeks or months.

Both conditions have been classified by the World Health Organization (WHO) into the category of “chronic primary pains”¹ (code: MG30.0) and are, per definition, associated with psychological distress or dysfunction. However, the contribution of biological factors to their biopsychosocial matrix has remained largely unclear. Recent discoveries potentially constitute a paradigm shift for our approaches to these conditions. It now turns out that both conditions may be caused by an autoantibody-related autoimmune mechanism which is undetectable by the available blood tests.

Complex Regional Pain Syndrome

- When transferred to hind-paw injured mice, serum-IgG derived from patients with *persistent CRPS* causes profound paw hyper-sensitivities to pressure, touch and cold, as well as enhanced swelling. These changes are strictly confined to the injured paw. The measurable signs in the animals resemble the clinical picture in CRPS patients, strongly suggesting that an autoimmune mechanism in persistent CRPS.²
- Serum IgGs derived from patients with high pain intensities (>7.5NRS) elicit stronger hypersensitivities in the animals than serum IgGs transferred from patients

Figure. Details are described in the text and here.^{5,6} Used with permission.



with moderate pain intensities.³ This suggests that distinct CRPS clinical phenotypes can be transferred to mice via IgG injection.

- All tested CRPS patient samples were active in this way.
- When the daily injection of human antibodies was stopped, the mice eventually recovered, suggesting that no lasting damage had occurred, and hence, also providing hope that a clinical treatment reducing such antibodies can effectively decrease patients' pain.

- It is at present unclear how the human IgG antibodies cause these CRPS-like signs in mice. There is no enhanced inflammation in the paw; rather, the cause may be an abnormal activation of cells within more proximal pain pathways, such as dorsal root ganglia (DRGs) or spinal cord. More research is needed to clarify this.
- The results strongly suggest that the development of diagnostic blood tests and immune therapies for CRPS should be possible.

Fibromyalgia Syndrome

- When transferred to naïve mice, that is, mice that have not been injured or manipulated in any way, serum IgG from patients with FMS causes profound, widespread sensitivity to pressure and cold in the animals (Figure).
- The animals' grip strengths are reduced; they move less during their peak activity periods, and they develop epidermal small nerve fibre loss. These signs resemble the clinical picture of FMS.
- Every single tested preparation donated by Liverpool patients (n=8) and preparations pooled from over 30 Swedish patients tested 'positive' in this way.
- The animals' sensory nerve fibres become abnormally responsive, not dissimilar to the abnormal activation of C-fibres which had already been reported in 2014 in microneurography experiments in FMS patients by Jordi Serra's group.⁴
- After injection, FMS IgGs bind preferentially to cells and structures in the mouse dorsal root ganglia but not in the mouse central nervous system; FMS IgGs also strongly stain *human* cadaveric DRGs.
- These results suggest that FMS is typically mediated by an autoimmune process.

These results also are also consistent with the possibility that a number of different pathways can trigger this autoimmune process. One pathway may relate to the patients' genetic vulnerability to develop an autoimmune reaction. In many patients such tendencies may have been 'cryptic', that is, with no previous autoimmune conditions. Others might have already had another autoimmune disorder such as rheumatoid arthritis (RA): 20%–30% of patients who have RA will also develop FMS, a much higher proportion than in the general population (2%).

Another pathway may be related to the experience of severe stress. For clarity, this pathway will not apply to all patients with FMS. Half of Liverpool FMS patients (4/8) in the recent study⁵ reported that their condition had started after the experience of severely distressing life circumstances, and events such as rape, domestic violence, loss of partner and job; indeed the literature suggests that FMS can follow such events.⁷ Hence, the experience of very difficult life circumstances and events in susceptible people (e.g. due to genetic factors), may lead to

abnormal activation of the immune system with consequent autoantibody production.

Unfortunately, once initiated, this autoimmune activation does not seem to easily revert to normal, even when any acute distress has passed. These considerations would suggest that it is no wonder that many patients we see in clinic may be distressed – not only may they deal with their condition, but they may also often be survivors of adverse situations and events. In a sinister twist, it may have been these experienced situations and events which may originally have triggered their pain conditions – in the process further augmenting the distress experience.

For clarity, in this pathway, psychosocial distress does not directly cause unexplained pain, which means that such pains are *not* abnormal responses of the brain in the context of a stress experience. Rather, the experience of psychosocial distress may facilitate a biological immune process in susceptible people, which changes the function of these patients' sensory nerves, consequently leading to the perception of pain with all its biopsychosocial consequences.

We hope that these findings can be confirmed by other groups and that they will contribute to causing a paradigm shift in how we understand, diagnose and treat chronic primary pains, towards a better future for those fellow citizens for whom we currently hold so few solutions.

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National Awareness Campaign – British Pain Society

David Pang *Council Member; British Pain Society*



Equestrian scene from the Hungarian campaign by August von Pettenkofen. 1851 Original Title: Reiterszene aus dem ungarischen Feldzug. Public domain.

*"ipsa scientia potestas est
Knowledge itself is power"-*

Sir Frances Bacon (1597)

Early in my career I often got surprised looks from patients about the existence of pain services. Even their doctors did not realise that there was a specific clinic that served patients with chronic pain and it was accessible with a simple referral. Are not all doctors experienced in managing pain? What is the purpose of pain management?

Pain medicine is still in its infancy – despite the increasing recognition that chronic pain has a crippling effect on patients, their caregivers and with a knock-on effect on society as a whole. There are many services that exist for our patients, yet access can vary.

The National Awareness Campaign was established by the British Pain Society (BPS) many years ago with the aim of trying to increase public knowledge and understanding of how pain can be managed. The public have access to more information than ever before, yet chronic pain management is still one of the most difficult areas of healthcare and outcomes do not appear to be improved despite advances in medicine. The

reasons behind this are still debated, but there is a need for a better understanding of what pain services are available and how to access them.

The aims of the National Awareness Campaign are as follows:

1. Improve public knowledge of how pain can be managed
2. Signpost patients and healthcare professionals to pain management services and resources
3. Develop patient-centred resources to support self-management of pain and the impact of pain on general wellbeing

Currently, resources have been limited and early work has highlighted to the public a number of posters, which have been made and distributed. We want to expand this early work and start to send our message to both patient groups and healthcare organisations.

One start is on having a presence on the BPS website. This will become the central point of information that will allow both patients and professionals to find information and get involved. With time we hope to develop:

1. Regional hubs so that services can be signposted to patients
2. Social media presence
3. Links to support groups for patients
4. Individual patient stories that can inform of their journey for others
5. Engagement with public health bodies and commissioners

While our campaign is small-scale it is hoped that we can develop momentum and expand into a much larger part of the BPS. A big part of this is enlisting help from the different regions in the United Kingdom who understand the services that are available, and we would welcome suggestions from our members and any volunteers who want to participate.

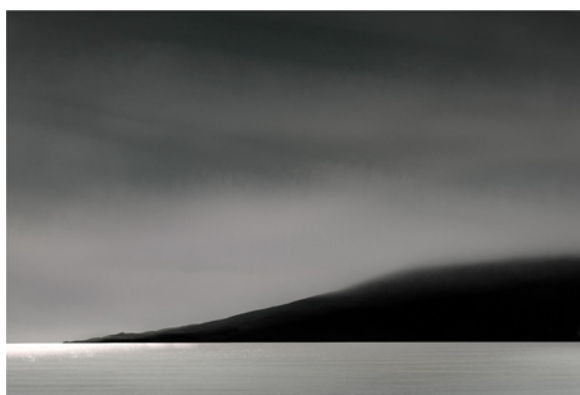
The next step is to reach out to our membership and our patients for this campaign and I will try and write a regular article in *Pain News* to update on progress.

Windsong and harmony

Valda Bailey

There are two medicines for all ills: time and silence.

Alexander Dumas.



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I remember when I first became aware of the remote archipelago off the west coast of mainland Scotland – I was probably about 8 or 9 and the introduction came during music class as we learned about Fingal's Cave courtesy of Felix Mendelssohn. The Hebrides Overture was a work I really connected to – possibly something to do with the fact that I also lived on a small island surrounded by water; the considerably more densely populated island of Jersey in the English Channel. As children, we rather take things for granted, and it really didn't occur to me that having the ocean crashing in on your back doorstep wasn't the way it was for most people. Now I live in Sussex and to my great regret, the nearest coast is 45 minutes away; my teaching commitments mean that I rarely get to spend time there.

I feel very lucky to have discovered the magical Hebridean islands anew, via the medium of photography. Remote and windswept, they are home to a vast variety of wildlife and natural vegetation. To visit the Outer Hebrides is to embark on a journey of adventure and discovery. One stands in awe and wonder at the sight of the wide sweeping beaches with their pure silver shell sand. One becomes entranced by the myths and legends that are woven into the history of the islands. The

gentle lapping waters have a turquoise luminosity that would rival anything one might see in the Caribbean.

The Hebrides are dotted with tiny lochans which, in summer, are strewn with delicate white lilies. They are home to 70% of the world's machair – a rare habitat that is disappearing at some speed. Machair is unusually fertile – nourished by the Atlantic winds driving tiny fragments of seashells across the sand. In June the display of wildflowers is a sight to behold and although the summer months can be plagued with clouds of troublesome midges, the sacrifice is worth it.

The landscape is like no other, and therefore it is not surprising that eager photographers gravitate to the region. They arrive expectantly, looking to take advantage of the great variety of colour and texture and the incredible light. The often stark and minimalist views are compositionally appealing, and for me, have the effect of invoking a sense of meditative calmness and contemplative solitude.

The popularity of the area among photographers is undisputed, and this means that it can become quite a challenge to say something about the place that hasn't already been said many times before. In a landscape where breath-taking panoramas seem to rise up at every turn, just begging for the photographer's attention, this can prove to be something of a frustration. How to put our own identity on the images that we make?



© Valda Bailey.

Sooner or later the creatively curious photographer will start to question why they are moved to press the shutter. What are their motives for doing so? When the world is awash with millions of images of iconic locations – doubtless taken by people with a better eye, with a bigger camera, in more elegant light, and so on – what possible value can there be in adding to that mountain?



© Valda Bailey.

I consider myself very fortunate to have discovered a way of making images that is not only immensely challenging but virtually impossible to replicate. Modern equipment will now allow us to combine multiple frames into one composite image. Of course people have been doing this for as long as photography has been around, but the cameras now merge images in a slightly different way, blending certain tonal values. It is an approach to photography that is controllable to a certain degree but still retains a significant element of unpredictability about it – not unlike painting (especially watercolour painting). Therefore, the results are unique and generally somewhat impossible to reproduce.



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One of the reasons I am drawn to multiple exposure photography is the way the sequence flattens the image and removes linear perspective. Images become flat and take on an almost Cubist quality. Or at least, they can do. I hesitate to use the word 'painterly' but that is the most accurate way to describe what happens.

My belief is that our job as photographers is not to record what we see—or at least, this may be so for certain types of photography, but not the genre which I find most fascinating. Instead, I go out to reshape and interpret. I take great delight in the fact that I get to play. I don't need to rely on the specific details of what Mother Nature has so thoughtfully provided; if I feel the grass needs to be red, then there is nobody pointing a finger at me telling me I am doing it wrong.

My motivation for going out with a camera is finding a narrative and telling my story. Plundering the depths of my imagination in order that I might bring something of myself along to put into the image. Of course I will be influenced by the light and the tide and the way the sun is reflecting off the marram grass but also by my own sensibilities. My state of mind, what I have been reading, how bad the news is, whether or not I have managed to ingest an adequate amount of caffeine before starting the day, and so on.

I have detailed what I hope are some objective observations about the area – however, delving a little deeper in order to try to unravel what they mean to me, I realise I have unearthed an uncomfortable truth. Although the Outer Hebrides remain one of my favourite places on the planet, the location for me will forever be associated with emotional torment and grief of one kind or another.

In September 2017, as I was gathering together the last few essentials to go in my suitcase, in preparation for a

Windsong and harmony

photographic workshop I was due to be leading with my business partner, Doug Chinnery, the phone rang. The news that my brother had been killed in a fire seems as shocking and implausible today as it was when it was delivered so unexpectedly on that early autumn morning.

For a few strange hours I seemed thoroughly convinced that I could continue with my plans, somehow managing to shoehorn a trip to Jersey to break the news to my elderly mother before my flight up to Scotland the following day. Rational thinking slowly returned. A stand-in was found and instead I spent that week sitting at our dining table with my mother and younger brother trying to come to terms with what had happened.



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Reports back from Doug suggested that the weather was fittingly bleak during that week – the winds were biting and the pitiless North Atlantic Ocean crashed against the rocks with a forceful momentum. I believe the workshop was a great success for all participants – the turbulent weather providing much inspiration for the eager photographer. I experienced it all secondhand, courtesy of Doug's bulletins and for much of the time, I'm afraid to say, through a haze of emotion-numbing red wine.

Haltingly, our family knitted back together the tattered fragments of our lives, some sort of routine was restored and my life as a photographic workshop leader continued. And so when March 2019 rolled around, I found myself once again preparing to leave Sussex in order to teach in the Hebrides. Another suitcase, and yet another sudden emotional disruption the day before I was due to leave.... thankfully far less final than the death of my brother, but a turbulent upset nevertheless.

This time I went ahead with the workshop and found the islands to be as captivating as ever. Between the teaching and

taking care of the needs of the group, I even managed to make some images. I was surprised to find that the pain and anguish that now seemed to be inextricably woven into my relationship with the islands was not apparent in the photographs I made. Instead, there appeared to be a sense of calm and serenity, although possibly tinged with a little sadness. I continued to seek out the motifs and themes that have always interested me—fragility, contrasts and contradictions and the ephemeral nature of our existence but perhaps the colour palette was a little more subdued.

I have long since realised that I tend not to let despair and sorrow manifest itself in my work. Or at least, not in a way that I am able to recognise. I have often wondered why this is—many photographers and artists process their anguish through their work. I think it comes down to the fact that, for me, my photography – creative endeavours in general, in fact – are an escape. A place to lose myself for a while and focus on the positive. Aforementioned tragedy aside, I feel very fortunate, and I am aware that I tend to take an optimistic perspective on life most of the time and I think this comes out in my work.

The week spent on the island of Harris was invigorating and life affirming. The weather was kind, the food nourishing and the workshop participants were a terrific crowd who brought much joy and levity to the proceedings.

However, as we were winding down and preparing to leave, we heard the shocking news that a female photographer had been swept to her death while photographing at the shoreline as a rogue wave caught her unawares. Although she was a participant in another workshop, the news obviously affected our group profoundly; not least because we had been standing on exactly the same spot just a few hours before the accident. Once again it hammered home the unseen dangers that exist on these islands – dangers so deftly concealed behind the calm and picturesque facade.

As I write, we are 14 months into the COVID-19 pandemic and so of course travel has been off the agenda for the vast majority of us. Slowly, almost imperceptibly, it seems that our little corner of the world is edging towards something approaching normality, and the opportunity to explore once more may not be too far away. Although I have innumerable rescheduled workshops backed up which will, come October, be commanding my time, I find myself wondering if just possibly, I can find a way to squeeze in a few days for myself in the Outer Hebrides. I might venture to hope that this time my travels will be happy and free from emotional torment. And yet, and yet....



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Perhaps it is entirely appropriate that the completion of this short essay has been delayed and disrupted as I have suddenly and unexpectedly found myself in the position of having to provide 24 hour care for my elderly mother, as a sudden illness has robbed her of anything that might reasonably be called a meaningful existence.

And so, once again I find myself immersed in beguiling daydreams of these magical islands as great sorrow very clearly looms on the horizon.



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Relational empathy: engaging with suffering

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*O, but they say the tongues of dying men
Enforce attention like deep harmony.
Where words are scarce they are seldom spent in vain,
For they breathe truth that breathe their words in pain.*

Richard II Act 2 Scene 1 William Shakespeare

Introduction

Healthcare professionals face challenges in managing the complexities of an individual suffering chronic pain. This article argues that empathy lies at the heart of the patient–doctor relationship, and in this overview of relational empathy, the role of emotions and boundary setting are explored. An individual's experience of chronic pain may be affected by their social context, which may also limit an empathic relationship. The multidisciplinary team, integral to pain management, requires support if it is to maintain empathic relationships with patients. The article concludes with suggestions for enhancing empathy in medical and nursing students, with references giving more details of the background research.

Evolving definitions: pain and empathy

Dame Cicely Saunders introduced the concept of 'total pain', which included physical, psychological, social and spiritual dimensions of suffering.¹ A recent revised definition of the complex concept of pain emphasises that pain is always a personal experience. A person's account of their experience of pain should be respected.² Listening to the patient's experience of pain demands empathy.

Empathy, like pain, is a dynamic multifaceted concept which has been defined in different ways. Medical practice has traditionally adopted a cognitive view of empathy.

'Empathy is a predominantly cognitive (rather than emotional) attribute that involves an understanding (rather than feeling) of experiences, concerns and perspectives of the patient, combined with a capacity to communicate this understanding'.³

However, a broader view of empathy is evolving which embraces emotional, behavioural and moral dimensions. Empathy can now be seen as a relational concept accounting for the doctor and the patient in the context of their meeting.⁴

Empathy: a dynamic relational process

Empathising is a subtle process by which both the patient and the doctor learn more about each other in an iterative deepening of their relationship.⁵ It begins with a doctor's attentiveness, an openness both to the patient's feelings and to their own emotions.⁶ Empathic concern between a doctor and patient ensures that empathy is ever an interpersonal process. The empathic doctor tries to see the world through the patient's eyes using imagination and curiosity, letting go of assumptions.⁷ Deep empathy demands face-to-face contact with the other person as the physician explores the underlying agenda each patient brings, taking time to listen to their experience of pain. Emotionally engaged doctors communicate more effectively with patients.⁸

The patient and doctor engage in a construction of meaning through interpretation to gain understanding. There is a need for a practitioner to develop 'narrative competency' to interact with patients in a joint process of making sense of their stories of pain.⁹ Reflection is central to empathising, acknowledging emotions, achieving *phronesis* (practical wisdom), recognising one's limitations and tolerating uncertainty.

Empathy has a moral dimension: an understanding of the patient's concerns will allow a doctor to respond in an ethical way. Frank suggests that it is at the time when two people share feelings of uncertainty, vulnerability and loneliness, that a natural dialogue results. Empathy can be viewed as a dynamic emotional dialogue between a patient and a doctor, each speaking *with* the other rather than speaking *about* them.¹⁰ The patient is acknowledged as a fellow human being; this feeling of shared humanity can create a sense of security in situations of great uncertainty such as in end-of-life care.¹¹

Empathy is linked to altruism as it includes a motivating force, a commitment to practical action to relieve suffering. Expanding the concept of empathy in this way to include action to relieve suffering maintains the focus on the patient rather than the doctor and takes account of the social context of the patient's pain.¹²

Emotions and clinical decision-making

The idea that emotions are disruptive and need to be controlled is deeply ingrained in medical education and practice.¹³ However, emotions contribute to clinical decision-making, playing an integral role in patient safety since a close empathic relationship fosters trust, allowing patients to disclose their deepest fears.¹⁴ Empathy involves feeling with the patient to gain an understanding of their suffering. Some doctors fear that emotional connection may impair their 'objective' clinical judgement or that they will become overwhelmed and suffer burnout. These concerns may lead to distancing from patients, adopting a professional stance of 'detached concern'.¹⁵ Nevertheless, empathic doctors have been found to suffer less burnout than detached colleagues.¹⁶

Setting an appropriate self-other boundary

Empathic concern involves a sharing of emotions; the doctor feels the pain of a patient while remaining aware of the self-other boundary.¹⁷ It is essential to remember that the other person is separate from oneself and one's family. Bondi¹⁸ describes the boundary as an unconscious process in which the doctor is both subjectively engaged in a two-person relationship and at the same time is an observer of that relationship. This 'third position' allows a doctor to be absorbed in a patient's narrative as well as having the capacity to step back and reflect on their relationship.

Empathy demands imagination; taking an 'other-orientated' perspective of the patient's experience of pain is part of forming an appropriate psychological boundary. 'Help me to understand what this is like for you' contrasts with a self-orientated perspective, 'How would I feel in this situation?'. The latter, self-orientated perspective plays a role in sympathy but risks causing personal distress and medical staff burnout.

Rogers stressed that empathy involves entering the perceived world of the other person 'as if' one were the other person, but never losing the 'as if' condition.¹⁹ To maintain this delicate psychological balance between detachment and connection, the doctor needs to be self-aware, to reflect on their work and to have access to support.²⁰

The context of empathy

Relational empathy is affected by the context of the meeting between patient and doctor. Patients want personalised care from a doctor whom they trust.²¹ Multidisciplinary team working is central to the effective management of chronic pain, yet it carries a risk of diluting personal responsibility, which may leave the patient feeling abandoned. Lack of continuity of care, lack of privacy, social distancing and personal protective equipment are examples of potential barriers to an empathic relationship. Lack of time, overwork and stress may constrain a doctor's ability to empathise as well as working in an organisational culture focused on technical efficiency. However, spending time with patients to listen to their concerns can avoid unnecessary tests and procedures.²²

Support for professionals

Healthcare professionals may distance themselves from patients when they feel stressed, reducing empathy and increasing the risk of clinical errors.²³ Providing support for professionals, encouraging engagement and the expression of emotion may help staff to respond to patients in a healthy way.²⁴ Space for reflection, mentoring and support should be available to all staff, not solely reserved for those perceived to be struggling.²⁵ It is not sufficient to provide staff with training and encouragement to be more empathic and expect them to work in an organisational culture which does not support empathy.

Enhancing empathy

Research suggests that medical students' empathy may be enhanced by providing positive clinical role models and by including the humanities into the curriculum.^{26,27} Positive, caring role models can encourage students to develop empathic relationships with patients.²⁸ Students particularly value working with experienced doctors who are prepared to admit vulnerability and who share emotions.²⁷ Bleakley argues that incorporating the humanities into the curriculum may address the biomedical bias of modern medicine. This approach to the humanities can provide an ethical pause, giving time and space for reflection, to challenge assumptions and to open students to possibilities. The arts encourage students and healthcare professionals to imagine the world through the other person's eyes, to empathise.

Conclusion

A relational empathy-based approach ensures that practice becomes more patient-centred. Healthcare professionals need to have time to establish empathy, to acknowledge the individuality of the patient and to address their real concerns. In conceptualising empathy in a broad relational way,

Relational empathy: engaging with suffering

professionals are adopting a phenomenological stance in engaging with the experience and emotions of each patient.²⁹ Phenomenology aims to gain a deeper understanding of the meaning of everyday, taken-for-granted experiences. It is also a way of seeing how things appear from another individual's experience of living with chronic pain.³⁰ Empathy is a special form of understanding, a way of humane practice.

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How much pain is painful?

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Foreword by Tim Nash

In 1976 when I was first appointed to Basingstoke, I was fortunate to visit Sam Lipton for a few weeks and saw his punch card system enabling analysis of outcomes, so I copied it. One thousand cards later, I dreaded putting a knitting needle through to gather up the cases I was interested in. (My secretary dreaded putting them all back in order!). Then came the Sinclair ZX81 with added processing and memory, and I wrote my own programme for a database. It was brilliant, but I decided to password protect and could never again open it!!! After my BEEB it was dBase on a desk top provided by the hospital, but really only was useful as a waiting list tool (my secretary quickly learned that pressing the wrong keys got rid of the waiting list!!!). So it was just my jumble of record cards, until Paul Griffiths developed the Pain Audit Collection System, or PACS. This was when we had been working together on the Clinical Terms Project of the NHS Information Management and Technology Strategy (the Read Code Project). We had recently learned, mid 1980s, that we had to do clinical audit and realised that was what we had been trying to do for years. National Institute for Health and Care Excellence (NICE) Guidelines then came along at the turn of the millennium, and of course, all the academic papers looked for a 50% reduction in visual analogue score (VAS). Clinicians appreciated this was not easy to achieve. So the idea of asking patients what levels of pain they felt they could cope with and what they hoped for from treatments. It seemed ideal for two medical students to run the project during an extended special study module. Previously, a medical student on an extended special study module had validated the Brief Pain Inventory (BPI) for my patients against the Oswestry Disability Score and the Hospital Anxiety and Depression Scale. So we have tried to find out 'How Much Pain is Painful?'

Summary

Introduction

A reduction of 50% in the VAS for pain is currently the gold standard for measuring the effectiveness of therapies. The

British Pain Society's PACS reported that 30% of patients discharged from clinic achieved 30% or more reduction in their level of pain, with patient satisfaction surveys showing 80% of patients were satisfied with their treatment. This study looked at the levels of pain and interference with life that patients considered would be commensurate with normal life and activity.

Methods

Consecutive patients attending a weekly Pain Clinic completed the Wisconsin BPI for their existing pain and its interference with mood and function. They were then asked to complete it for the levels of pain and interference they considered tolerable and commensurate with normal function, and again for the levels they would like to achieve from treatment.

Results

Averaged scores of 99 patients showed they considered they could cope and function normally with scores for worst pain of 5.5 and average pain of 4.62. Overall scores for coping and functioning normally were 4.57. Hoped for post-treatment scores were 4.58 for worst pain, 3.87 for average pain and 3.68 for interference with life and activity. Worst pain reduction of 36.81% and average pain reduction of 34.75% was considered acceptable for normal function, though reductions of 44.14% and 42.8%, respectively, were hoped for from treatment.

Conclusion

These patients considered they would cope with pain and interference scores reduced from severe to moderate levels and wished post-treatment scores to be moderate or mild. The levels of pain and interference scores based on patient evaluation help to calibrate the non-linear visual analogue or numerical rating scales and suggest strongly that the 50% reduction in VAS is an unrealistic target for treatment outcome.

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Introduction

The ideal outcome for treatment of chronic pain is clearly to obtain total control such that the patient is pain free. This counsel of perfection is rarely achieved. The PACS introduced by the Clinical Information Special Interest Group of the British Pain Society showed that around a third of patients discharged from the clinics in the United Kingdom achieve 30% or more reduction in their level of pain.¹

A common comparator in assessing the effectiveness of therapies in randomised controlled trials is a 50% reduction in the VAS for pain, as used in assessing the NNT or 'Number Needed to Treat'.²⁻⁴ These figures for reduction in pain levels have been chosen arbitrarily, with no reference to patient perception as to what is useful. Commonly, satisfaction surveys in Pain Clinics show 80% of patients to be satisfied with their treatment.¹ Acceptable relief of pain may therefore not relate so much to levels of reduction in pain, but more to reducing to more acceptable levels of pain and function.

This study was conceived to attempt to quantify what levels of pain and interference with function were generally considered commensurate with normal or near-normal functioning.

Methods

The study was designed for two medical students on an extended Special Study Module to run the trial and collect the data. The Local Research Ethics Committee and Hospital Clinical Governance approved the protocol. Written informed consent was obtained from patients prior to participation in the study.

Patients who attended a weekly Pain Clinic routinely completed the BPI on arrival in the clinic. During the duration of the study, they were then asked to complete the BPI a second time, this time completing it for pain and interference levels that they considered would be acceptable and enable them to function at normal to near-normal levels. Finally, they were then asked to complete the BPI once more, this time giving levels of pain and interference that they would hope to achieve from their attendance at the Pain Clinic.

Results

Demographic data was not collected specifically for the study subjects. Data from the PACS for patients attending this clinic showed that for the standard clinic used over the time course of the study, 60% of patients had had pain for over 2 years, 60% were female and 40% male. The main diagnostic groupings were low back pain (32%), other musculoskeletal pains (19%) including neck pain (8%), neuropathic pain (16%), and face pain and headache (5%).

Ninety-nine patients participated in the study. After enrolling the first 25 patients, the survey instructions, originally on a separate sheet of paper, were incorporated into the questionnaires to make them easier to follow. The wording itself was not altered. The Local Research Ethics Committee approved this change.

The scores for the levels of pain and its interference with aspects of life and activity that patients considered commensurate with normal or near-normal life, and the levels they hoped to achieve following treatment in the clinic are displayed in Table 1.

Thirty-five of the patients were new patients. The pain scores for the new patients were higher than those of the follow-up patients, with their worst pain scoring on average 8.23 compared to 6.92, and their average pain 6.74 compared to 5.46.

The BPI scores at presentation in the Pain Clinic for the 35 new patients' existing pain, and their scores for the levels they considered commensurate with normal or near-normal life, and wished for after treatment are displayed in Table 2, together with percentage difference from actual levels.

Discussion

The levels of pain and its interference with various aspects of life that would be tolerable and commensurate with normal function, and also hoped for after treatment, have been presented from this Pain Clinic sample of 99 patients.

These patients considered they could function normally or nearly normally with their worst pain scoring on average 5.5 out of 10, and with their average pain at 4.62. They hoped for their worst pain to reduce after treatment to 4.58 and their average pain to 3.87. Considering the New Patient actual scores on assessment, the percentage reduction to levels commensurate with normal or near-normal functioning was 36.81% for their worst pain and 34.75% for their average pain. They hoped for reductions after treatment of 44.14% for worst pain and 42.8% for average pain. These results suggest that the research tool gold standard 50% improvement in VAS for pain is a more demanding outcome than that looked for by patients.⁴ These results support the satisfaction of 80% of patients with a third obtaining 30% reduction in pain scores in the PACS.

Patients tend to avoid the lower half of the scale when scoring their pain, thus Numerical Rating Scales (NRS) and Visual Analogue Scales may be more logarithmic than linear.⁵⁻⁷ Percentage changes in visual analogue or numerical rating scales therefore seem totally irrelevant to assessing outcomes

Table 1. Averaged Brief Pain Inventory scores for 99 Pain Clinic patients, completed with levels they considered commensurate with normal or near-normal functioning, and also for levels they hoped for after treatment.

Brief Pain Inventory scores averaged from 99 Pain Clinic patients		Commensurate with normal/ near-normal function	Hoped for after treatment
Pain scores (averaged)	Pain at its worst	5.5	4.58
	Pain on average	4.62	3.87
Interference factors (averaged)	General activity	4.96	4.01
	Mood	4.51	3.66
	Walking ability	4.53	3.78
	Normal work	4.91	3.73
	Relationships with other people	4.35	3.49
	Sleep	4.16	3.34
	Enjoyment of life	4.59	3.74
	Average of all interference scores	4.57	3.68

Table 2. New patients' actual numerical rating scores for pain and for interference with aspects of life and activity, compared with the levels they considered acceptable for normal function, and levels hoped for from treatment (percentage reduction to achieve these levels shown in brackets).

		Actual scores	Acceptable (% reduction)	Levels hoped for after treatment (% reduction)
Pain scores (averaged)	Pain at its worst	8.23	5.2 (36.81)	4.51 (44.14)
	Pain on average	6.92	4.4 (34.75)	3.86 (42.8)
Interference factors	General activity	7.43	4.97 (33.08)	4.06 (45.38)
	Mood	6.31	4.46 (29.41)	3.86 (38.91)
	Walking	6.77	4.74 (29.96)	4.17 (45.38)
	Normal work	7.29	4.51 (38.04)	3.6 (50.59)
	Relationships	5.71	4.6 (19.5)	3.71 (35)
	Sleep	7.29	3.83 (47.45)	3.14 (56.86)
	Enjoyment of life	7.2	4.51 (37.3)	3.63 (49.6)
	Overall average scores	6.86	4.52 (34.11)	3.74 (45.48)

of pain treatments. The assessment of pain relief in percentage terms does not acknowledge the studies examining the impact of different severities of pain on patient function in both cancer pain and diabetic peripheral neuropathic pain, neither does it reflect self-reported improvements by patients to small changes in pain intensity. There was little correlation between percentage improvements in NRS pain scores with patients' perception of percentage improvement.⁸ A clinical improvement with a 2-point reduction in pain score⁹ has been used as an outcome measure, but does not take account of the original pain level, or whether the improvement is sufficient for a patient to live normally with their pain. Pain verbal descriptors can be related

to numerical pain rating scales, with mild pain rating 0–3, moderate pain 4–6 (mid-range of NRS) and severe pain 7–10.¹⁰ The mid-range of pain analogue or numerical rating scales (NRS) represents a critical level of pain, below which patients have little disability, but above which there is impairment of functional status and an impact on disability.¹¹ Our patients considered they could function normally, and would be satisfied with treatment, if their pain levels were brought down to mid-range or moderate levels or lower.

The new patients in our study had an average worst pain score of 8.23 (severe pain), with their average pain score 6.74,

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at the upper limit of moderate pain. They considered they would be able to cope if their pain scores came down to 5.2 and 4.4, respectively, that is, in the moderate range. They hoped that treatment would reduce their pain levels to 4.51 for worst pain and 3.86 for average pain, such that their worst pain would be of a moderate level, and their average pain just within the mild range. This suggests that a pain level of 7 (severe) or more does represent a real problem to patients and is a level they seek help at. Our findings suggest that levels below 7 may generally be coped with.

Patients may regard the NRS for the various factors interfering with life and activities in a similar way to pain scales. Our new patients were looking for an improvement in their overall interference scores of 34.11% to be able to cope and were hoping for improvements of 45.48% after treatment. Their interference scores at assessment in clinic averaged 6.86, at the upper limit of moderate interference if considered in the same way as the pain scores, and they felt they would cope if these were reduced to 4.52 (lower moderate levels of interference) and hoped for post-treatment reduction in interference to 3.74 (mild levels of interference). General activity was worst affected, with an initial score of 7.43, and 4.97 considered a level at which to be able to cope and live normally, and 4.06 hoped for after treatment. This represents reductions from severe to moderate scores to be able to function normally and also hoped for after treatment. In percentage terms, this represents a reduction of 33% and 45%, respectively.

The data presented does suggest that the most important improvements patients wish to see are reductions in pain intensity from severe to at least moderate levels. Clearly, these results are from a small Pain Clinic population, and the results cannot therefore be generalised to the total Pain Clinic population. However, this small study does raise interesting results that could be valuable in future considerations for clinical research and audit, and when assessing patients in Pain Clinics. The BPI, like other visual analogue and numerical rating scales, is most appropriately used for assessing change in the condition of patients. We have used it in a novel way to consider what change patients perceived they would require in relation to their BPI scores to be able to cope and function with their pain conditions and also would like to see after treatment.

The perceived pain levels that patients consider they can cope with and lead a normal life, and would like to achieve after treatment, would seem a sensible approach to use at initial pain assessment, and would enable a more realistic assessment of success from Pain Clinic treatment and to

inform treatment goals. This approach has already shown value in relation to the Canadian Occupational Performance Measure.¹² We found that our patients attend clinic in severe pain, but considered that they could function normally and be satisfied with treatment with moderate pain levels. To evaluate improvement in terms of percentage change in pain or other visual analogue or numerical rating scales takes no cognisance as to how these scales are viewed and completed by patients, making these scales align more with logarithmic than linear scales. To assess outcomes of treatment in relation to a more patient-oriented approach to pain outcome targets would be far more relevant in a clinical, and possibly also in a research environment. All scientific instruments rely on calibration. Using patient-oriented anchors, guided either by at least a general assessment as achieved by this study or using a more time-consuming specific patient-tailored assessment, gives a more accurate assessment by which to measure success. Generally, our patients did not feel they required a 50% reduction in their NRS for pain to function normally or were looking for this from treatment. Is it time to accept that a 50% improvement in pain is unnecessarily rigorous as an outcome measure?

Conclusion

The standard outcome measure of 50% improvement in pain score has severe shortcomings relating to percentage change in scores of non-linear pain scales. Patient satisfaction assessments have proved beneficial, but using the BPI our patients considered they would cope and function normally if their pain was reduced from severe levels to moderate levels. Similar post-treatment reductions were also desired. All scientific instruments require some form of calibration. These results help to guide that calibration and give more realistic goals for treatment. These patients were not looking for 50% reductions in pain. This 'gold standard' is now surely tarnished and may not be appropriate for assessing outcomes of pain treatment. Setting targets at first assessment allows treatment success to be evaluated against their achievement. This approach would also help in enabling appropriate expectations for the pain team as well as for the patients.

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The BPS SIG for Philosophy and Ethics – a potted history

Peter Wemyss-Gorman *Retired Consultant in Pain Medicine*



The cancelled 2021 meeting of the SIG should have been the 20th anniversary of our first in 2001

Background

When I decided to try to set up a pain clinic in Haywards Heath in the mid-1970s, I was riding the crest of a wave. Although John Bonica had been the first to recognise the need for treating pain as a medical problem in itself rather than as the by-product of disease more than 30 years earlier and had published his seminal work *The Management of Pain* in 1953, and had set up the first multidisciplinary pain clinic in Seattle in 1960, pain medicine as a speciality had been slow to take off. At the first meeting of the Intractable Pain Society of Great Britain and Ireland in 1967, there were only 17 doctors, virtually all the people in the United Kingdom working in this field. But the ensuing 10 years saw a veritable explosion not only in the number of pain specialists and clinics and in the number of treatments available but also in clinical and basic research which seemed to promise an exciting future where the curse of chronic pain would be banished forever.

But it did not take long for my starry-eyed optimism that we would be curing lots of people to be deflated. At first, I attributed my failure to reproduce other people's published results to my lack of technical skill, but it soon became apparent that I was not alone. My experience in the ensuing years of trying to build a comprehensive pain service in which intervention played

an important but not necessarily central role never left me in any doubt that what I was trying to do was supremely worthwhile, but nevertheless, I had to come to terms with my frequent failure to fulfil my and my patients' expectations.

All of us in the pain business have had to experience the disappointment of being unable to help our patients in the way we expected but the subject never seemed to be addressed in conventional clinical and scientific meetings.

At the Vienna Congress of the International Association for the Study of Pain (IASP) in 1999, we had been, as always on these occasions, bombarded with science and the message from the multimillion-dollar drug industry that no effort or expense could ever be spared in the battle to defeat pain. A colleague and I were discussing the relatively little obvious relevance of much of what we had been hearing to the everyday realities of dealing with distressed human beings in the pain clinic. We recalled how we had first met some 20 years previously at a conference convened by the late Keith Budd and designed to bring 'pain' and 'hospice' doctors together, in the tranquil surroundings of Scargill House in the heart of the Yorkshire Dales. It occurred to us that it might be useful to try to arrange some sort of meeting there to reflect on what we were trying to achieve and should be realistically expecting to achieve, and how to accept and cope with our relative impotence in the face of so much unrelieved pain.

And so in the summer of 2001, a group of doctors, nurses, psychologists and others working with people in pain got together at Scargill House to tackle some of these questions – not perhaps expecting to find answers but at least to share some of our perplexities and anxieties. This conference, entitled 'The Inevitability of Pain?' was intended as a 'one-off', but the need for a forum for further discussion about such things became immediately apparent and has resulted in a series of annual gatherings.

Style and format of the meetings

This was copied from the pattern Keith Budd had established for the meetings alluded to above and designed to maximise

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participation by the audience, and the remit of speakers is to stimulate rather than to inform the debate which, both in full session and informal conversation, takes up a major proportion of the time. The meetings last two and a half days. Our days start before breakfast with a session of tai chi or yoga in the garden (one of the most memorable was in the pouring rain on the bridge overlooking the waterfall at Rydal Hall) and more recently, for the hardy among us, with wild swimming.

The mornings are spent in hour-long sessions. The speaker introduces the subject for the first 30 minutes or so and the rest is devoted to debate, which is often lively and stimulating but in such an atmosphere that even the shyest and least articulate among us feel confident to participate. Discussion carries on over coffee and lunch, after which we have a 2- or 3-hour break for recreation. For the younger and more energetic, this usually involves walking in the surrounding countryside, where the conversations continue and indeed are sometimes the most important and memorable parts of the meetings. Then after tea, we meet again for another formal session before dinner. After dinner, we usually repair to the pub down the road where the excellent local beers lubricate the continuing debate!

Although we have been addressed by many distinguished speakers from the realms of philosophy, ethics and theology as well as medicine, including two former presidents of IASP and two former presidents of the Royal College of General Practitioners (RCGP), some of the most memorable contributions have been from 'ordinary' members of the group speaking out of their experience and reflection on the rewards, frustrations and dilemmas of the practice of pain medicine.

The venues

The venues, retreat centres in the Yorkshire Dales, Leicestershire and the Lake District, are in areas of famed natural beauty and provide an atmosphere particularly conducive to contemplation and reflection, and to the physical and spiritual recreation so much needed by people wearied by their daily work with human pain and distress.

Scargill House is in Wharfedale near the village of Kettlewell (the location used in the film of *Calendar Girls*.)

It is run as a conference centre by a Christian community and hosts both religious and lay meetings. The accommodation is fairly basic, but this is more than compensated by its situation and its extraordinary atmosphere of tranquillity. You could hear the birds singing and see the background from the conference room, and it was tempting sometimes to allow



one's attention to wander! Scargill House closed in 2008 but although it has since reopened, we have not been back.

Launde Abbey in Leicestershire is an Elizabethan mansion (mentioned in Hilary Mantel's 'Cromwell' series) which was adopted as a diocesan retreat house in 1957.



It also hosts lay conferences as well as religious retreats. It is very comfortable, and the food is excellent. It has its own beautiful grounds and gardens, and the surrounding countryside of rolling hills, woods and pastures is ideal for walking.

For the first few years, we alternated between Launde Abbey and Scargill House, but when the latter closed, we were fortunate to find a new home in Rydal Hall near Ambleside in the Lake District, with the most spectacular views and loveliest surroundings for walking of all our venues. Although primarily a Christian retreat, it too hosts lay conferences and has become our regular venue.

The conferences: 2002–2019

The first few meetings were independent of the BPS, but the core group was recognised in 2004 as the British Pain Society

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Rydal Hall with Nab Scar as a backdrop and Rydal Water on the left (Rydal, Lake District). With kind permission of Rydal Hall.

Special Interest Group for Philosophy and Ethics. We had some difficulty in deciding on a title: we feared that this might give the impression that our deliberations are somewhat ‘cerebral’ and divorced from the realities of everyday clinical practice. But although we have greatly benefitted from the guidance of philosophers, theologians and ethicists, the participants are mostly those whose daily work is essentially clinical and practical, and whose first priority is to try to relieve pain. But as well as the limitations of our ability to achieve this, there are many ethical and other dilemmas involved in the practice of pain medicine which give rise to uncertainty and anxiety. These meetings have provided a unique opportunity to share doubts and problems and to learn from the insights of colleagues.

Our talks and discussions have all been recorded and transcribed and were published as booklets until escalating printing costs obliged us to abandon this, but the transcripts are all available as downloads from our BPS web page: <https://www.britishpainsociety.org/philosophy-ethics-special-interest-group/>

What follows is a brief and necessarily inadequate overview of the many and diverse topics we have covered which will I hope encourage readers to explore the manifold riches of wisdom and insight to be found in the transcripts. I have been re-reading some of them in the preparation of this article and have been repeatedly struck by their quality and value.

At our first meeting at Scargill House, we covered a miscellany of subjects, including The Tao of Pain; questioning the role of scientific reductionism and dualism in understanding pain; the implications of theories of consciousness for treating chronic pain; the need for clinicians to candidly accept their own therapeutic failure if they are to guide patients on the road to acceptance of their pain; stress in pain practitioners; iatrogenic pain resulting from the perceived imperative to provide biomedical diagnostic labels; theology and pain; and

the search for meaning in suffering – all topics we returned to many times over the years.

We seemed often to have succeeded only in raising more questions rather than finding answers, so we decided to have a second meeting the following year at Launde Abbey to attempt to build bridges between the apparently irreconcilable paradoxes we had identified, such as the necessity of accepting that much suffering is inevitable against our duty to try to prevent or relieve it. Of the other topics we covered at that meeting, such as the use of art and poetry to help patients to cross the bridge of communication between us, my most vivid memory was psychotherapist Kate Maguire’s account of her work with the victims of torture.

Our next few meetings were more focussed on such themes as Dilemmas in Pain Medicine, including the place of interventions of unprovable benefit in comprehensive pain management, managing the demanding and manipulative patient and animal experimentation in pain research and the 2004 Montreal Declaration of Pain Relief as a Human Right.

The search for meaning in suffering, which seems to have no protective function and robs us of any choice other than to accept it, remained a recurrent theme. At our 2006 meeting, we first encountered the concept of healing, of restoration to health and wholeness, which includes but is so much more than the relief of physical pain, and which we can still aspire to even when this fails.

We had touched on religion and theology in many of our previous meetings, but the 2007 programme was mainly devoted to exploration of the contributions of the major world religions to finding meaning in pain and bridging the apparently unbridgeable chasm between the concept of an omnipotent loving God and the existence of suffering in the world. As well as a formidable intellectual challenge this is a matter of great practical importance, as countless millions throughout history have found solace and comfort in their faith and the courage to go on in the darkness.

The following year, we endeavoured to investigate the ways in which science could help to answer such questions as ‘Why do we suffer?’ It seemed possible that chronic pain and suffering, although they had long outlived any protective adaptation, were the inevitable consequence of the evolution of such a complex brain as ours and the ‘higher’ consciousness which ‘lower’ animals seem not to share. In the face of such an enigma, it was perhaps appropriate that we concluded with a moving illustration of the contention that we need poetry and stories to help us understand the mystery of suffering.

In 2009, we tackled one of the most difficult of all ethical questions facing health professionals: that of Justifiable Deceit. Trust has always been seen as an essential component of the doctor–patient relationship, and lack of honesty on the part of the doctor is a betrayal of that trust. But the unvarnished truth may cause the patient unnecessary distress. The biomedical model is a very inadequate medium for arriving at truth in such a complex area as that of human suffering and healing. Pain medicine involves treatments for which there is probably inadequate evidence of efficacy from gold-standard randomised controlled trials (RCTs) and may to some extent depend on the placebo response. Enhancing this or avoiding a nocebo response may involve some departure from ruthless honesty. Is this wrong?

Culture is among the many factors which influence the conscious perception and tolerance – and intolerance – of pain. The implications of this neglected topic, for instance in the assessment and treatment of pain by health professionals caring for people from a different ethnic group than their own, and the acceptability of unrelieved pain in societies with inadequate medical resources, preoccupied our minds for the 2010 meeting.

We returned to ethics for our themes for the next 2 years, in particular two branches: virtue ethics and the ethics of care. Virtue ethics emphasises the role of character and virtue in moral philosophy over doing one's duty, or acting to bring about good consequences. It became apparent that in many ways the ideas it embodies have underpinned much of our discourse over the years, and indeed in the ethos of the group. Many of us felt that what we have learnt from our speakers and each other has helped to shape what we are as human beings and in our practice of pain medicine. The ethics of care are essentially relational; they carry an imperative to act in response to another's needs. Our attitudes to our work and our patients must be underpinned by awareness of the need for care. The many failings of the health and healing professions in recent times could be attributed to loss of an ethos of care – not because their practitioners are essentially uncaring but because of the many financial, organisational and other pressures that impose other priorities.

In 2013, we tasked ourselves with identifying the culture of pain medicine and its progressive deterioration, examining the influences that have threatened it, such as the insurance industry in the United States and the increasing dominance of a profit-driven business model in the National Health Service (NHS). We were guided in this by John Loeser, one of the pioneers of our profession who as co-founder of the IASP was uniquely placed to command an overview of pain management

throughout the world, and who identified education as a vital contributor to the process of bringing about the needed change.

We resolved as a group to evangelise the case for a more effectively integrated approach to the multidisciplinary management of chronic pain and prioritisation of the needs of the patient over the interests of the profession and all other managerial, financial and political considerations. To what extent we have been successful in this is a matter of doubt but we are encouraged by the words of Margaret Mead:

Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.

We pursued this vision the following year, when the title was 'Compassion in Modern Healthcare: a Community of Care'. We had for long tended to diverge from pain into the ethical problems facing the whole of medicine and healthcare. One theme in particular has dominated our discussions: reconciliation of the demand for effective science-driven medicine with recognition of the total needs of individual suffering human beings. Two words had come up time and time again: care and compassion. So our ambition was no less than the restoration of compassion to the culture of all healthcare.

Our title for the 2015 meeting was 'The Tyranny of Diagnosis'. Pain practitioners are accustomed to seeing many patients either without a diagnostic label or because the label they have acquired has set them on a fixed but futile therapeutic pathway. But the experience of illness is of more importance than any disease label. The lack of any convincing explanation for their pain can add immeasurably to patients' distress and perception of not being believed or listened to. But we can try to overthrow the tyranny of diagnosis, not by abandoning it, but by recognising that we need many levels of diagnosis to explain the experience of illness, from the biomedical through the psychological and social to the spiritual, all requiring attention to the patient's narrative.

We seem to have spent much of our discourse over the years lamenting the shortcomings of biomedicine without finding a route out of the impasse of impotence so it was refreshing at our 2016 meeting to explore a new approach that holds a glimmer of hope, or at least promises to point us in a new direction: The Power of the Mind in Pain. There appears to be a far bigger untapped resource of power for healing, and dealing with pain and suffering, within our own minds than we

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have hitherto realised or even imagined. It seems that this power is latent both in ourselves and in our patients, even those who most make our hearts sink, and can be manifested in the interaction between us in the therapeutic encounter. It even seems possible that it can operate at a distance! Our speakers presented evidence that the most hardened sceptic would find difficult to ignore, leaving us with renewed optimism that even if we may still have a huge mountain to climb, we may have found one promising route.

The thread of healing continued to run through our following year's meeting when our topic was Living Well Right to the End of life: maximising wellbeing in the face of terminal disease, living with the uncertainty of cancer and the unpredictable response to treatment, and intractable symptoms such as pain and breathlessness. We talked about the need for acceptance rather than 'fighting' the inevitable, and for maintaining meaning and purpose even when hope seems elusive. We identified the roles of mindfulness, meditation and hypnotherapy and creative approaches such as music therapy.

In 2018, we covered two topics: first, the inadequacy of language for patients to express their suffering, and the potential for our words as clinicians either to set a person down a path of fear and catastrophisation or to start them on a journey to wellness and recovery. Our second subject was that of Burnout: the vortex of problems resulting from escalating demands with diminishing resources, aggravated by the failure of the traditional system of mutual support among health professionals, and of which sleep deprivation and insomnia is a frequent component.

It was evident from our discussions that many of us were aware of the effects of the language we use to ourselves, which is often critical and unforgiving when we ruminate about our perceived inadequacies in providing care. There is an evident need for us to talk to ourselves in language which is self-loving and forgiving.

Our last meeting to date in 2019 explored a variety of themes ranging from the link between childhood trauma and chronic pain to the future of pain medicine and caring for the clinician as well as the patient. A welcome departure from our past tradition was that two of our speakers were general practitioners, reflecting the neglected reality that the great majority of chronic pain sufferers, and indeed all of them for most of the time, are cared for by their general practitioners (GPs). Topics included integrating the art of healing and the science of medicine, the challenge of providing a truly holistic pain service in a large complex department and facing the reality that almost everything we think we know about pain is probably wrong!

The future of the SIG and Pain Medicine

So what of the future? As I write in the summer of 2021, we are approaching the hoped-for end of the pandemic with some uncertainty and trepidation. So it is difficult to visualise where the SIG is going to go in the coming year, but there are grounds for optimism. Our residential meetings in 2020 and 2021 have been abandoned, and there is still some uncertainty even about our plans for next year, so we have organised a series of monthly Zoomed webinars. The response to these, which have been fully booked, has been very gratifying. The attendance at our summer meetings has been dwindling in recent years, but we now have ample evidence for our conclusion that this has been due to the escalating cost rather than any lack of interest.

We have covered a variety of topics including the management of pain in primary care, critical appraisal of self-management, trauma informed care and the importance of work and meaningful occupation, or lack of it, both in the causation of chronic pain and recovery from its consequences. But the two most significant insights we have gained have been, first, that Adverse Childhood Experiences are more nearly universal features in the background of chronic pain patients than most of us had realised, and second, recognition of the association of poverty, inequality and deprivation not only with chronic pain and illness but also with abuse of the medication prescribed for it.

Transcripts of the webinars are to be found in the web page of the BPS SIG for Philosophy and Ethics.

Although our emphasis on acceptance of the intractable nature of chronic pain may have given the impression that as a group we would advocate abandonment of the search for better biomedicine, this would be quite mistaken. It would be true, however, that the perception has emerged from many of our discussions that chronic pain has often been over-medicalised to the detriment of attention to the psychological, social and spiritual needs of our patients. For many of them, this must be the first priority, not something to fall back on when biomedical intervention has failed.

Being long retired from clinical practice, my impressions are mainly gleaned from what my friends in the Philosophy and Ethics SIG tell me, rather than firsthand experience, and I hope that the picture is not as dark as it may appear, but it does seem to me that pain medicine has been on a downwards slope in recent years, at a time when it has never been more necessary. Membership of the BPS has been falling, and only the valiant efforts of the current leadership have saved it from suffering the same financial fate as the American Pain Society. Recruitment to the specialty has

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sometimes been problematic, perhaps as a consequence of the realisation that the crest has long broken of the wave of optimism that we could one day cure most chronic pain, and the relative attraction of specialties which present more tangible rewards for *doing* things. So there is a great need to present the less obvious rewards of pain medicine in the education of students and trainees.

The way forward must include recognition that we doctors will have to learn to work better in partnership, both with our colleagues in allied professions and with our patients in helping them to manage their pain within a less paternalistic relationship. We must also acknowledge that the main burden of caring for pain patients in the long term must lie in General Practice, and work for better communication and cooperation between colleagues in primary and specialist care.

Interventional practice has been severely delayed by the Covid epidemic and restricted by the National Institute for Health and Care Excellence (NICE) recommendations, and this will have obliged people to think long and hard 'out of the box' as to what they can offer instead.

The Philosophy and Ethics SIG will continue to offer ever more needed opportunities to face these and many other problems in a hopeful and constructive way, and try to provide inspiring alternatives to pessimism and impotence.

We have published two books of essays by former speakers at our annual meetings: *Pain. Suffering and Healing, insights and understandings* P.B. Wemyss-Gorman (ed.) Radcliffe Publishing 2011, and *Innovative Approaches to Chronic Pain, understanding the experience of pain and suffering and the role of healing*, P.B. Wemyss-Gorman (ed.) Jessica Kingsley Publishers 2021.

A new pain management programme designed for sustainable self-management

Joe Parsons and Chris Bridgeford



Joe:

For the past 8 years, I have suffered with chronic back and neck pain, and after seeing more than 30 different medical professionals, there is still a great deal of uncertainty about the cause of my pain. Scoliosis, Scheuermann's disease, ankylosing spondylitis, Marfan's syndrome and Ehlers-Danlos syndrome have all been suspected or diagnosed as well as several suggestions of growing pains and one suggestion of fabrication. Searching for a diagnosis felt so important to me. Every time scans would return clear I would be faced with the same dilemma that faces so many chronic pain sufferers: why am I devastated that nothing is wrong with me?

All that I have sought for so many years is to feel that my pain is validated, that I can put a name to it and that I can finally use it to help explain the way I feel to those around me. The lack of diagnosis left me with an inability to explain the pain to others so I set about writing a book with the hope of explaining what life is like for a chronic pain sufferer. I have interviewed tens of chronic pain sufferers to try and give a more representative view of life in constant pain.

However, every individual to whom I spoke inspired me to write a new section. One inspired me to write about the

specialists one might expect to see as a chronic pain sufferer and to detail the examinations and treatments one might receive, to make referrals less intimidating. One inspired me to write advice of how loved ones of those with chronic pain can provide constructive support. One inspired me to write about the biology of chronic pain and the mechanisms behind different analgesics and anti-inflammatories. Currently I am 150 pages in and have so much more to write and I hope that in a few years I will be able to share the book with the general public to raise awareness of all things chronic pain.

During the process of writing this book, I had the privilege to meet and interview Chris Bridgeford regarding his experiences of chronic pain. Chris however is no ordinary chronic pain sufferer (not that there could ever be such a thing); he runs a chronic pain support group and charity in Scotland called Affa Sair (or 'Awfully Sore' in Scots) which provides emotional support and education to chronic pain sufferers. Chris spoke of negative experiences that he had in pain clinics, of frustrations that he shared with clinicians about the lack of access to necessary resources such as psychological support and advice about benefits applications for those disabled by their pain. Having been under the care of two pain clinics myself here in the United Kingdom, I had similar sentiments and I set about researching pain clinics across the United Kingdom to determine the services that are available. Some provide extensive physical, psychological and occupational support, while others cannot access enough funding to provide anything outside of guided mindfulness and a couple of group exercise sessions. A postcode lottery is an understatement. Among clinicians I interviewed for my book, those who specialise in pain management agreed on the best centres in the country consistently and admitted that services were lacking in so many areas.

Given the issues with existing pain management, I toyed with the idea of developing a pain management programme but thought better of it. My thought process following the pattern 'I am a PhD student, I don't have the time. I am not a doctor, I don't have the expertise'.

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These excuses disappeared when the new National Institute for Health and Care Excellence (NICE) guidelines were announced in August 2020. Patients are to be encouraged to self-manage and will be pushed away from pain services. So I set about asking myself 'What is self-management?' and where can I get support for this. After reading hundreds of articles from patient voice to the International Association for the Study of Pain (IASP), I realised that self-management is two things:

- A beautiful concept;
- An empty statement.

Self-management has the potential to allow patients to take control of their lives if supported correctly; however, the support available to patients is found fragmented across tens of different websites and is often buried pages-deep into Google search results (where realistically no one is looking past page 1). Even if patients are able to trawl through and find all that is available, it is still insufficient to support the complex array of patient needs that come under the umbrella of pain management.

So I began making a list based on my own experience and the experience of those I had interviewed. What support do you want in your daily life? Physical therapy, psychological support, benefits and welfare advice, dietetic advice, education on drug mechanisms and side effects, relationship advice, coping techniques, guided mindfulness and so many more came out. That same day, I began writing an outline of an ideal pain management programme and contacted Chris to ask if he would like to be involved. Chris agreed and has subsequently become a dear friend and a great mentor. Over the past 6 months, we have developed a pain management programme that we propose to be standardised across the United Kingdom. Even more importantly, the programme would be delivered in a secondary setting so that patients can learn vital self-management skills without needing a firm diagnosis of the cause. I wasted 8 years of my life hoping someone would help teach me to manage my pain, and we hope that this will not be an issue faced by chronic pain sufferers again. There is no reason for patients to have to wait for a firm diagnosis before they learn to manage their pain. Maybe if patients learned earlier, their dependence on National Health Service (NHS) services would be reduced, which is the ideal situation for the patient, clinician and finance department.

A Christmas list of clinicians and services however would, understandably, be laughed all the way to the shredder by the NHS as it would not be financially viable within pain services in their current form. Therefore, all aspects of the new programme were costed using NHS Reference Costs (where

possible) and subsequently have gained the support of NHS Future Finance Leadership, though admittedly comparing costs against other programmes precisely is proving challenging as NHS finance departments all run very differently depending on the Trust they are in. However, we are confident our programme will reduce costs compared to existing pain management services.

In addition, a lack of clinical insight is likely to see the proposal veering back towards the shredder; therefore, a team of physiotherapists, psychologists, pharmacists, dieticians, rheumatologists, pain consultants, occupational therapists, benefits and work advisors and chronic pain sufferers has been assembled to advise on the programme and to ensure that the programme provides the best possible support to patients. We hope this programme will allow self-management to move from being a term associated with abandonment to one associated with empowerment.

Despite our extensive team of advisors, more guidance is always welcomed from clinicians and pain patients like those associated with the British Pain Society and thus any comments that you would like to make regarding the programme, we would be very grateful to hear, so please send them to joseph.parsons@postgrad.manchester.ac.uk



Chris:

I'm nearly two generations apart from Joe, so it is a disappointment that his experiences of trying to get help from the NHS for a chronic pain condition are so similar to mine. We both share experiences of disbelief (though consultants are generally far more open than they were in the 70s, and actually speak to the patient at the bedside these days), hours of painful prodding and poking asking if it hurts while you openly

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swear and cry a lot, exploratory deep digging expeditions for unexplained reasons (possibly training opportunities for junior doctors) and endless diagnoses. One main difference is medication. In my day more and more new powerful pills were handed out, these days they are taken away whether they actually work for the individual or not.

One of the most concerning problems for me is what the Scottish Government is proposing for the 1.09 million pain sufferers in Scotland – the move to self-managing their conditions. Although the Scottish NHS has saved my life more than once, they have had very little effect on my chronic pain condition, so I quite welcome the idea of self-management as long as I do not have to pay for such treatments like a private patient. So, although self-management is the current mantra from Scottish Government advisors and politicians, they do not say how the patient is going to be able to access such treatments. It looks like they see the move to self-management as a way of cutting the cost of dealing with chronic pain to the Scottish NHS and landing the sufferers with the full cost of their own (often private) treatment.

Joe and I came across each other when he approached the Aberdeen Pain Clinic when he started writing his book, and they in turn passed his request to me as Chairman of 'Affa Sair'. I do so love it when the universe makes connections.

So here we are, two people generations apart and also,

- One an Englishman,
- One a proud independence-seeking Scot.

Yet both of us share a need to fight for the good of chronic pain patients wherever they live in the British Isles and beyond.

Parsons-Bridgeford pain management programme

The programme will last approximately 25–30 hours depending on how many of the optional one-to-one sessions patients request, and would likely be completed in 5 hour days over 5–6 weeks with sessions split into approximately 90 minutes each. The session would be delivered to groups of between 5 and 20 and would be available on-demand online for patients registered to the programme to ensure that those who are housebound or happen to be ill at any point during the programme do not miss out.

The programme would be a referral from the primary care setting where general practitioners (GPs) could enable patients to manage their pain while other secondary or tertiary examinations are being undertaken.

Patients will be asked which aspect of the programme's one-to-one support they feel is most essential to their self-management and their programme will begin with this. Not only does this help patients address their most important needs but it also ensures that patients feel autonomy and feel able to guide their own treatment. Pain management programmes are plagued by drop-outs, and thus, we feel that this choice is more likely to engage patients in the programme.

All sessions will also benefit from additional materials on a centralised chronic pain website which will be explained in the sections below.

The programme will comprise the following sessions:

Physiotherapy

Patients will receive 1 hour of one-to-one physiotherapy support to help develop an exercise regime within their capabilities that can be scaled up or down depending on how the patient feels on any particular day. This will reduce patient dependence on physiotherapy support from within the NHS and will enable better physical self-management.

A bank of hundreds of physiotherapy exercise PDFs and videos will be available on the centralised chronic pain website with explanation of their biological effects, how to scale them and who should/should not do them. With this patients will be able to choose to further their rehabilitation and even look for additional ways to improve their fitness.

Psychotherapy

Patients will receive a 2-hour individual psychotherapy session to identify those who may have large psychosomatic aspects of their pain and those who are at risk of mental comorbidities such as depression and post-traumatic stress disorder. This will help to inform clinicians of which patients could benefit from long-term psychological support. This session aims to reduce costs of mental health referrals by identifying patients who can benefit from support and treating them promptly, rather than waiting for much larger issues to arise. In addition, with the crucial role of psychology in pain presentation, this session will be important for improving patients' attitudes towards their pain, which frequently couples with subjective improvement in symptoms and quality-of-life.

A key point regarding this session is that patients will receive educational material in advance of the programme that will also be available on the centralised website, to better explain that psychology does have enormous impacts on pain and that psychotherapy is not a suggestion that it is 'all in your head'.

Occupational therapy

A 1-hour individual session with an occupational therapist will be used to discuss methods of improving the workplace environment for individuals to reduce the impact of work on their condition, for those in work. For those hoping to return to work, it will be used to discuss potential appropriate jobs or mechanisms of support by which patients can return to the workforce more easily. For those unable to work, this session will be used to determine how the home environment could be improved to ease symptoms of the patient, including information regarding grants that are available for disability home improvements.

This session aims to help patients feel more comfortable in the workforce or at home and to maintain or regain a greater degree of independence. In addition, enabling chronic pain sufferers to remain in, or return to, the workforce will have positive economic impacts.

Information regarding grants, training and more disability-friendly workplaces will be available on the centralised chronic pain website.

Pharmacy

A 3-hour group session with a pharmacist will be used to discuss the efficacy, mechanism of action and potential side effects of different analgesics, anti-inflammatories and other chronic pain-associated drugs, for example, anti-depressants. This is essential for educating patients that drugs do not provide a guaranteed cure and that certain drugs are not appropriate for certain pain. For example, a patient with Crohn's disease will be negatively affected by the constipating effects of opiate pain relief.

This session will allow patients to identify potential medications that are appropriate for their condition but more importantly it will prevent patients pushing clinicians for prescriptions that are inappropriate to their condition. Not only does this improve patient safety but it also prevents patients from developing negative opinions of clinicians 'denying' them drugs, further increasing the likelihood of patients cooperating with clinicians.

Patients will be able to opt-in to an individual 1-hour session with a pharmacist to discuss their specific medication. This will help patients to understand why previous medications have been unsuccessful, how they can avoid side effects and what medications may be the best choice in future.

Information about the aforementioned mechanisms of action, efficacies and side effects will be available on the centralised chronic pain website.

Dietetics

A 2-hour group session with a dietician will be delivered to help patients understand the role of diet in pain and how it should be used to avoid comorbidities such as diabetes and hypertension. In addition, a number of fad diets and exclusion diets are recommended across the Internet for pain patients, so the dietician will also seek to address the scientific merit in these diets and explain whether or not they are of any benefit, and more importantly, whether or not they are safe.

With the information gained in this session, patients can understand how better to use their diet to manage their condition and they can understand whether any exclusions could be beneficial to them or if any of their previous or current diets need to be stopped as they are likely doing more harm than good.

To supplement this information, videos of cheap, healthy meals will be provided on the centralised website. These meals will range to fit various dietary requirements and exclusions. Videos will also be provided detailing useful kitchen equipment for patients with chronic pain conditions to help allow patients to maintain or regain the capacity to cook comfortably.

Acceptance and commitment therapy

Six hours of psychologist-guided, group ACT will be provided to help patients identify negative thought processes and behaviours and to help them address how they can alter these so their mental state has reduced impact on their physical health. With better acceptance of their condition(s), patients will be able to understand the importance of self-management and may be able to reduce their clinical dependence.

Mindfulness is commonly recommended in the management of chronic pain and proves highly beneficial for some and ineffective for others. However, it is often recommended alongside ACT, and thus, mindfulness exercises guided by several different instructors will be provided on the centralised website so patients can access these resources at all times, not solely within the programme.

Coping techniques

A 3-hour, psychologist-led session discussing coping techniques will be used to discuss coping techniques with scientific backing, for example, breathing techniques, and for patients to discuss their coping mechanisms with one another. This may enlighten patients of better ways to deal with flare-ups and will hopefully reduce the impact of pain on their relationships.

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Breathing exercises and similar coping techniques will be demonstrated and described on the central chronic pain website.

Facilitating passions

A 3-hour session led by patients with 'lived experience', also known as those who have been in pain for a long time who have developed beneficial, healthy self-management practices. In chronic pain, patients often lose their passions; my own condition prevented me from continuing to play basketball which was my greatest passion. However, by now attending more games, I have managed to develop a sense that this passion of mine is still in my life. This is important for patients as maintenance of their passions, in some form, despite potential deterioration of physical state, can be crucial for maintaining a positive mental state.

For patients lacking in passions or hobbies, chronic pain-friendly hobbies will be detailed on the centralised website as well as methods by which the impacts of less friendly hobbies may be reduced, for example, how to reduce the impact of sports on joints with effective warm-ups, joint braces and so on.

Complementary therapies

A 2-hour session will be used to discuss complementary therapies that are not commonly provided by the NHS but that may provide benefit for pain such as acupuncture and chiropractic. The literature-based evidence for these methods will be discussed and how they can be accessed within or outside the NHS will be explained.

Ideally savings from the programme compared to existing programmes will be used to offer small grants to patients so

that they can try therapies such as acupuncture before committing to spending large amounts of their own money on receiving these treatments.

Family and friends session

A 2-hour group session with friends and family of patients within the programme will be used to help better explain the mind-set of patients and how loved ones can provide constructive help.

An optional 1-hour session for individual patients and their loved ones will be available for specific discussions regarding how individual patients can be helped and how problems generated by the patient's condition can be addressed to help maintain healthy relationships.

Extras

Currently, the format of any extra sessions is not complete, but it is likely that optional sessions of chair yoga, sleep hygiene, relaxation techniques, social sessions between patients on the programme and virtual reality methods will be added to the programme. Suggestions of further additional sessions would be greatly welcomed.

It is our hope that this pain management programme will be provided both online and in person by teams of clinicians specific to different areas of the United Kingdom. With this programme, we hope to improve standardisation of care delivered by pain management services and to provide more comprehensive patient support for their self-management. This service will preferably be provided in the secondary care setting so patients are able to learn to manage their condition while other investigations are ongoing, rather than having to wait until a dead-end in their diagnosis or treatment to receive self-management guidance.

Older people the ICD 11 and NICE

Margaret Dunham RN BA (Hons) MSc PhD



Old women 1909 by Gustav Klimt Public Domain

Defining chronic disease and pain in particular, in language that is unambiguous and useful to support the effective recognition and appropriate management of pain, is to be welcomed. Agreeing a definition validates the experience of the many people living with chronic pain that their pain is real not just 'in their heads'.

The World Health Organisation (WHO) has acknowledged that there is a need to establish differential diagnoses to inform care delivery. More recently, the widely anticipated National Institute for Health and Care Excellence (NICE) guidance has focused on one of these, chronic primary pain and that should similarly validate support for people experiencing chronic pain.

Background

The International Classification of Diseases¹ (ICD) as established by the WHO is an internationally recognised approach to the diagnosis, treatment and management of many disorders, including chronic pain. Many health care

providers rely on ICD categories to sanction and fund interventions. The recent introduction of new pain classifications and definitions gives all working in pain management something to consider.

The ICD 11² is the first time the WHO has formally classified chronic pain. The previous International Classification (ICD 10) was limited in its scope for the range of things which equate to an individual's experience of chronic pain and consequently may have stymied an individualised approach to assessment and management. However, the need for a new classification is not in doubt.

The new diagnostic codes for chronic pain were approved by the WHO, within ICD-11 in May 2019, and hailed as having the potential to '... improve patient care by facilitating multimodal pain treatment and by boosting efforts to measure the quality and effectiveness of care and new research on the prevalence and impact of chronic pain' (International Association for the Study of Pain (IASP) press release).³

In 2015, Treede et al.⁴ noted the limited WHO categories for chronic pain; these lacked current epidemiological detail in the range and clinical nature of chronic pain. In 2019, the IASP proposed a new overarching definition of pain, opening up the opportunity for discussion about the meanings and definitions associated with various chronic pain disorders.

The previous 1994 IASP definition of pain was as follows:

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

And this was reworded in 2019 to the following:

An aversive sensory and emotional experience typically caused by, or resembling that caused by, actual or potential tissue injury

and chronic pain given a temporal qualification as

... persistent or recurrent pain lasting longer than 3 months

Older people the ICD 11 and NICE

This new terminology has not come in without criticism. Words have never been able to adequately describe the unique individual experience of pain ... However, many will welcome the development of new wording in pain classifications to aid diagnosis and safe, effective pain management. The classification of diseases according to their clinical and pathological characteristics is, of course, nothing new.

The WHO relies upon currently available epidemiological and research data to evidence classifications. Hence in 2018, the IASP, under the chairmanship of Professor Rolf-Detlef Treede (former President of IASP), was charged with development of the 11th iteration of pain classifications.³

The IASP journal *Pain* has subsequently published 10 review papers promoting the new ICD categories, a narrative review⁵ and 9 further articles detailing the pain components of ICD 11 namely chronic primary pain,⁶ chronic cancer-related pain,⁷ chronic post-surgical/trauma-related pain,⁸ chronic neuropathic pain,⁹ chronic secondary headache or orofacial pain,¹⁰ secondary visceral pain,¹¹ secondary musculoskeletal pain,¹² applicability in primary care¹³ and the functioning properties of chronic pain.¹⁴ The first thing which is apparent is that within the associated codes, subcategories and definitions in each of these papers, age is not noted as a discreet factor.

Treede et al.⁵ note that the lack of appropriate codes has contributed to the limitation of possible treatment pathways for patients with chronic pain. Considering each of the ICD 11 themed papers in more detail, age (physiological or chronological) as a factor is barely considered in the terminology identified by the working party. Nicholas et al.⁶ acknowledge the potential for emotional distress and functional disability associated with chronic primary pain, where chronic pain itself is the disease, yet the examples cited all relate to younger adults (>45 years of age).

In considering chronic cancer-related pain, Bennett et al.⁷ describe the considerable issue of people surviving longer after their cancer diagnosis, experiencing hitherto unacknowledged long-term complications of cancer treatment and survivorship including cancer pain. The case of a 78-year-old woman with pancreatic cancer is offered as an example; however, the complexity of ageing is not noted. Similarly Aziz et al.¹¹ note a case of a 70-year-old with visceral pain and acknowledge some of the potential degenerative contributory factors which are common to visceral abdominal pain.

Brief reference to children's chronic post-surgical pain experience is made by Schug et al.⁸ but again no mention of older adults. Similarly, factors of ageing are not noted in the

papers relating the category of chronic neuropathic pain or musculoskeletal pain.^{9,12} Benoliel et al.¹⁰ relate that age is a factor in the experience of headache and orofacial pain, and Smith et al note increasing age may affect pain in primary care as do Nugraha et al.¹¹ in the consideration of ageing's effects on body function. Hence, age's contribution is generally alluded to throughout these recent *Pain* publications but only in a very limited fashion.

The 2021 NICE¹⁵ guidelines have focused on the management of chronic primary pain, quite a complex and challenging, almost niche, aspect of chronic pain conditions. The reader might not initially realise that the guideline has quite such a narrow focus. Here was a great opportunity to take an holistic approach to a complex concept and many have commented on its limitations.

Conclusion

As the first systematic classification of chronic pain that is also a part of the ICD, this is a very welcome addition but age, and an ageing population, has such huge social and economic implications it warrants inclusion in future iterations. For older people in particular, the paucity of a solid epidemiological and research evidence base for chronic pain definitions and appropriate management is apparent.

Within the framework of classification, there are clearly options to include 'sub categories' and 'extension codes' for other factors such as disability and psychosocial effects so why not the effects of age, multiple co-morbidities and physiological decline?

There is limited evidence for much of the recommendations in the NICE report, and nothing for the older person with chronic primary pain. There is great potential for further research to strengthen the evidence base, and to adopt an inclusive approach that acknowledges chronic pain in all its forms and presentation in all ages.

Sadly, as ever in health care, it is the financial implications rather than the humanitarian ones which are likely to advance the needs of our ageing world population living with chronic pain. Hopefully in the post-pandemic world, research colleagues will work together to consolidate and enhance the evidence base, for supporting the needs of the increasingly aged global population with chronic pain, so that older people can be formally supported in all health care provision.

Twitter: @BPSPainOlder

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Survey of chronic pain patient experience during the COVID pandemic background

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The COVID-19 pandemic has impacted the lives and health of persons worldwide, with potential for further effects in the future. The experience of living within this pandemic has disrupted daily life across all sectors, including those living with chronic pain. The toll of this pandemic extends beyond physical illness, with important psychosocial stressors that include prolonged periods of limited interpersonal contact, isolation, fear of illness, future uncertainty and financial strain. Chronic pain conditions can be triggered by psychosocial stressors. In this context, we have done a survey of 28 chronic pain patients regarding our pain services during the COVID pandemic.

Primary goals

To assess the experience of chronic pain patients during the first wave of the COVID pandemic. This may help us to flex our services to meet the needs of our patients during this time and to ensure our services are modified to optimise safe practice during the pandemic.

We looked at the following domains:

1. Pain intensity
2. Ability to carry out day-to-day activity, mobility and self-care
3. Anxiety and distress
4. Their overall experience with our chronic pain services
5. Their experience about telephone calls and if they think video calls will be beneficial
6. If they received our letter and they know how to contact the chronic pain department when needed.

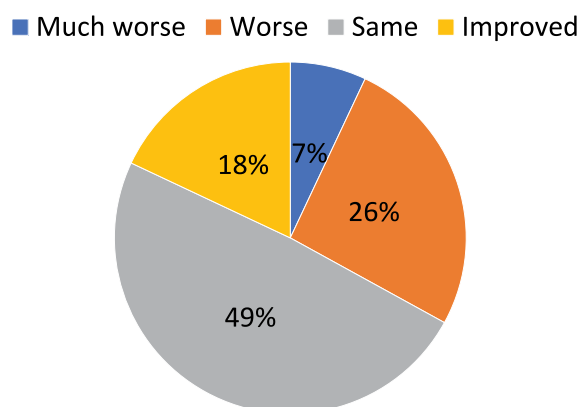
Method

We sent a letter with questionnaire to our patients then collected their responses through a telephone call 2 weeks after posting the letter.

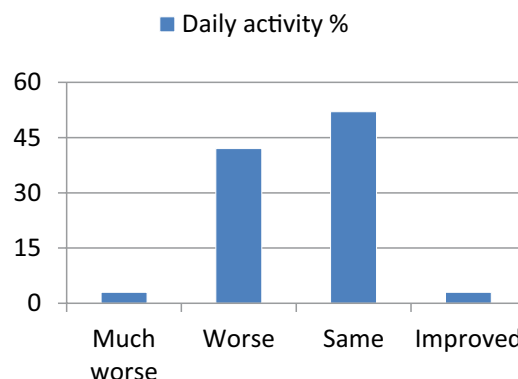
Results

We sent the questionnaire to 40 patients and received 28 complete responses, so the response rate is 70%. The results we got are as follows:

Pain intensity: Much worse 2 (7%), worse 7 (26%), same 13 (49%), improved 5 (18%) and much improved 0%

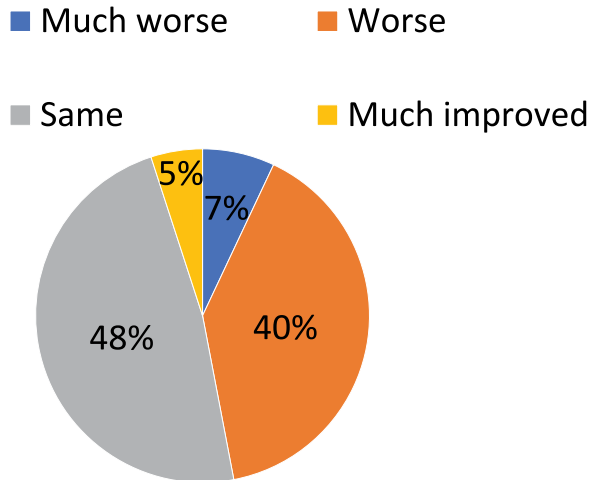


Day-to-day activity: Much worse 1 (3%), worse 11 (42%), same 14 (52%), improved 1 (3%) and much improved 0%

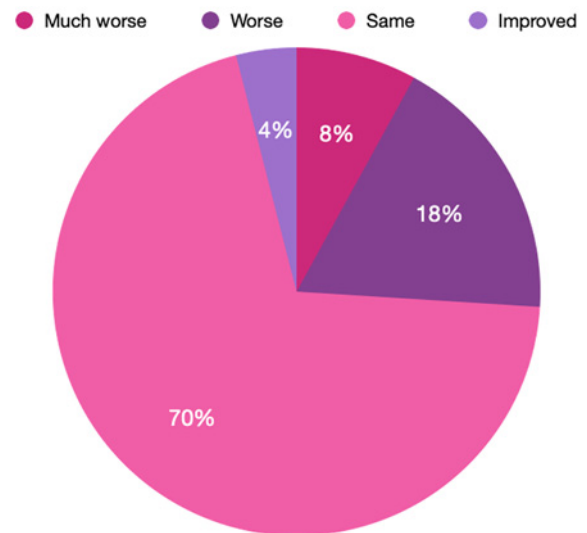


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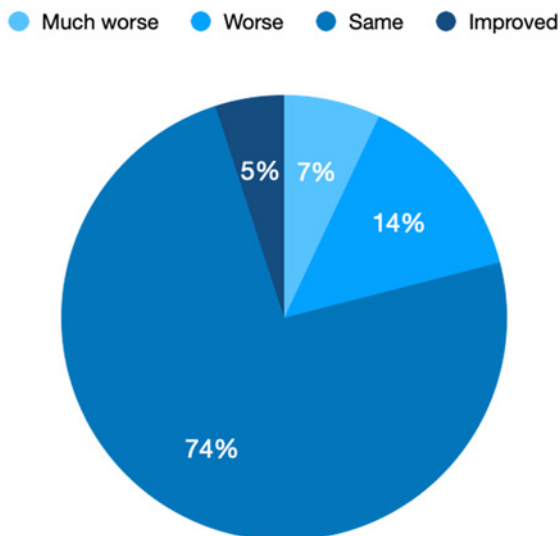
Mobility: Much worse 2 (7%), worse 11 (40%), same 13 (48%), improved 0% and much improved 1 (5%)



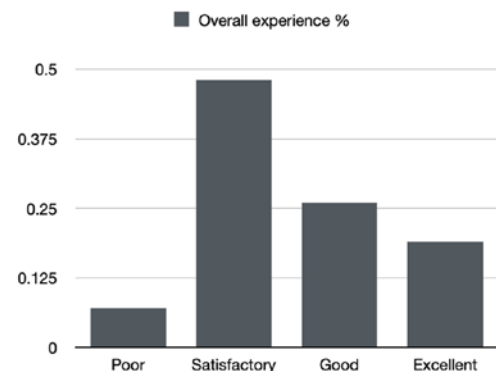
Level of anxiety: Much worse 2 (8%), worse 5 (18%), same 19 (70%), improved 1 (4%) and much improved 0%



Level of distress: Much worse 2 (7%), worse 4 (14%), same 20 (74%), improved 1 (5%) and much improved 0%

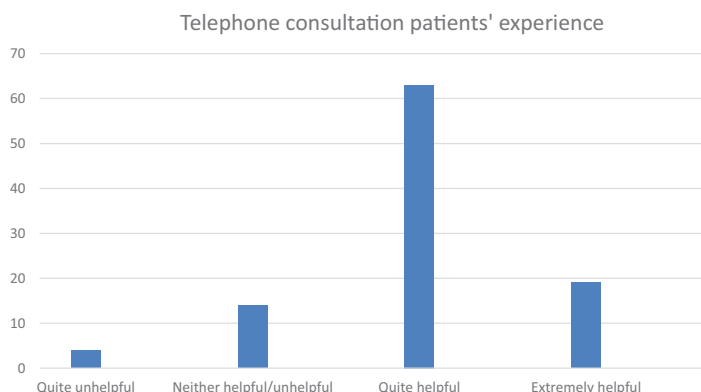


Patients' overall experience: Poor 2 (7%), satisfactory 13 (48%), good 7 (26%) and excellent 5 (19%)

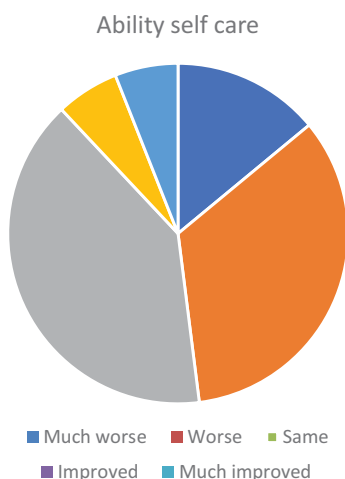


Survey of chronic pain patient experience during the COVID pandemic background

Patients' experience with telephone consultation: Quite unhelpful 1(4%), neither helpful nor unhelpful 4 (14%), quite helpful 17 (63%) and extremely helpful 5 (19%)



Ability of self-care: Much worse 14%, worse 34%, same 40%, improved 6% and much improved 6%



Patients' suggestions for communication with chronic pain team

	Yes	No
Telephone to continue	88%	12%
Video consultation	41%	59%
Received the letter	81%	19%
Contact pain department	85%	15%

Discussion

Patients' responses about chronic pain services during COVID pandemic were quite interesting and reflecting the challenges we have faced as health care workers to deliver pain services at this critical time. One of the main targets of chronic pain services is to reduce the pain scores and improve patients' function capacity.

Pain intensity remained the same in just under 50% of patients. This is similar to activity levels, mobility and self-care. Pain levels did show improvement in almost 20%, which may be due to direct access to the pain management team during the COVID pandemic through telephone calls for advice and adjusting medical treatment.

Activity, mobility and self-care showed improvement only in a very small percentage. This may reflect the demographic of our clients, many of whom will have had their freedom to go out curtailed due to age or other illness.

In these four categories, a significant proportion, 25%–45%, noted worse or much worse symptoms. Again it is difficult to be sure why. It does, however, illustrate the importance of running and maintaining services for this group of patients.

The overall experience of this service is very positive, considering the patients have not previously been used to remote consultation and had no choice regarding this. In the first wave, definite appointment times were not given due to fluctuations in staff availability, and this may have influenced responses. In addition, patients may have had different expectations at that time. Remote consultation became more familiar and acceptable.

Patients' expectations for future consultation are to do more face-to-face consultation. Some patients want more video consultations as well so they can see the doctor but without coming to the hospital. Pain management programme is to be done as a virtual programme as well.

Finally, we conclude that receipt of their record of consultation and management plan plays a vital role in moving forward with the plan and in patients taking control over their progress and outcomes. It is also helpful, especially during times of restricted outside contact, for patients to have a contact for the department.

Survey of chronic pain patient experience during the COVID pandemic background

Future study

It would be interesting to see if these parameters change in later stages of the pandemic.

Conclusion

Although we had great disruption in chronic pain services during the COVID pandemic, patients' feedback, especially

with the overall experience, is quite satisfactory which shows the importance of communication with chronic pain patients over the telephone. To make further progress, video consultations and patient selection for face-to-face consultation and continue giving patient access to chronic pain management services would be considered, and this can be reviewed at a later stage of the COVID pandemic.

Spinal cord stimulation: letter from a patient

Malcom Currie

Dear Dr. Patient between 1999 and 2014

Nicola and I hope you and your family are keeping well and that Covid has not personally affected any of you, although I suspect there will be a great deal of research for you to do into the effects of Long Covid.

I wanted to first let you know how fundamentally my life has improved since your recommendation that I go ahead with a spinal cord stimulator and second, and most importantly, to thank you for allowing us to remain in regular contact with you over the years, which allowed my wife to contact you, with the end result being the stimulator.

When we first met in late 1999, you said then that I was young enough to one day benefit from the significant advances being made in pain management science, and so it has been proved.

I had the stimulator fitted in 2014, and having slowly weaned myself off Oxycontin by mid-October 2015, I have continued to make steady progress (apart from bladder cancer in early 2016, now under control). This has been achieved by continuing with regular exercise and keeping my weight under control, which had see-sawed while on Oxycontin.

I have progressed to such an extent that when Nicola was asked by our Parochial Church Council in 2017 to help with their long-held ambition to instal an equal access WC and servery in All Saints Church Hitcham, I felt able to get involved. We took back control of The Friends of Hitcham Church to raise the necessary funds.

We quickly realised that raising funds just for a WC and servery was not going to garner much interest so we turned it into a major Tower Restoration Project to include the restoration of the bells which had not rung for over a hundred

years. We were fortunate to have had Rev. Prof. John Stevens Henslow, Darwin's mentor and friend, as rector here so we were able to use his profile and the fact he installed two bells on the coronation of Queen Victoria as an opportunity to win significant grants from the National Lottery Heritage Fund, Viridor Credits, other grant-making bodies and some very generous private donations. Nicola was personally responsible for raising the entire £340,000 plus required to complete the project. I acted as proofreader, fact and figure checker – something I could never have done while on Oxycontin.

Little did we realise that in order to keep costs down, a significant amount of the bell restoration work would rely on volunteer labour from the village and the Suffolk Guild of Ringers. Covid lockdown meant we had to keep volunteer numbers to a minimum, which meant I had to roll my sleeves up and get stuck into some significant physical work. I attach a photograph of myself digging the first of 10 wall pockets to take the new bell frame: the bulk of this fell onto me as my assistant had to be careful because of earlier heart problems. This was the most physical of the various tasks but you can imagine that there was a great deal of shifting of very heavy materials, all of which was done under the strict control of the bell foundry's bell hanger. I learnt a great deal about moving large objects without putting oneself at risk.

Despite Covid and lockdowns, we were able to complete the entire project on time at the end of March this year.

I would never have achieved any of this without your care over the years. Being back in a working environment again with a great group of people has done me no end of good both physically and emotionally. My confidence also improved tremendously. Although I was understandably tentative to start with, I achieved so much more than I ever believed possible.

Spinal cord stimulation: letter from a patient

Just a huge thank you again.

With kind regards and our very best wishes,

Yours sincerely,

Malcolm
Malcolm Currie



An excellent advert for the Spinal Cord Stimulator

Hopeful



Hopeful 1909 by Sir Lawrence Alma-Tadema

Location: Clark Art Institute, Williamstown, MA, US. In The Public Domain. Lawrence Alma-Tadema is one of the most highly renowned romantic artists of late-19th century Britain.

As a child, it was decided that Alma-Tadema would pursue the career of a lawyer, but he suffered a mental and physical breakdown when he was 15 years old. He was diagnosed as consumptive, given a short time to live, and thus free to pursue a life of leisure and pleasure. He decided to study art and he regained his health and studied at the Royal Academy of Antwerp in 1852. In 1869, Alma-Tadema lost his wife of 6 years. Disconsolate and depressed, he ceased painting and his health was failing. Under the advice of his physician, he travelled to England for a medical diagnosis, where he was invited to the house of a fellow painter, Ford Madox Brown. It was here that he laid eyes on Laura Theresa Epps, who was 17 at the time, and fell madly in love with her. He proposed, and they were married shortly thereafter. Alma-Tadema was 34 years old, and the bride 18. A perfectionist and obsessive worker, he also innovated a new numbering technique, which made it difficult for forgers to pass off unoriginal works. In his later years, although his artistic output decreased somewhat, he enjoyed continued success, eventually becoming one of the wealthiest painters of the 19th century. He was knighted in England in 1899. In 1912, Alma-Tadema travelled to Germany to undergo treatment for stomach ulcer and died in Germany at the age of 76. After his death, his work was mostly ignored. Due to the drastic changes taking place in art, Alma-Tadema's artistic genius would not come into the public eye again until the 1960s. (From wikiart.org, copy right free)

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Reducing muscle tension
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Prescribing information

Myopridin tablets containing pridinol mesilate. Consult Summary of Product Characteristics before prescribing. For the treatment of central and peripheral muscle spasms: lumbar pain, torticollis, general muscle pain, in adults. **Dosage and administration** 1.5–3 mg pridinol 3 times daily. The duration of administration is decided by the treating doctor. Administration is independent of meals, with the onset of the effect being faster when taken before meals. Tablets should be taken with sufficient fluid (e.g. 1 glass of water) and not chewed. **Contraindications** Hypersensitivity to the active substance or to any of the excipients, glaucoma, prostate hypertrophy, syndrome with urinary retention, gastrointestinal obstructions, arrhythmia, first trimester of pregnancy. **Special warnings and precautions** Use with caution in the elderly, and in patients with severe renal and/or hepatic insufficiency, because higher and/or longer-lasting blood levels must be expected. In patients who suffer from hypotension, the risk of circulatory problems (fainting) may be increased. Myopridin contains lactose. Patients with the rare hereditary problems of galactose intolerance, total lactase deficiency or glucose-galactose malabsorption should not take this medicinal product. **Interaction with other medicinal products** Myopridin potentiates the effect of anticholinergics such as atropine. **Pregnancy and breastfeeding** Myopridin is contraindicated during the first trimester of pregnancy and should be avoided during breastfeeding. Myopridin may only be used later in pregnancy after careful consideration, under medical supervision and only if absolutely necessary. **Side effects** The following adverse effects may occur, particularly during concomitant administration with other anticholinergic medicinal products: dry mouth, thirst, transient visual disorder (mydriasis, difficulties with accommodation, photosensitivity, slight increase in intraocular pressure),

redness and dryness of the skin, bradycardia followed by tachycardia, micturition disorders, constipation and, very rarely, vomiting, dizziness and unsteady gait. Other side effects occur in fewer than 1 in 100 patients. Prescribers should consult the Summary of Product Characteristics in relation to the treatment of overdose and for details of other side effects. **Effects on ability to drive and use machines** Owing to potential anticholinergic effects on eyesight, greater caution is advised when driving vehicles and operating machines. **Presentation and Basic NHS Cost:** Presented as a white round tablet diameter 9 mm with a score on one side. May be divided into equal doses. 3 mg x 20 tablets (£5.36) 3 mg x 100 tablets (£26.16). **Marketing Authorisation Numbers:** PL 49452/0010 **Legal Category** POM **Date of Last Revision:** May 2020 **For further information, please contact:** Mibe Pharma UK Ltd, 6th Floor, 4 Coleman Street, London EC2R 5AR, United Kingdom

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UK/MYO/20/001a Date of preparation: Oct 2020

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