Can drawings assist us in understanding children’s pain better?

Breaking the silence – FGM and Chronic pain
Language specific PMP
Social Ecology where politics meets pain
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- Mr Neil Betteridge
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The Editor welcomes contributions including letters, short clinical reports and news of interest to members, including notice of meetings.

**Next submission deadline:**

8 January 2016

Material should be sent to:

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https://www.britishpainsociety.org/
for-members/pain-news/
British Pain Society Calendar of Events

To attend any of the below events, simply book online at: www.britishpainsociety.org/mediacentre/events/

2015

Pain the Hidden Epidemic
Patient Liaison Committee Annual Seminar
Thursday 17th December
Churchill House, London

The seminar will include a mixture of lectures about Pain and Neuropathic Pain, as well as an afternoon dedicated to working together to see how we can all make a difference and raise awareness of pain.
To view the full programme and book a space please visit our website: https://www.britishpainsociety.org/mediacentre/events/patient-liaison-committee-seminar/

2016

Opioid Study Day
Monday 14th March
Churchill House, London

More information will be added to our website when available

Annual Scientific Meeting
Tuesday 10th – Thursday 12th May 2016
Harrogate

The multidisciplinary nature of the Society’s is pivotal to the continuing success of its Annual Scientific Meeting, which has attracted an average of over 600 healthcare professionals to its previous five Meetings. This multidisciplinary nature is reflected throughout the scientific programme, with lecture, workshop and seminar topics chosen specifically to be of interest to all participants, whatever their specialty. Further information can be found on: https://www.britishpainsociety.org/2016-asm/

The Power of the Mind in Pain
Philosophy & Ethics SIG Annual Meeting
27th to 30th June 2016
Rydall Hall, Cumbria

This meeting promises to be a most stimulating conference considering the power of the human mind in pain. There will be a number of speakers looking at a wide range of subjects including spirituality, hypnosis, healing, the placebo effect and other mind-body connections.
It will be held at Rydal Hall near Ambleside in the Lake District and during the conference there will be time to explore the gardens and grounds of the hall as well as the beautiful surrounding lakes and hills.

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

Happy Christmas and Happy New Year

Dr Arasu Rayen  Editor
pns.rayen@gmail.com

Days are becoming shorter with increasing darkness. While I write this, Christmas is not far and we are almost at the end of the year. As the President mentioned in his message, it is a busy time for the Society. The Secretariat is gearing up and getting ready for the next year Annual Scientific Meeting (ASM). There is an advert in this issue of Pain News. Please look at the dates and book your leave so that most of you can attend the meeting.

As ever, this issue of Pain News carries lots of interesting articles. Female Genital Mutilation (FGM) refers to procedures that intentionally alter or cause injury to the female genital organs for non-medical reasons. Even though it is illegal, it is estimated that around 20,000 girls under the age of 15 are at the risk of FGM. There are nearly 66,000 women who are living with the consequences of FGM (http://www.nhs.uk/conditions/female-genital-mutilation/Pages/Introduction.aspx). The consequences can be physical, sexual and emotional (http://orchidproject.org/category/about-fgc/impacts/). The article ‘Breaking the Silence’ puts the spotlight on another impact of FGM – chronic pain. This article, even though short, gives us some glimpse on the impact of FGM. There are two real-life stories in this article.

There are two articles in this issue on art and drawing. One article by Alessandro Falmouth, ‘Can drawings assist us in understanding children’s pain better?’ shows some insight into the world of children and how they express themselves, feelings and their life experience through drawings. There are two examples of drawings and their description accompanying the article to give us some example. Juliet King in her article ‘Art therapy in pain management – personal experience’ details her experience in a paediatric pain management team through her placement in psychology department.

You might have noticed that from September issue of Pain News, we have moved Spotlight to the ‘Regulars’ section. We also would like to publish Spotlight on members of BPS, not only Council Members. If you think there is anyone in your Department who is worth a spot in Spotlight, please contact me on pns.rayen@gmail.com.

There is nothing more to say at the moment. Have a Happy Christmas and Fabulous New Year.

See you in 2016!
Now that we are well into the autumn months, many activities with and without the British Pain Society (BPS) are getting into full swing again. Your Council has as usual been very busy with a wide range of matters involving pain commissioning, education, liaising with likeminded organisations and highlighting the burden of pain on the community, as well as the day-to-day running of the BPS. There is an enormous amount of email traffic, depending on each Council member’s agreed activities within the organisation. Jenny Nicholas, our new CEO, is concentrating very much on financial support, on top of overseeing the activities of the BPS.

For most of the past year, Ken Obbard has been quietly working away at membership matters, educational days and Special Interest Groups (SIGs) support, as well as taking over as temporary Secretariat Manager. A massive amount of work and Ken is to be applauded. Meanwhile, Niraj Karki has been working in a supportive role for the past 8 months, and this has permitted some valuable membership surveys to be carried out, as well as taking some pressure off the other Secretariat staff.

Rikke Susgaard-Vigon continues to very effectively organise our Annual Scientific Meetings – the next being in Harrogate 10–12 May 2016, with details on the website and via push email. A big thank you to the Secretariat.

Dr William Campbell

The BPS website
As mentioned in a previous issue of Pain News, the new website is more orientated towards you as members. John Goddard crystallised the project very early this year – a major task and I hope that you are all becoming familiar with it. Since the layout is different to the previous version, you will need to delve into it frequently to familiarise yourself with it and get the best value from it, including personal updates and notifications. Some material, such as the current issue of Pain News, is only available to fully paid BPS members. Non-members can access a ‘taster’; this we believe is reasonable and will hopefully encourage people to become members of the Society. With the new website set up, the Secretariat can now make changes to the website almost immediately. In addition, over time, much more can be done online than in the past and it will save us money to run.

This is YOUR website. We would ask that SIG Chairs start as soon as possible to populate the website for the benefit of the membership. We would also welcome material from the membership in general as this could be considered for the website as well.

The European Federation of the International Association of Pain Chapters Pain Schools
Over the past couple of years, I have been the UK representative for the European Federation of the International Association of Pain Chapters (EFIC). The current President of the BPS normally fills this role. EFIC, or more correctly now called the European Federation for Pain, offers pain schools to all healthcare disciplines, who are currently members in good standing with their chapter (i.e. for United Kingdom, they are current members of the BPS).

When pain schools are offered, the applicant sends their application form to me via the BPS Office, on a closing date prior to that given by EFIC. This permits me with a small multidisciplinary group to decide who to support. Generally, a maximum of two applications per country will be accepted, and only with a letter of support from the UK representative – directly to EFIC. Applications made directly to EFIC will not be accepted, regardless of how eminent your supporter is. Only BPS members can apply and only then if selected and supported by the UK EFIC representative. I hope that this clarifies any misunderstanding of non-BPS members applying for these schools, which include a grant. We have had a good acceptance rate this year, for these well-respected schools.

Meeting at the House of Commons
The Chronic Pain Policy Coalition (CPPC) has arranged a meeting at the House of Commons for 18 November 2015. The Pain Consortium, comprising the CPPC, the BPS, the Faculty of Pain Medicine of the Royal College of Anaesthetists (FPM) and the Royal College of General Practitioners, together with Pain UK...
feedback all added to the material to be presented – the latter in particular for the 10 key messages mentioned below.

Speakers
- Mr Neil Betteridge, CPPC Co-Chair – Chair
- Lord Richard Luce
- Dr Beverly Collett, Chair of FPM Professional Standards Committee and co-editor of Core Standards for Pain Management Services in the United Kingdom
- Dr Anna Weiss, Member of FPM Professional Standards Committee and co-editor of Core Standards for Pain Management Services in the United Kingdom
- Professor Roger Knaggs, Honorary Secretary Elect, BPS, Associate Professor, University of Nottingham, Specialist Pharmacist in Pain Management, Nottingham University Hospitals National Health Service (NHS) Trust, and Clinical Co-Lead of Opioid Aware

Topics
- CPPC Strategy
- Booklet for Parliamentarians
- UK Pain Messages
- Core Standards for Pain Management Services in the United Kingdom (FPM)
- Opioid Aware (FPM/Public Health England collaboration)
- Pain Charter (Pain UK)

Pain Summit Northern Ireland – a 3-year follow-up
The Pain Alliance for Northern Ireland (PANI) have arranged a follow-up meeting on 18 November 2015, to discuss progress since the Pain Summit meeting held in 2012. The original meeting was well attended by parliamentarians, including the then Minister for Health, the Chief Medical Officer and senior healthcare commissioners. People living with long-term pain described how their lives were so dramatically changed by their pain, as well as the problems they had in having healthcare professionals acknowledge the cause of their problem and hope to help them manage if appropriately. This included a person with juvenile onset arthritis and a PhD student in the process of developing pain due to multiple sclerosis.

Undergraduate pain training and Scotland
I had been keen to follow on from Sir Michael Bond’s approach to the Gwinnett Medical Center (GMC) regards improving undergraduate pain training.

From the massive amount of information gathered by the National Pain Audit (NPA) team, led by Dr Cathy Price, showing the many problems associated with untreated pain and the benefit of attending specialised pain services, together with the results of a major study of undergraduate medical students throughout Europe led by Dr Emma Briggs, showing the value of good structured pain teaching and assessment, I wondered if it would be worth approaching the GMC again – but with this material. Dr Briggs provided evidence that isolated organisations in other countries had not been successful in initiating change. As a result, the BPS with the FPM made a joint approach to the GMC last year.

I presented the NPA details to show the problem, as well as a poster by Dr Emma Briggs to illustrate what could be done at an early stage in doctors’ training. The FPM presented work based on Essential Pain Management (EPM) carried out in developing countries, and how this could be introduced to many pilot site medical schools, as EPM Lite.

This was well received and GMC wish to see the results from six EPM Lite sites before making further comment. Unfortunately, some universities believe that they are teaching ‘pain’, but this may be too rudimentary to cover acute, not mind the basics of long-term pain. Fellows from the FPM have been successful at introducing EPM Lite at about four universities.

In Scotland, Neil Clark is seeking to influence lecturers to incorporate a greater amount of pain training within the physiotherapy curriculum. In addition, the Physiotherapy Pain Association has published a competency framework regards pain training and continue to develop this. In Edinburgh and Glasgow, there is a very active physiotherapy educational programme. Dr Steve Gilber is continuing to successfully drive undergraduate medical pain education forward at several sites in the east of Scotland.

Pain the hidden epidemic
I trust that you will already know about the Patient Liaison Committee Seminar day. This is to be held at Churchill House, 35 Red Lion Square, London, on Thursday 17th December 2015. The day is open to patients and healthcare professionals alike. This year, we are pleased to have Professor Sir Michael Bond starting the first of an annual series of ‘Professor Sir Michael Bond’ lectures looking at rehabilitation after the onset of persistent or long-term pain. The day is continuing professional development (CPD) accredited for healthcare professionals alike. So if you have not already booked a space, do try and attend on that day. Details from: kenobbard@britishpainsociety.org or see: https://www.britishpainsociety.org/meeting-booking/pain-the-hidden-epidemic/

Wishing you all a very happy Christmas break.
Spotlight – Despoina Karargyri

Despoina Karargyri
London

The width and breadth of BPS membership is testimony to the diversity within the organisation and in the pain world. The Editorial Board would like to acknowledge this richness by shining a spotlight on some of our members. In this edition, we speak to Despoina Karargyri, physiotherapist at Royal Free London NHS Foundation Trust.

1. What is your professional background and what attracted you to the world of pain?
   I am a physiotherapist with a special interest in pain since undergraduate years. I was always more attracted to a rehabilitation approach to treatment as the power of the body to self-heal and its neuroplasticity fascinated me.

2. What brought you in contact with the BPS?
   What first attracted me to BPS was the Annual Scientific Meeting as a postgraduate student.

3. Apart from being a member, do you contribute in any other way to the work of the BPS?
   I currently act as a co-opted member for the Education SIG and hold a lead role in the Patient Education Subgroup.

4. Are there any further developments you would like to see happening within and through the BPS?
   I am really looking forward to Pain being recognised as an autonomous diagnosis, and I am aware of the hard work the BPS is putting to achieve this. Working in chronic pain, I also look forward to pain being involved in all long-term conditions programmes. Finally, I feel the allied professions representation within the BPS is still low and would like to see further efforts in attracting that type of membership.

5. What do you feel is the role of the wider BPS membership?
   The BPS membership is the BPS. BPS members are the scientists, clinicians, care providers and pain champions that work towards the national improvement of pain relief and management.

6. If you were President of the BPS for a day, what would you do?
   Onset the ‘Pain: Public Education and Communication’ Year.

7. What are you known for professionally?
   Over the years, I have developed a reputation of working well with patients that have particularly complex needs.

8. What are you most passionate about professionally?
   Integration of services and pain education.

9. What do you have a knack for?
   I would think coming up with new ideas but can really fail in implementing them.

10. What are you passionate about personally? What do you really enjoy? What can’t you stop talking about?
   My passion is walking. I have many interests, and I am very close to my family and friends, but what soothes my soul is endless hours of walking.

11. Where can we find you in your spare time? What is your favourite way to spend a weekend or a Sunday afternoon?
   I will be somewhere walking or playing with my nephew.
12. Any other volunteer activities apart from the BPS that you’re passionate about?
Equality rights and freedom of speech.

13. Any favourite non-profit organisations that you support and why?
Oxfam, as they always support the worst crisis at any given moment but also have long-term work in areas of need; Shelter, as they do a great job with both homeless people but also in supporting people in their living rights; Wateraid, as not having water is incomprehensible to me; NSPCC; and the Greek equivalent ‘Smile of the Child’. Especially, the last at present is the only support mechanism of children in Greece, where there is no state support. This organisation is currently under the threat of closure which is beyond heartbreaking as then all children in Greece, whether orphans, abused, victims of trafficking, refugees will be left with no support.

14. What would be impossible for you to give up?
Caring for others and the world we live in.

15. How do you want to be remembered?
As a person who at least tried to be kind towards others.

16. Any life achievements you are particularly proud of?
Running half a marathon as for the life of me I cannot run.

17. Anything else you’d like to tell people about yourself?
I feel very passionate about the work of the Education SIG that I also think is a very supportive SIG of all its members and everyone has an opportunity to contribute.

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

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

Thank you for supporting the BPS!
UK Pain Messages

British Pain Society is pleased to publish the “UK Pain Messages” in this edition of Pain News. As you know, there are a large number of facts and figures on Chronic Pain being used by a variety of organisations. The Pain Consortium - comprising the leaders from the Faculty of Pain Medicine, the Royal College of General Practitioners, the British Pain Society, the Chronic Pain Policy Coalition and Pain UK – have come together to gain a consensus relating to these facts and figures, highlighting the burden of Chronic Pain in the UK.

The result of this work is within the following factsheet. Each statement was already in the public domain, and its source is referenced throughout. The UK Pain Messages are for everyone to use as they wish, and we hope that they will help individuals and organisations to communicate effectively with their stakeholders.

You may want to send these documents to your local Member of Parliament, CCGs contacts, Health and Wellbeing Board or any other health authority/individual to raise awareness of Chronic Pain. A copy of the Pain Messages can be downloaded from: https://www.britishpainsociety.org/static/uploads/resources/files/UK_Pain_Messages_final_Sep2015.xlsx.pdf

The document was launched by representatives from the organisations involved at a Parliamentary meeting held in the House of Commons, at noon on 18 November 2015.

There are a large number of messages used for chronic pain by a variety of organisations. The aim of the UK Pain Messages is to define and gain consensus and consistency over the facts and figures used when highlighting the burden of chronic pain in the United Kingdom. These messages, separately in the public domain, have been approved by the following organisations/individuals: Faculty of Pain Medicine, Royal College of General Practitioners’ Chronic Pain Lead, British Pain Society, Chronic Pain Policy Coalition and importantly patients via Pain UK:

- The Department of Health1 recognises chronic pain as a long-term condition in its own right and as a component of other long-term conditions.
- It is estimated that 14 million people live with chronic pain in England alone. In 2011, 31% of men and 37% of women reported persistent pain. Of these, 25% (or one in four – 3.5 million) said that their pain had kept them from usual activities (including work) on at least 14 days in the previous 3 months.2
- A person living with pain will have a very poor quality of life – much worse than other conditions and as bad as significant neurological diseases such as Parkinson’s disease.2
- Low back pain is ranked highest out of 291 conditions studied by the Global Burden of Disease study, ranking number one for years lost to disability worldwide. In fact, 4 of the top 12 disabling conditions globally are persistent pain conditions (low-back and neck pain, migraine, arthritis and other musculoskeletal conditions).3
- In total, 41% of people who attended pain clinics report that their pain has prevented them from working, and 13% have had to reduce their hours.4
- In total, 66% of people attending accident and emergency (A&E) departments seeking help with pain had more than three visits to a healthcare professional in the preceding 6 months.4
- The 2008 Chief Medical Officer report states that 25% of pain sufferers lose their jobs; 16% of sufferers feel their chronic pain is so bad that they sometimes want to die.5
- Men and women in the lowest income households are more likely to report chronic pain (42%), compared to those in the highest quintile (27%).6
- Severe chronic pain is associated with increased risk of mortality, independent of socio-demographic factors.1

References

Pain Toolkit mini update and what’s new!

Peter Moore, Pain Toolkit

Working on the Pain Toolkit has been like watching a child grow. Next year, the Toolkit will be 10 years old. It has been an interesting 10 years watching it grow and be an important piece of resources for not only patients but also healthcare professionals here in the United Kingdom and around the world.

The Pain Toolkit website
- The new website has been up-and-running since last December and already it has had 580,000 visitors.
- There is now a healthcare professional section.
- The news section seems to be popular as visitors can leave comments.
- There are now 18 different versions of the Toolkit in 13 different languages – Danish and Norwegian in 2016.
- Second most visited link is the Pain Cycle.
- The Pain Toolkit is very active on Twitter running #TweetChats which are interactive worldwide conversations.

So what is new now and for 2016?
Yes there is now a Pain Toolkit App
Who would have thought it back in 2006, when I first came up with the Pain Toolkit idea, 10 years later, the Toolkit would be developed into an interactive concept, where patients can download an app and learn how to self-manage their pain on their own or with the help of their healthcare team.

So how does it work? It’s really easy …
All the 12 tools within the App are animated and help patients with simple pain self-management information, techniques and self-monitoring tools to facilitate self-management for people living with persistent pain.

- Self-Assessments to be shared with the patient healthcare teams including the body chart and DoloTest
- 12 animated Pain Toolkit Tools
- Diary and Can do Meter

During the development stages, we trialled with many patients who gave us really important feedback. You can see what they thought in this video.

To download the Pain Toolkit App, go to http://www.paintoolkit.org

Pain Toolkit quiz
From early 2016, members of the Pain Toolkit will be able to test their pain self-management knowledge via the Pain Toolkit Quiz. It will be very interactive to help increase self-learning and, of course, fun to do.

Pain Toolkit on-line board game
Also early in 2016, members will be able to use the Pain Toolkit. The game will be content-driven and tell a story. They’re easy to play but deliver a learning experience.

The game will encourage interaction, engagement, teamwork and fun. They’re designed to motivate changes in thinking and behaviour.

For more information about the Pain Toolkit, please contact Pete Moore: pete.moore@paintoolkit.org
Supporting Young Adults with Chronic Pain: A multimedia-based specialised Pain Management Programme, Dr Hannah Twiddy, The Walton Centre NHS Foundation Trust, Liverpool

The overall aims or the project are as follows:

- To address the specific and unmet needs of young adults with chronic pain in self-management interventions
- To utilise web-based and multimedia tools to aid both the delivery of the Pain Management Programme (PMP) and engagement
- To develop multi-speciality links with paediatric services to enhance transition into adult care pain services and improve/expedite appropriate referrals to the young adult PMP at The Walton Centre
- To evaluate the outcome of this intervention through physical and psychological measures of functioning and patient evaluation feedback, as well as systemic service level audit of benefit (i.e. transition service)

Young adults with chronic pain have been and will be directly involved in contributing to the content and format of a young adult PMP with the anticipated benefit of allowing relevant and meaningful content and accessible formatting. We would hope this would produce better engagement with self-management strategies in managing chronic pain and therefore improved outcomes in terms of psychosocial and quality-of-life measures. Strong links will be made with local paediatric services to smooth the transition for patients at age 16 years from paediatric to adult service. We hope that the development of web-based tools and mobile phone applications will help young adults to maintain positive progress once they have completed the PMP and will provide a useful and familiar format for these patients to continue to engage with self-management – allowing access to varied resources for longer term support in managing a long term health condition.

Analgesia provision and pain prevalence associated with cardiac device implantation. Rachel Anderson, The Royal Brompton and Harefield NHS Foundation Trust, London

Interventional procedures undertaken by non-surgeons are increasing. The profile of post-procedural analgesia is perhaps less obvious than in the surgical field. The aims and objectives of this project are

- To determine peri-procedural pain intensity levels for patients undergoing cardiac device implants
- To optimise peri-procedural analgesia during and after cardiac device implantation with an anticipated reduction in pain intensity
- To reduce the number of patients requiring extended length of stay because of inadequate analgesia
- To develop evidence-based guidance which would standardise peri-procedural analgesia
- To develop the use of discharge analgesia packs alongside targeted patient information
- To determine the prevalence of, and reduce the risk of, persistent post-procedural pain

This project will explore the patient experience of cardiac device implantation using focus group methodology and patient shadowing. These data would be used to inform the development of interdisciplinary evidence-based procedural analgesia guidelines for the cardiology team. We believe this is an important unmet need. Cardiac device insertion is not included in the procedure list of day surgery recommended by the British Association of Day Surgery (BADS). However, cardiac device insertion does fit the definition of short stay surgery (and has the potential to be performed on a day case basis). Currently, the permanent pacemaker (PPM) implant rate in England is 524 per million population. This is well below the target rate of 700 pacemaker implants per million population, and much less than the number of implants in Europe. However, it still represents a large population of patients, whose analgesia needs require addressing. Kehlet states the ‘ultimate goal’ of fast-track surgery is to achieve ‘a pain and risk free’ operation. The pain management service will work with patients, pharmacy and cardiology colleagues to develop this aspect of
care. We aim to document the current level of pain intensity in this population. This should additionally identify any neuropathic components requiring specialist pain management. Patients will also be followed at intervals of 6 months to determine the prevalence of persistent device-related pain, analgesia consumption and pain/device-related healthcare utilisation in primary and secondary care.

The Analgesic App. Dr Amelia Davies (Foundation Year 2 Doctor), Andrew Brent (Consultant Physician), Dr Jane Quinlan (Consultant in Anaesthesia and Pain Management), The John Radcliffe Hospital, Oxford

In 2014, an audit at the Oxford University Hospital (OUH) Trust identified a significant short fall in analgesia prescribing. In all, 59% of the patients who experienced pain reported it was poorly controlled, and only 47% of analgesia prescriptions were compliant with the trust’s guidelines.

The findings of the audit highlighted the need for readily available guidelines. It was decided that a mobile phone app would be the best way to deliver this – making the guidelines easily updated and available in every junior doctor’s pocket.

The app will provide the guidance to allow more appropriate selection of analgesic agents and doses. Improved analgesic prescribing will result in better pain management resulting in better patient care. Patients will experience less pain, have fewer pain-related complications and make faster recoveries.

The app will also provide a quick reference guide for managing complications of analgesia, resulting in better and faster management of these potentially life-threatening complications. The OUH Pain Audit is being re-audited in October 2015. This will give a well-timed opportunity to examine the impact of the App and inform its further development.

The app platform also allows detailed review of the use of the app; it will be possible to examine how often it is downloaded, how often it is opened and which aspects of it are referenced most often. This information has already proved very useful in the further development of the antimicrobial guide app and will be pivotal in maximising the potential of the Pain App.

Developing criteria for requesting magnetic resonance imaging in chronic orofacial pain patients, Dr Naomi Rahman and Maria Devine, Kings College Hospital Foundation Trust, London

Currently, routine magnetic resonance imaging (MRI) for all patients with facial pain is recommended as a screening tool as it can highlight if there is vascular compression, a space occupying lesion, demyelination or exclude an intracranial lesion. Routine MRI requests are common in this patient cohort but as yet not evidence-based. Due to King’s College Hospital (KCH) leading in neuroscience and imaging, we have excellent access to MRI scanning with dedicated head and neck radiologists using fast imaging employing steady-state acquisition (FIESTA)-based trigeminal nerve scanning paradigms.

Guidelines for MRI of spine and joint pain and unexplained headache already exist; however, there are no guidelines for requesting MRI screening for the orofacial region.

The study will evaluate the reported presence of pathology based upon the MRI scans (demyelination, space occupying lesions or vascular compromise) in a sample of patients with orofacial pain (OPF) and trigeminal neuropathy seen at the KCH OPF service.

The history, demographics and clinical features will be compared between the groups with and without reported MRI pathology. If the patient group with reported pathology presents with specific clinical history or features that correlate to positive MRI findings, these could be used to develop a criteria to clinically select high-risk patients for MRI investigation.

The objective is to develop criteria for accessing whether certain patients presenting with chronic OPF or neuropathy necessarily require MRI as a screening tool. OPF can be a diagnostic dilemma for clinicians and poses a problem for patients as they are often misdiagnosed. Trigeminal neuralgia and atypical pain are among the most challenging painful conditions in the orofacial area.

If effective criteria can be developed, this could potentially decrease the number of MRIs ordered, optimising patient management and reducing costs to the National Health Service (NHS).

Is buying paracetamol over the counter for pain relief safe (non-pharmacy establishments) to prevent accidental overdoses? Phillip Molloy, Keele University Medical School, Staffordshire

Paracetamol misuse is the number one cause of overdose within the United Kingdom. Up to 90,000 presentations with paracetamol overdose are witnessed in healthcare settings per year in the United Kingdom and around 200 deaths occur annually as a direct consequence of paracetamol self-poisoning. In 2009, the Medicines and Healthcare Products Regulatory Agency (MHRA) released guidelines governing over-the-counter (OTC) drug sales in the United Kingdom to try and reduce the rate of paracetamol morbidity and mortality. Our preliminary research involving mystery shoppers established whether these guidelines were being
adhered to across stores in Staffordshire and Shropshire. We found that more than half of retailers were willing to sell more than the MHRA guidelines recommended for paracetamol and aspirin. We also observed that a quarter of retailers were willing to sell ≥96 tablets of aspirin or paracetamol with no questions asked. With literature also suggesting that a significant proportion of morbidity and mortality was caused through accidental use of both ‘raw’ paracetamol and paracetamol-containing ‘flu remedies’ to manage pain, we devised a similar investigation targeting the same stores. Outcomes – We will increase pressure on the MHRA to regulate stores much tighter to enhance the safety of OTC drugs from non-pharmaceutical establishments. There has already been a 43% reduction in the number of deaths after these guidelines were introduced in 2009; however, increased adherence to recommendations will see this cut further. Consequently, the number of hospital admissions and burden on A and E will reduce, decreasing avoidable healthcare usage. We also expect to decrease deliberate misuse of pain-related pharmaceuticals, reduce morbidity and mortalities linked to mismanaged pain. Finally, we will improve the literacy of OTC drugs through the creation of a nationalised logo for products containing paracetamol or aspirin and through the creation of information packages for all stores nationwide on OTC safety.

References

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This Award will recognise excellence in the field of pain management and significant improvement in patient care, however the project will involve the commissioning of a successful pain management service.
Awards of £3,000 and £2,000

**PAIN - PATIENT**
This Award will recognise projects which have a direct patient benefit and would be seen as the most useful from a patient’s perspective.
Awards of £3,000 and £2,000

“Since winning the Award, our project has gone from strength to strength. What was really impressive was the recognition from the CCG, secondary care and community service and the endorsement to communicate with them and improve the service”.

Dr Scot Richardson, GP Principal, Hull Community Stroke Rehabilitation Clinical Lead, Elliott-Chappell Health Centre, Hull and past winner of the Pain Commissioning category

For further information and an entry pack please email the Awards secretariat at: harrietp@jangocom.com or call 01344 860612

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University of Birmingham Interventional Pain Management Cadaver Workshop

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- Thoracic splanchnicectomy
- Trigeminal ganglion blocks
- Sphenopalatine ganglion procedures
- Stellate ganglion block

Spinal and peripheral nerve percutaneous lead insertion and specific programming session

SPECIALIST WORKSHOPS

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When she was 11 years old, Valentine Nkoyo was told by her mother it was ‘time to become a woman’. The whole village gathered together and, amid dancing and singing, she and her sister were taken to a clearing. There they were held down by the arms and legs. Valentine recalls feeling every cut of the razor on that day when, she says, ‘something about my life was taken away’.

Female genital mutilation (FGM) – medically unnecessary removal of or injury to the external female genitalia – affects millions of women and girls around the world and tens of thousands in the United Kingdom. Now living in Britain, Valentine was involved in setting up the Mojatu foundation, a non-profit organisation based in Nottingham that raises awareness of issues affecting African and Caribbean communities, including FGM. She is working to inspire other survivors to share their experiences and get involved with breaking the wall of silence around FGM and supporting at-risk girls.

**Long-term impact**

FGM is typically performed without adequate sterilisation or anaesthetic and can cause severe pain, heavy bleeding and blood poisoning. The longer term effects on physical and psychological wellbeing that follow are often devastating, explains Juliette Albert, Specialist FGM Midwife and Project Lead for the Acton African Well Woman Clinic. She sees women with persistent pain and complex problems in the pelvic region as a result of FGM, many of whom had not previously realised that treatment was available: ‘Women think pain is their lot in life. A lot of their pain may not be solved, but we know where they can get the best care possible’.

Although surgery can help some women – one of Albert’s patients was relieved of pain after 14 years – it is not possible to undo the physical damage caused by most types of FGM. In all cases, Albert’s clinic also offers counselling to help women come to terms with this traumatic event in their adolescence and its knock-on effects on their physical and mental health and their relationships.

Long-term pain is widely recognised as a problem associated with FGM, but there has been only limited research on this topic. A study in Nigeria found that women who had been cut were more than one and a half times as likely to report persistent abdominal pain as those who had not been subjected to FGM. ‘The women we see are the tip of the iceberg’, Albert says, ‘there must be so many women suffering long-term pain who are too frightened to seek help’.

**Chance to talk**

Hana Gibremedhen, who was cut as a 9-year-old girl while living in Ethiopia, says she has pain on a ‘daily basis’ in her pelvic area. The pain was made worse by pregnancy, and she describes her delivery, which lasted for 4 days and nights, as ‘an unforgettable nightmare’. She believes the complications she experienced were related to the effects of FGM not being properly addressed by medical staff: ‘The nurses didn’t know about it, didn’t realise how much pain I was in’.

Three miscarriages followed the birth of her daughter and she has found it difficult to get appropriate care for her problems: ‘they don’t have time to give you chance to talk’. She did not realise the pain was related to FGM until she was seen by a general practitioner (GP) with a special interest in it.

Training for healthcare professionals on FGM should be mandatory, the people we spoke to all agreed. Ignorance and misunderstandings can be both upsetting for FGM survivors and create barriers to accessing healthcare. When having a smear test, Valentine was asked by the nurse, ‘why did you do this to yourself?’

**Culture shift**

Raising awareness of FGM among those working in healthcare, social work and
education will not be easy, but changing perceptions in the communities where the practice is deeply established may be even more challenging. ‘People move with their culture’, Valentine says, and girls may be sent home for the holidays or even visited by a ‘midwife’ brought over the United Kingdom to perform FGM. Women who have been cut themselves may be unwilling to acknowledge that FGM could be responsible for their pain and can be determined to see their daughters carry on the tradition: ‘it’s a cultural thing that people want to pass on – they wouldn’t want to think it is part of the reason they are suffering’.

Getting men onside is also crucial but requires breaching a subject usually shrouded in secrecy and challenging deeply held views about gender roles and sexuality. Hana believes FGM has played a part in past relationship troubles with partners unable to understand the damage it has done to her. She says men need ‘more education’ about the long-term pain, psychological trauma and other complications it can cause.

The first priority has to be ensuring that girls at risk of undergoing the procedure are protected. Attitudes can be changed as Valentine’s experiences show. She managed to ensure that none of her nieces in her large extended family were cut and believes that FGM can be eliminated in a generation, if women can be supported to speak out about their experiences. ‘It’s everybody’s business to look after our girls’, she says.

Acknowledgements
This article was originally published in Pain Matters. You can hear more on this topic in episode 71 of Pain Concern’s Airing Pain radio programme.
Professional perspectives

Evaluating Pain Matters

Tom Green  Editor-in-chief at Pain Concern
editorial@painconcern.org.uk

Last year Pain Concern asked readers of our magazine to let us know more about whether and how Pain Matters is helping them.

A total of 161 readers filled out paper or online questionnaire forms. Around 90% of readers who responded are people living with chronic pain, although healthcare professionals are also reading Pain Matters and recommending it to their patients. People often discover the magazine through their pain management clinic or programme or in other healthcare consultations and sometimes through other pain charities, so it’s important for us to make sure we raise awareness of Pain Matters across the pain community. A pain specialist nurse commented, ‘Pain Matters is of enormous benefit to patients in clinic and on our pain management programme’.

What readers want

We asked which groups of people our readers wanted to hear more from – ‘people in pain’ was by far the most popular answer, followed by ‘doctors’, ‘researchers’ and ‘psychologists’. When we asked whether there were topics to which we should give more or less attention, ‘policy and campaigns’ and ‘medications’ came out on top, although most respondents seemed happy to maintain the overall balance of topics – calls for decreasing coverage were in single figures.

We’ll continue to cover the whole range of voices across the pain community (people in pain, carers and the various healthcare professions) and a wide range of topics, but we’ll try to give more space in future to areas we now know are of particular interest.

A good read?

Almost all (97%) of the readers who filled out the questionnaire said that Pain Matters had met their expectations, and similar numbers thought that the magazine was good value for money and easy to read. One reader said that it gives ‘a lot of information for not a lot of money’, and another commented, ‘I find it very easy to read, however, I return to the issues again and again’.

Perhaps the strongest endorsement our respondents gave is that more than half have already recommended the magazine to someone else and the vast majority would do so in the future.

One reader commented, ‘I have met people in pain who didn’t know that it was a condition in its own right and have given them some editions and it has helped them’.

Making a difference

The survey responses suggest that readers gain the following benefits from Pain Matters:

• Reduced feelings of isolation (among a majority of respondents)
• Affirmation: reinforcing the message that pain is real and is recognised as a condition in its own right; this is supporting some readers in communicating with those around them
• Learning or reinforcing of self-management skills (for around 40% of respondents)
• Keeps readers informed and up-to-date with policy and research news on pain

Summing up

We were overwhelmed by how positive the questionnaire responses were about the magazine and delighted that people in pain and the broader pain community are finding it informative and helpful. Better publicity of Pain Matters should be our priority to ensure that more people can benefit.

A number of valuable suggestions for future topics have been gathered from readers’ comments ranging from dealing with loneliness to stem cell research to how people in different cultures cope with pain. We shall make use of these topic suggestions in future issues – keep them coming!

To see the full evaluation report, visit www.painconcern.org.uk or contact us to request a hard copy.
Art therapy in pain management – a personal experience

Julliet King  HCPC and BAAT registered Art Therapist
kingarttherapy@gmail.com

While training as an Art Therapist, I was interested in physical health and how Art Therapy could be used in a hospital setting. I was extremely lucky to get a placement with a prestigious paediatric psychology department at a prominent children’s hospital. As part of this placement, I worked with the paediatric pain management team for a total of 2 years. After attending clinics and finding out more about pain management, I came to understand the importance of good psychological support in physical health. At this point, my goal was to work out if Art Therapy had something positive to contribute to a patient’s pain management.

First, I had to understand my role within the team and what it was that I could offer. My objectives were to facilitate resilience, hope and positive mental attitude when it comes to physical health. At this point, I looked at ways the individual and their family could achieve this, how to identify when things were improving and how they would know when they were successful.

Although patients are free to draw whatever they want in therapy, sometimes I found it beneficial to have directed exercises. Through art, we could look at what support is in place to help with their pain management. For example, when asked to draw a family scene, we explore ’Who is there? What are they doing? Who is closest to the young person? Is the young person even in the picture? How has pain affected your family?’ This exercise is designed to see how pain is impacting their family dynamics. As an example, sometimes in drawings, we found that Mum was crying a lot or always Dad is outside doing chores in the garden. We help the family to think about how the pain has impacted them, what would help them to function well as a unit and the best support they can offer for the child in pain.

We will also look at the patient’s social support systems through art. As an example, we ask ‘Could you draw your school with your friends? Who is there for you? What is your plan when you need a break? Do your friends have different ways that they can help?’ In this exercise, we are looking to see how scary or supportive school or college is. Friends come with different talents, and it is good to identify that some friends are better at making you laugh whereas others maybe better at letting the teacher know when you need help. We are exploring ways that school and larger networks can be identified and improved to provide the best support for the young person.

Another important tool we use is externalising the pain. The patient will draw their body with the pain and we will help them to see the pain as the problem rather than the patient being the problem, for example, ‘the pain from my CRPS stopped me from going to the movies’ versus ‘I ruined the night because I was in too much pain to go’.

The goal of this exercise is to help the patient from internalising any guilt and looks to empower a whole family team to help with the problem of pain.

We also use visualisation techniques when drawing. When pain is depicted, it is often drawn in orange or red on the body. Through Art Therapy, we can try to help the patient to imagine those lines of pain changing into soft blue lines and what that would feel like. These visualisation techniques can promote a sense of control over one’s body and introduce a form of meditation to the patient.

One basic level of intervention that art can help with is the power of distraction. The brain finds it hard to focus on too many things at once, and if you are drawing a mandala or sketching, the brain will have to focus on that for a while, perhaps giving the focus of pain a break. Adult colouring books, computer art and sketch pads can be a fun tool when looking for distractions. These are just some of the themes that we touch...
Art therapy in pain management – a personal experience

upon during therapy, although we are responsive to a range of subjects that arise.

During Art Therapy, I also provided a space for patients where they could come and explore their experience and what it means to them – a safe place where they could let out their frustrations and fears without being judged. I came to understand the importance of being present and providing that space for people, even young people, when they feel like the world is a terribly difficult place because of the amount of pain they are in. Art Therapy helps people to say, or rather draw, their experience. The art has a soulful ability to enable communication that words can't seem to capture. We all have the power to filter our words, but art tends to allow for an honest depiction of our inner narrative. Drawing provides a way for difficult emotions to be expressed, where sometimes words can't hold the enormity of a feeling. The art itself seems to keep the emotions safe and contained within the art work, allowing a wealth of rich and unconscious communication to flow onto the page.

I have to admit, I found the placement immensely rewarding but also one of the hardest jobs I've ever done. I considered one of my roles was to help children and young adults who have been in terrible pain for many years to have hope. At times that seemed like a very steep path to walk and I probably took on some of their bleakness in the therapy setting. I had to change my definition of success as a psychological therapist while working in pain management; I had to let go of the idea of success being completely in control of their pain to “things are better than they were last time” and that's enough for now.

When I started, I had little appreciation for the relationship between psychology and pain management. Through the chance to do this placement and with the support of an open and knowledgeable paediatric psychology team, I came to find that Art Therapy can positively contribute to pain management. I believe this to be true for both adults and children. A good frame of mind and some psychological tools can go a long way to support pain patients in their health journey. I think the most valuable thing I learned was the importance of not giving up. As long as you are there to support someone in pain, then you bring them the hope that sometimes slips their grasp.

Acknowledgements
As part of her placement, Julliet worked in the Paediatric Psychology department at Sheffield Children's Hospital. This later became an employed position where she specialised in Pain Management and Paediatric Oncology with an interest in the mind–body connection. Julliet now works in Edinburgh, Scotland for the Teenage Cancer Trust and as a private practitioner.

Reference

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Professional perspectives

Five windows on suffering: understanding, forgiveness and love in action

William House  Retired GP, Researcher and Chair of the British Holistic Medical Association and Chair of Keynsham Action Network

This article is the transcript of the lecture given by the author at 2015 Philosophy and Ethics SIG meeting at Launde Abbey

Window 1: About me
A lot of my talk will be about who I am, and I hope you will begin to understand why as the talk unfolds. I was a general practitioner (GP) for 35 years, 27 of those in one practice in Keynsham, near Bristol. As time went on, I guess like many medics, I grew more and more frustrated when I asked myself 'what am I doing? What have I been doing seeing all these thousands of patients?' I came to the rather depressing conclusion that we were propping up a system that was not only bankrupt but was actually generating illness in at least equal degree to the extent that we were actually curing anything.

As we have already heard, one of the manifestations of a sick society is this junk category of illnesses. For instance, much of so-called Medically Unexplained Symptoms (MUPS) and chronic pain is medicalised to no effect. My response has evolved over time. I got involved in research into this as best I could as a GP with very little available time and very little money. I will mention one project later. I joined the British Holistic Medical Association (BHMA), and I am now the Chair. I am tasked with modernising, or rather shifting the organisation, so that it addresses what I have just been talking about. More recently, I have moved into society. While most of my career was spent inside houses, now I'm out in the street among the dustbins. The Keynsham Action Network is an experimental organisation that aims to find a way of shifting the social norms of a typical middle-class town in a way that generates health.

Today, we are discussing the problem of the tyranny of diagnosis, and I want to talk about some of the possible solutions, or at least directions in which solutions might be found. Incidentally, I don’t agree with Rosenberg that diagnosis is essential. Quite a lot of consulting we do can be done without involving diagnosis.

In 2014, the Second International Conference on Preventing Overdiagnosis was held at Oxford and I submitted a proposal for a workshop which was accepted. The title was ‘If we are diagnosing too much what are the alternatives?’ It was sold out and much of what I have to say is a development of what happened there. We asked the participants, GPs and consultants from all over the world to bring stories about real patients for whom diagnosis was not terribly helpful. We divided them into groups to share their stories and asked them to try to work out why diagnosis was not helpful and then what might help. I was struck most by the lack of ideas – the frustration that they didn’t know what else to do.

Window 2: Jenny
A long time ago, I was called at about 11 o’clock at night by an anxious mother who said that her 7-year-old daughter Jenny, as we will call her, had a high temperature and seemed quite ill. I found that she was very hot and listless but quite lucid and I couldn’t find anything on examination. So I gave my usual advice and went home. At 6 o’clock the next morning, I got a call from the mother to say she’d got the spots I had told her about, and these were of course those of meningococcal infection. I was there in my pyjamas in about 5 minutes and she was in hospital within 10 minutes of that. Many years later, I happened by chance to meet her mother who reminded that I came to see her daughter who went to hospital and was very quickly treated, but developed meningitis from which she recovered after a long time. About 2 years later, she had a grand mal-fit and turned out to have epilepsy. Maybe she would have got this anyway. The mother continued,
She was never very good at taking tablets, but we made sure she did and she was OK. When she left school, however, things started going wrong for her; she started elicit drugs and stopped taking her prescribed anticonvulsants. One day she was found dead in her room. She was 27 years old.

I didn’t know how to respond. Her mother told me this story calmly, and there was no sense of blame attached to me. But I asked myself, although there was no evidence of it whatever, if by some sixth sense I had identified that the child was developing meningococcal septicaemia … I was left profoundly moved by that little conversation, and thought about it a great deal. And a fair bit of what I have to say is informed by that.

Window 3: labels
Maria Bello is an American lesbian icon. She talks a lot about labels. One of her memorable quotes is ‘Figure out which labels disempower you and which labels shine with the light of the beauty of who you are or are meant to be’. Jenny had a label ‘I am an epileptic’. Whether that had any impact on what subsequently happened I don’t know, but it made me think a lot about labels.

In 2006, I became a GP commissioner. And I thought, right! – now I can make changes in the Health Service … ever naive! At that time, the Primary Care Trust didn’t want Practice-Based Commissioning (PBC) because we were poaching on their territory, and made it as hard as they possibly could for us to do anything. The PBC executives, of which I was a part, were encouraged to undertake the Belbin Team Role Inventory, based on Jungian personality types. I learnt that I was a PLANT. This means that I was individualistic, serious-minded and unorthodox. PLANTS may also have genius, imagination, intellect and knowledge … and be impatient with and disregard practical details and protocols. In business, the former are seen as ‘positive’ qualities and the latter as ‘allowable weaknesses’. I felt empowered by both sorts of quality!

Then recently, a friend identified me as a ‘tempered radical’; described by Meyerson and Scully as:

individuals who identify with and are committed to their organisation and also to a cause, community or ideology that is fundamentally different from … the dominant culture of their organisation. Their radicalism stimulates them to challenge the status quo. Their temperedness reflects … what they see as injustices or ineffectiveness, and are inclined to seek moderation …

So, being tempered, I would always stop short of causing serious trouble. My strategy has been to tell them what was crazy about the way things were; but, in the end, to just knuckle down and get on with working the system as it is. So this was another label to add to my collection. We can have several different labels for ourselves at the same time even if they are contradictory and may choose which to use in a particular situation such as a consultation. We may have to be two different people: the scientist at one level and the rounded individual at another and kind of slip between those roles.

Window 4: psychological inflexibility
ACT – Acceptance and Commitment Therapy – was developed by psychologists from elements of cognitive behavioural therapy (CBT), mindfulness and other aspects of Buddhist practice. It’s about people having fixed ideas and responses: ‘I am a pain patient’, ‘I am an epileptic’, ‘I am a PLANT’. Anything in the world around you that doesn’t correspond to that, you discount. I was involved in a research project run by Professor Lance McCracken in the pain unit in Bath. It was a pilot study undertaking ACT with primary care patients with chronic pain – in his amazing collection of essays ‘On Dialogue’, developed by David Bohm, quantum physicist and philosopher, between 1970 and his death in 1992. He describes his observations of productive dialogue which are very close to the fundamentals of ACT. I suspect that ACT could have much wider applicability across the spectrum of suffering in society because it challenges people’s fixed ideas and views that become part of their identity.

These fundamentals include the following: Acceptance – accepting
something that you hear or think and not rejecting it, but ‘suspending’ or ‘parking’ it. Cognitive diffusion – trying to distinguish between the content of thought and the process of thought, and in particular between thoughts and evaluation. (‘I am feeling hopeless’ is thought and ‘I am hopeless’ is an evaluation.) ‘Self as context’ has to do with distinguishing thoughts from beliefs. Values – something you might aspire to, reflect on and incorporate into your decision-making. Committed action – not walking away when it gets hard.

Psychological inflexibility – an inability to change and adapt. Everybody can change, but some people find it very hard. A fixed viewing package of yourself can legitimate behaviour. For instance, I might legitimate my outspokenness by saying I can’t help it, I’m a PLANT, and you’ll have to make allowances for me!

Window 5: creative art

We all know art is not truth; art is a lie that makes us realize the truth. (Picasso)

I am not talking about medicine with art, but medicine as art – the process of medicine understood as art:

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

My own variant of this famous saying is: ‘It is much more important to know what sort of physician has medical knowledge than what sort of medical knowledge a physician has’. This is why I have been talking about myself.

When Tony Blair carried forward the changes, begun under Margaret Thatcher and then John Major, to make the National Health Service (NHS) more like an industry and more commodified, I struggled with the stupidity of it all and turned again to research where I could feel I was at least trying to make changes. One of my projects, on what is written in patient notes, involved putting a novelist, Pat Ferguson, into GP surgeries, asking her to write a vignette about every patient, and sharing these with the doctor who saw the patient. In one she wrote,

Doctor: ‘So you’re artistic’. She couldn’t agree: too clear, too simple, and much too like praise, for the patient to accept that it might fit any of the chaos she knew to be inside her. The doctor only recorded the blood pressure.

This is creative art. When I showed selected vignettes to focus groups of doctors, the effect was extraordinary. They were appalled by the sudden realisation that they had sometimes completely missed the issue. This is a kind of kernel of what I have been talking about: that it is possible to understand someone’s suffering with a new pair of eyes – the eyes of a novelist.

Rita Charon, one of the founders of the Narrative Medicine movement, in a spell-binding lecture I heard her give in 2004, said, ‘When we see things in the world, we rescue them from formlessness by giving them form’. This is what the creative artist is doing: the artist in me knows that there is something in my mind that I can’t quite get or formulate into explanatory language, but I know it is there. She drew on the Aristotelian concept of mimesis which involves a three-fold process of attention: the process of taking notice, looking and listening (including history and examination) you go through when assessing a patient; representation (such as a diagnosis): you are giving what you see in your mind some visible and/or audible form; and affiliation: sharing the representation with others. This is a creative and imaginative process still pursued by most artists and with obvious resemblance to the medical consultation. Less obvious is its resemblance to science, still less biomedical science, but science can be regarded as a creative act. Aristotle said an artist’s copy of nature could be true, and Plato disagreed: I’m with Aristotle. Faced with the European Enlightenment belief that the scientist’s interpretation is considered truer than the artist’s, medicine has fallen in with the science camp. I hope we are beginning to build a bridge between the two.

In the book The Case for Working with Your Hands – or why office work is bad for us and fixing things is good, Matthew Crawford, who did a degree in philosophy and ended up as a motorbike mechanic, wrote ‘to be capable of sustaining our interest, a job has to have room for progress in excellence’. This really resonated with me. I had spent my GP life developing a way of practising that became progressively detached from the mainstream – but it worked – my surgeries were always full with low use of hospital resources, high satisfaction and no complaints. Maybe I had at last found my way of being the creative artist that I was born to be? I realised, partly through that book, that this is art, and mending motorcycles is art. It’s not about the machine as mechanism, it’s about the relationship of the mechanic to his materials. He loved the bikes he mended. He brought them back to health.

Epilogue: forgiveness

Forgiveness is not about excusing people but about embracing human frailty and fallibility and taking responsibility for a society we may have helped to create. (Marina Cantacuzino)

That relates to the girl with meningitis. I had to forgive myself for not sending her into hospital at my first visit and perhaps preventing her from developing epilepsy, taking drugs and dying at 27, and her mother had to forgive me. When I retired, I reflected that I really loved my patients; some weren’t easy to love, but they became part of my family and I miss them. And finally!

It is difficult to get a man to understand something when his salary depends upon his not understanding it. (Upton Sinclair)
Professional perspectives

Animal farm: the meaning of being a ‘Lay Patient’

Antony Chuter, Chair, PLC, BPS

The value of diagnosis and effects on Patients and Healthcare Professionals – We’re all patients, aren’t we?
What does having a diagnosis – or not having one – mean to a patient?
What does it mean to me now and what did it mean in the past?

My story
I am going to tell you all about my life because it interacts with my experience with clinicians, and every interaction is with a whole person.

My early childhood was a happy one, but my mother’s breakdown when I was five was the starting point for some very difficult years lasting into my teens. I suffered sexual abuse and bullying and reacted to the latter by developing a skill in causing ear infections and a faked dislocating jaw which kept me out of school on many occasions, but finished up with me having an unnecessary operation. School did not feel like a safe place, being home alone felt safe. I had become very isolated with a profound mistrust of adults. When I left school I went to catering college where I started having blackouts. I was diagnosed with Marfan’s syndrome and the specialist wrote to my general practitioner (GP) recommending that I should not be told; this letter was lost in my notes.

Around this time I met Nick, who gave me my first taste of happiness in life as we shared our love of mountain climbing and sailing. But then I started getting renal colic. I did not know what it was; I just knew I was passing white powder in my urine and frequent attacks of colic, sometimes twice a week. My GPs just gave me pethidine which was great for the renal colic but bad for the rest of my life. I entered a black hole; that year I lost my job, my relationship with Nick and my home.

All this time I had never had a diagnosis and I really wanted one. I had a jumble of symptoms and contradictory positive and negative tests. Every time a test was negative I felt I was not being believed. I got really angry with my clinicians, with whom I had experienced a lifetime of poor relationships. They had not given me a magic pill to take away my pain and give me my old life back. I bounced around different clinics and saw urologists, nephrologists and other specialists but I still do not have a name for my condition even today.

I became depressed and anorexic. I went out once a week to the supermarket at 3 o’clock in the morning because I could not cope with being around people. I grew my hair long because I couldn’t face having it cut. My life had disintegrated. I felt suicidal. I received lots of well-meaning suggestions from people trying to cheer me up, but they could not really know what it is like to be in pain day and day out. I was completely hopeless and never thought my life would change.

Then I joined the Samaritans. I do not know who was helping whom most, but it did give me a bit of my life back as I felt useful again for the first time in a number of years. Eventually I was sent to a pain clinic. The most useful thing that was said to me there (by an occupational therapist) was ‘no-one can say you’re not in pain – you know you are’. Until that point I had always felt disbelieved, perhaps some of this was guilt about the operation that I had, but the occupational therapist really helped. I did not find the pain consultant very helpful. He enrolled me in the Pain Management Programme which did not work for me: I felt it was a group of professionals telling me how to live without living my life with me, there was no empathy. The consultant decided to do some sort of procedure involving a long needle; I still don’t know what it was. And when I was in recovery he came in and asked me ‘are you in pain?’

When I replied that I was, he said, ‘well, it didn’t work then’ and walked away. In other words ‘YOU HAVE FAILED’.

The expert patient
A few years went by and I found a new GP who was the first to say ‘I don’t know’. He showed me that he was human. He got me ‘into’ psychotherapy and I started to sort my head out about my past and my childhood. The therapist was also very good at helping me to come to terms with
Living with pain that it was not going to go away, I found the Expert Patient Programme and became a volunteer which gave me a job 3 days a week. I became involved in my local Strategic Health Authority and set up my first patient group. I also became involved with the Royal College of General Practitioners, in setting up a patient group, and before I knew it I was elected chair and ended up speaking to 70 GPs at the College Council and telling them how it was for patients.

My confidence increased and I became an activated patient. The aim of becoming an activated patient is for patients to go from being passive and inactive to active in their own care. So in 2005, I was still in pain but had a new perspective. But, then I developed a heart arrhythmia. When the cardiologist’s secretary went through my notes she found the letter about my Marfan’s that had been lost all those years ago, and the cardiologist suggested my condition ought to be treated. I was then referred to another specialist who said that the original diagnosis was wrong! So I went from not having, or not knowing about, a diagnosis buried away for 20 years to having a diagnosis and then not having a diagnosis! And I am now told I have osteoporosis as a result of my kidney condition. So the search goes on …

The value of diagnosis

So does diagnosis mean something different to patients and health professionals? For the patient, having a diagnosis can be reassuring, but it can cause anxiety about the future path of a condition. It can make symptoms less worrying and put them into perspective, depending on the condition. I believe that for the health professional diagnosis provides a certainty about treatment and also a checklist of potential disease progression and perhaps a satisfaction in having solved a problem. But something can be lost. In solving the problem you can lose something from finding the right treatment for the person. In the best case the diagnosis will help the relationship between the doctor and the patient and in shared decision making. But, in the worst case diagnosis can create a very rigid care plan where the doctor dare not stray from the guidelines and the patient feels unheard.

We’re all patients, aren’t we?

All animals are equal but some are more equal than others. (George Orwell’s Animal Farm)

An estimated 1 million people work in the National Health Service (NHS) out of a UK population of 65 million. So there are some 64 million people who have never had any medical training or worked in a profession allied to medicine.

The psychologist Albert Bandura studied the ways in which people and groups learn and how behaviour changes. Bandura showed a video of some adults beating up a clown to some kindergarten children who were then sent out to play. They found Bobo the clown in their play area and they hit him and shouted ‘YEE HAI!’. This is the basis of Bandura’s theory of learning by modelling, once something is learned it changes our behaviour.

If you have bought a car you have been to a second-hand car dealer, you may have felt a little disempowered and wonder whether you have paid a fair price or been ‘ripped off’. There is always that niggling feeling that they know more about cars than you do. Sainsbury’s do a lot of market research and collect data on us but would not want market research people talking to their own staff. So anyone who has had clinical training or who has ever worked in, even a minor role, in a clinical establishment has had their behaviour changed and has a different outlook on life.

The health service trains you in how to deal with the health service, so that when you first come into it as a patient you are unprepared to get the best out of it. You have not learned to get the best out of appointments so you come away feeling that you have missed much. It takes time to really get organised around dealing with health professionals. The first time you see them you are ‘sussing each other out’ and the next time you have got a better idea of how to get the best out of the few minutes you have got with them.

My present day job involves recruiting lay patients for research projects. My definition of lay patient is someone who has not received any clinical training of any kind and/or has never worked in any profession allied to medicine.

I have found that patients fall into four main categories:

1. Healthcare Professionals with experience of a long-term health condition and/or a life-limiting or life-changing health condition

A long-term, life-limiting or life-changing health condition can change Healthcare Professionals into more sensitive and empathic individuals. It can add a level of humbleness to them and the care they give; in short, it makes them more human. But, insider knowledge can be uncomfortable as well as comforting. Understanding how the system works and knowing people can also be a double-edged sword. Their knowledge mixed with their work and their own health experiences can mean that they will be looked on as experts on both sides...
of the fence. Their training and experience may be seen to have created an unacceptable bias.

2. Lay patients or public members with experience of a long-term health condition and/or a life-limiting or life-changing health condition

With the right support these can become ‘activated patients’ and learn to self manage many aspects of their symptoms to improve their quality of life and do some of the things they want to. This is a growing group of people, the NHS and society needs them. They make good lay reps but can be stuck in their area of experience. They can be great at running things like Expert Patient Programme ‘self management’ courses. They can be less helpful in public health research as they carry bias towards their condition being more important than others. Misinformation on the internet may give rise to confusion, misunderstandings, worry, anxiety and frustration.

3. Healthcare Professionals without experience of a long-term health condition and/or a life-limiting or life-changing health condition

These people have been on the other side of a desk and have been involved in some way in a patient’s treatment. Their experience of health care is very biased by their training and their work with patients and the public. They probably think that they know how to get the best out of the system. While they may not be experts on the whole system, they have much more insight into how things work from both system and disease perspectives. They have contacts who will help and advise them. This advice would not normally be shared with the public.

4. ‘Green’ Lay patients or public without experience of a long-term health condition and/or a life-limiting or life-changing health condition

These people may have used health services, on an occasional basis, or even had small operations and treatments which have been time limited. Most of the population fit into this category and their voice is usually under-represented in healthcare research and service re-design. Their experience of healthcare is very limited, and they are unaware about how the system works and how to get the best out of it. They too may have been misinformed by the Internet. They are also a desirable group for involving in Healthcare Research teams, but there needs to be a balance between them and lay patients in the other categories.

There needs to be a change in the way ‘green’ people are involved in decision making. The British Pain Society does try to engage with decision makers and is supportive of patient informed research and care. The Patient Liaison Committee is probably not funded sufficiently to do all that is needed at present, but it was involved in the care pathways which attempted to inform the commissioners the way to improve commissioning for pain.

Join our Special Interest Groups (SIGs)

The British Pain Society recognises the importance of providing members who have specific interests with a forum (Special Interest Groups) to discuss their interest in more depth. The Society actively encourages and supports the development of such Special Interest Groups, as they are an important element of our multidisciplinary Society and are a key member benefit. There are currently 14 SIGs;

- Acute Pain
- Clinical Information
- Headache
- Information Communication Technology
- Interventional Pain Medicine
- Medicolegal
- Neuropathic Pain
- Pain Education
- Pain in Children
- Pain in Developing Countries
- Pain in Older People
- Pain Management Programmes
- Philosophy & Ethics
- Primary & Community Care

For more information about any of our SIGs and how to join please visit: https://www.britishpainsociety.org/for-members/special-interest-groups/
What is diagnosis?

Paul Dieppe  Professor of Health and Wellbeing, University of Exeter Medical School

Like many of you, I find medical practice confusing and this issue of diagnosis one of the most confusing aspects of it. Is diagnosis getting in our way? Is it good or is it bad? – well, it’s actually both. So what then is diagnosis? Wikipedia defines it as ‘the process of determining which disease explains a person’s symptoms and signs’. Another definition states that ‘it is uncontroversial … that diagnosis means a medical, disease related explanation of symptoms’ (!) What those definitions add up to is that diagnosis is now being interpreted as being about a single disease within a biomedical framework to explain what are considered abnormal symptoms and signs. And this covers a lot of the evils and problems around this area.

But what are we for? I would posit that this is to help people to find out what is causing their sense of disease, and help them find their own way to resolving those problems. This is quite different to finding a single biomedically related disease and may involve finding many different, complex and interacting predisposing factors. My mentor at Barts, Dr H.W. Balme, used to say, ‘There are three principles to appropriate treatment in medicine: Diagnosis, Diagnosis and Diagnosis’. Later, I realised that he was saying something much more profound than I had supposed: that there were many levels of diagnosis, and always multiple issues around a patient’s problem. Our problem is that most of us can only cope with one epistemological framework within which to find a single diagnosis; we are stuck in linear positivism: this causes that and through that pathway. But we are complex human beings living in a complex society. We get into trouble by invoking Occam’s razor and saying you must look for single causes for everything before you start looking for multiple causes. I think that is horribly dangerous in medicine and we need a more pluralistic approach.

I am going to illustrate what I mean by discussing some painful rheumatologic diseases involving the knee and four diagnostic scenarios.

Scenario 1

A middle-aged, obese, hypertensive man. His knee is hot, red and swollen. The most likely diagnosis is gout, with septic arthritis as the most important alternative. You make the diagnosis by taking off some fluid, looking for uric acid crystals with a polarised light microscope and culturing it. What is the best treatment for gout? – probably nothing at all, because as Hippocrates was well aware, an acute attack of gout usually goes away within a week, meaning that any treatment you offer (or none) is going to be successful. I explain it as being to do with uric acid crystals and Hippocrates explained it in terms of humeral theory and ‘excess’. His and my patients both got better, and we both provided them with an explanation and meaning. This and reassurance that it would go away was all they really needed. So we both did good within completely different diagnostic paradigms. Hippocrates’ diagnosis was ‘syndrome-based’ and ours more aetiolologically based, but both address the cause and neither of us is ‘wrong’. Gout needs to be diagnosed and differentiated from things like septic arthritis and lot of good medicine does involve accurate diagnosis within a biomedical framework, but it is important, in our diagnostic angst, that we don’t throw the baby out with the bathwater. Certain diagnosis is not a tyranny, but it’s a very good thing to get it right.

Scenario 2

A woman in her 30s who is feeling generally unwell with joint pains in her hands and feet as well as her knee, and morning stiffness. Many of her joints are tender and a little swollen. The diagnosis is almost certainly rheumatoid arthritis (RA) which doesn’t seem to have existed...
in Hippocrates’ time, but we now think it is a discrete disease that we can diagnose and understand. The treatment is a highly contested area, dominated by industry and lots of nasty drugs, some of which are very expensive, and all dangerous. The cheaper ones are probably as good as the expensive ones, but the important point is that whatever we do, some of our patients will respond and others won’t. And within biomedicine, we can’t understand that.

One possible explanation is that it’s not really a homogenous ‘disease’, and there is evidence from other healthcare systems that that is the case. Take the approach of Chinese medicine to polyarthritis. They would diagnose this lady with RA, but then they would go further and diagnose it as being either ‘hot’ or ‘cold’ according to other symptoms and clinical findings. ‘Hot or cold’ means something different from what we understand within biomedicine and does not link or correlate with serological subtyping, and is more to do with the balance of your body and the totality of your person. There is evidence that a systems approach combining Chinese and Western Medicine to make a more sophisticated diagnosis, taking us out of the purely biomedical paradigm, will probably work better in terms of individualising treatment. The lesson here is that many of the ‘diseases’ that we diagnose are not discrete entities; rather, they just provide a convenient way of classifying our patients until we can understand things (and people) better. Things like polyarthritis, however, are more like gout in terms of the helpfulness of understanding the disease process than they are in my next two scenarios which are much more problematic.

Scenario 3
A 69-year-old man who used to be very athletic in his youth, who is very overweight but otherwise fit. On examination, you find crepitus in his knee. It’s actually me, and according to diagnostic medicine, I have osteoarthritis (OA). My x-rays show a lot of narrowing of the medial joint space with some osteophytes and even a bit of chondrocalcinosis, which would be classified as Grade 3 OA. It’s pretty symmetrical in both knees. So what is the treatment for this? … well, Lord alone knows. The treatment has nothing to do with the diagnosis as we have nothing that affects the changes in my x-rays, and even if we did, there is no certainty that it would make any difference, so is there any point in diagnosing it at all? One knee hurts sometimes and the other one doesn’t bother me, but they are both the same on x-ray; there is a very poor correlation between x-ray changes and pain, so we are diagnosing a pathology which doesn’t actually relate to the symptom. Do I know how they relate? – I have no idea and I’m supposed to be an expert in OA. My orthopaedic colleague has offered a replacement but I haven’t let him do that yet. So what are the advantages in having a diagnosis for my knee pain? Well, first of all, it legitimises my being able to say ‘sorry guys – I really can’t come for a long walk with you this afternoon’, and it opens the door to some caring pathways like having a nice young physiotherapist treating my knee. But it does have some serious disadvantages. I may have pain for different treatable reasons. OA within our culture is considered to be chronic, progressive and untreatable. That’s nonsense, but I might choose to believe that if I wasn’t a rheumatologist who specialises in OA.

And I might avoid walking in case I might make myself worse. OA is difficult in people like me but there is a group of people whose joints fall dramatically to pieces and are cured by surgery – one of the miracles of modern biomedicine. We are doing about 100,000 joint replacements in the United Kingdom now and at least 80% of them are helpful. So modern biomedicine is making a big impact on something in the mix here. Where is it in the mix and what is going on with the rest of us? How we deal with it diagnostically is frankly beyond me – I don’t know and I’m supposed to be an opinion leader in OA.

Studies of placebo in OA which have a no-treatment control group in the study (otherwise you don’t know whether it is just regression to the mean) suggest that the real effect of sham treatment is rather bigger than tablets or physiotherapy or anything else with the exception of joint replacement. So doing nothing is the most effective thing to do provided you do it in a way that maximises the placebo effect. You are much more likely to be able to do this in clinical practice than in a clinical trial situation, and in the real world, placebo is fantastically effective for conditions like this. Suggestion may be involved but I think it’s more to do with one human being interacting with another. I have had healing for my own knee joint which in a sense is one of the most powerful forms of positive interaction between two human beings. And it’s worked pretty well. (Our recent work on placebo suggests that placebo is not the issue, it’s nocebo. We mostly do harm most of the time. Nocebo is about five times more powerful than placebo – that’s deeply scary.)

I recently learnt from a homeopathic practitioner who treats knee pain, that as well as the arthritis, he takes into account of what else is happening in the patient’s life and the whole totality of the person – detecting a sort of pattern from this and prescribing accordingly. No two individuals with OA of the knee would
What is diagnosis?

ever get the same remedy. I think that is fascinating and who are we to say it is wrong? The results may be more to do with the interaction than what is in the bottle, but I think it’s somewhat arrogant of us to say that it can’t possibly work because of the dilution, and it doesn’t accord with our understanding of the physics of the universe now.

So the lesson from scenario 3 is that it is a mistake to always try to explain symptoms by finding some pathology or pathophysiology even when there is no justification for that approach.

Scenario 4

My final scenario, one you are all familiar with, is that of a 46-year-old woman with knee pain and a history of migraine and irritable bowel syndrome, who says she is sleeping badly and seems anxious. She has pain all over her body and multiple tender points. Diagnosis? Fibromyalgia, somatoform disorder, chronic pain as a disease, medically unexplained symptoms (MUPS)? Or any other equally meaningless option. They’re all useless …

How do we make the diagnosis? By exclusion? This is where the biomedical model becomes really stupid. We are trying to apply the gout paradigm to this patient who demands tests to exclude diseases such as lupus or cytomegalovirus which she has heard can cause her symptoms. What she is doing is searching for the meaning and legitimisation which our biomedical system can’t give her. And we can’t give it to her by chasing a diagnosis.

And of course you can never completely exclude the possibility of an organic disease. Diagnosis is about probability but statistics don’t really help us at all because this isn’t a scientific dilemma, it’s an ethical one. The search for a biomedical diagnosis as a way of finding meaning can be counterproductive and get in the way of understanding the patient.

Instead of using ridiculous terms such as ‘Chronic Pain as a Disease’ or ‘Medically Unexplained Symptoms’, why can’t we just say we don’t know? This isn’t necessarily the same as saying we can’t help, but it might be if we are stuck in a biomedical paradigm.

Are we as doctors, imbued as we are with the biomedical concept, the right people to help such fellow human beings? The priest and the community at large used to provide the way out but we have lost that in our culture, so for most people, there isn’t anywhere else to go.

The situation suits industry perfectly, and we are helping the great evil of industrial control and commercialisation of medicine to succeed. Biomedicine and research are in control of companies with a vested interest in the maintenance of disease and in turning symptoms into diseases whenever possible.

The matrix

According to the concept of the matrix which was originated by the philosopher Hacking, diseases are a construct of society working in conjunction with the dominant medical narrative – we all have latent disease (symptoms and signs that might be considered abnormal) and they can easily be turned into a disease by a healthcare professional, a well-meaning friend or a medical test. People with low resilience are often happy to be legitimised by being given a stupid label like MUPS, and they will find a way of fitting into a given syndrome like fibromyalgia (or neurasthenia, or multiple allergy syndrome, or whatever is ‘in’ at the moment). Within this concept of the matrix, ‘looping effects’ occur. Fibromyalgia and MUPS are in at the moment and multiple allergy and neurasthenia and repetitive strain injury are out, but it doesn’t matter because the looping effect with the dominant narrative in society means in effect that whatever society wants you to get at the moment you will get. And the best way to make sure that happens is a self-help group.

Helping people like my patient in my fourth scenario requires us to abandon our biomedical, diagnostic paradigm, and if we are to be any help, it has to be at the level of working with them as another distressed human, just like ourselves.

From the discussion

Isn’t the fundamental problem the delusion that diagnosis is a form of explanation? Whereas in almost every case, it is only a form of description – so that a more truthful thing to say is ‘I may be able to describe what is happening to you but I can’t explain it, and we have to look elsewhere for an explanation’.

As a clinician, you can be most effective if you can help a patient find their own key to their own way of getting better. Many patients are actually holding this key but they don’t know what it is or what to do with.
Neuropathic pain – an update

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Neuropathic pain, defined as pain caused by a lesion or disease of the somatosensory system, is common with some estimates for neuropathic pain prevalence as high as 17.9% and set to increase as global populations grow older and major drivers of neuropathy, such as diabetes mellitus, increase in prevalence.1 Strongly associated with neuropathic pain, either as predisposing factors or as complications, are comorbidities such as anxiety, insomnia and depression. Subsequently, neuropathic pain greatly impairs quality of life and incurs a high economic burden for both the individual and the society.

Neuropathic pain is unquestionably a major global health problem and has as such been recognised as a distinct clinical entity. A major obstacle in our understanding and effective treatment of neuropathic pain is the heterogeneous nature of neuropathic pain. The aetiology of the underlying disease process, genetic and environmental factors all interact in complex and unpredictable ways. Therefore, the underlying aetiology and abnormal neural plasticity have to be considered as equal contributors in the pathogenesis of neuropathic pain.

The last decade has seen significant advances in our understanding of the complexity of neuropathic pain in humans, stemming largely from the identification of rare genetic variants that substantially alter an individual’s perception of pain2 to improved phenotyping of the somatosensory nervous system of patients.3

Mendelian disorders of pain perception and small fibre neuropathy

In very rare cases, gene mutations can lead to complete insensitivity to pain, while other mutations can lead to increased pain perception. These mutations have been described in the voltage-gated sodium channels (Na+) 1.7, Na+ 1.8 and Na+ 1.9; in the transient receptor potential cation channel (TRPA1);2 and in the transcriptional regulator Prdm12.4

The voltage-gated sodium channels are expressed in peripheral sensory neurones and alter nociceptor excitability. Loss-of-function mutations in Na+1.7, encoded by the gene SCN9A, typically result in a clinical phenotype of congenital insensitivity to pain, congenital anosmia and no other detectable abnormalities in the peripheral or central nervous system. However, a small kindred in Japan and a single patient in Norway were identified, which demonstrated abnormalities within the autonomic nervous system and large nerve fibres. This distinct phenotype has subsequently been classified as hereditary sensory and autonomic neuropathy type IID. The mechanism of how loss-of-function mutations of Na+, 1.7 result in congenital insensitivity to pain is unclear. Potential explanations are a failure of nociceptor transduction, the failure of transmission of impulses to the dorsal root ganglia or failure of neurotransmitter release at the level of the spinal cord. Gain-of-function mutations in Na+,1.9, encoded by SCN11A, have been identified in two unrelated children and thought to result in congenital insensitivity to pain. These patients differ from those patients with loss-of-function mutations of Na+, 1.7 as they retain their sense of smell and suffer additional neurological problems, namely, muscular weakness, gut dysmotility and hyperhidrosis. The mechanism of how loss-of-function mutations of Na+, 1.9 result in congenital insensitivity to pain is most likely through the inactivation of other voltage-gated sodium channels with a resultant conduction block of nociceptor transmission. The loss-of-function mutations in PRDM12 result in congenital insensitivity to pain through the failure to form the PDRM 12 protein.5 PDRM 12 is a member of a family of transcriptional regulators that participate
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in the control of vertebrate neurogenesis and is thought to play a key role in nociceptor development. A key phenotypic characteristic of these patients is the complete absence of small nerve fibres in the skin.

In contrast, the gain-of-function mutations affecting Na\textsubscript{1.7} produce pain syndromes such as inherited erythromelalgia and paroxysmal extreme pain disorder. Inherited erythromelalgia patients suffer from episodic burning pain that involves the feet, usually accompanied with erythema of the painful areas. The pain is triggered by warmth and relieved by cooling. Most patients present by 20 years of age. Paroxysmal extreme pain disorder is characterised by episodic pain involving the midline of the body, especially the face and sacrum, and the pain is accompanied by erythema of the painful area. The onset of the pain is usually at birth, and defaecation is a common trigger. Familial episodic pain syndrome type 1 is caused by mutations in TRPA1, encoded by the gene TRPA1, and familial episodic pain syndrome type III is caused by mutations in Na\textsubscript{1.9} encoded by SCN11A. Familial episodic pain syndrome type 1 was identified in a large Colombian family, and the disorder is characterised by episodic pain involving the chest and arms. The pain is usually precipitated by stressors such as hunger or exercise and typically presents at birth or infancy.

Familial episodic pain syndrome type III was identified in two Chinese families that presented with episodic pain affecting the hands and feet. Pain episodes usually happened towards the end of the day and arose in clusters; triggers included illness and fatigue after exercise, and most patients presented within the first decade. The mechanism of familial episodic pain syndrome type III is postulated to be from hyperexcitability of dorsal horn neurones. In both familial episodic pain syndromes, the neurological system is completely normal as assessed by clinical examination and detailed investigations. Gain-of-function genetic variants in Na\textsubscript{1.7}, Na\textsubscript{1.8} (encoded by SCN10A) and Na\textsubscript{1.9} have been identified, which may cause small fibre neuropathy. Small fibre neuropathy is characterised by structural injury selectively affecting small diameter sensory and/or autonomic axons. The most debilitating consequence of small fibre neuropathy is chronic neuropathic pain that is length dependent, that is, primarily involves the feet and legs but can also involve the hands. The mechanisms of small nerve fibre neuropathy are not fully understood. Some gene variants cause altered neuronal outgrowth, while others alter sodium/calcium exchange with a subsequent axonal calcium influx that causes axonal degeneration.

Novel analgesic therapies have been developed based on the understanding of ion channels in nociceptive transmission. Na\textsubscript{1.7} blockers have recently been trialled in trigeminal neuralgia, and preliminary results demonstrated remarkable analgesic efficacy. The next step for these agents will be to be trialled in patients with acquired pain syndromes. There is sound rationale for this approach as polymorphisms have been identified in ion-channel genes, including SCN9A, that might affect an individual’s susceptibility to, and severity of, chronic pain after tissue or nerve injury. Polymorphisms in a variety of ion-channel genes have been associated with chronic neuropathic pain in disorders such as sciatica and HIV polyneuropathy.

Somatosensory phenotyping of neuropathic pain

The last decade has seen significant advances in a number of techniques used to define somatosensory phenotype in patients suffering from neuropathic pain. These include screening questionnaires, such as DN4 and painDETECT, that are designed to distinguish neuropathic pain from other types of pain using patient-reported pain descriptors; standardisation of quantitative sensory testing (e.g. the standardised protocol of the German Neuropathic Pain Network) that assesses evoked sensory perception in response to a defined sensory stimulus; and improved diagnostic tools of neuropathy such as skin biopsy for intra-epidermal nerve fibre assessment that allows easier and more reliable diagnosis of small fibre neuropathy. These techniques have shown that there are distinct subgroups of patients that have particular patterns of sensory symptoms and signs that may reflect particular pathophysiological mechanisms and potentially predict response to therapy and that previously unrecognised neurological injury may contribute to disorders such as fibromyalgia.

Two broad somatosensory profiles termed either the ‘irritable nociceptor’ profile with preserved small fibre function together with hyperalgnesia\textsuperscript{7} including dynamic mechanical allodynia or the ‘deafferentation’ profile dominated by sensory loss have been described.\textsuperscript{7} The ‘irritable nociceptor’ profile has been described in diverse conditions, such as polyneuropathy and post-herpetic neuralgia. A recent study demonstrated that oxcarbazepine is more effective for relief of peripheral neuropathic pain in patients with the irritable versus the non-irritable nociceptor phenotype.\textsuperscript{7}
Oxcarbazepine targets primarily sodium channels; thus, this study, although not definitely proving, suggests that upregulation of sodium channels on nociceptors may be an important pain-generating mechanism in at least a subset of patients. Importantly, this study was in line with a large amount of the experimental literature published on the role of sodium channels and neuropathic pain.

The ‘deafferentation phenotype’ is characterised by sensory loss in both large and small fibres. Neuropathic pain caused by diabetic polyneuropathy and HIV-related polyneuropathy are some examples of the ‘deafferentation phenotype’.

Sensory phenotyping has demonstrated that there are subgroups of patients that may share common mechanisms for the development of neuropathic pain; however, the sensory phenotype will be affected by the underlying aetiology of the neuropathy. For example, HIV and diabetic polyneuropathies both cause significant sensory loss with associated neuropathic pain; however, dynamic mechanical allodynia can be elicited in painful diabetic neuropathy but not in HIV polyneuropathy, and innervation for deeper structures is preserved in painful diabetic polyneuropathy but not preserved in HIV polyneuropathy. Such detailed phenotyping provides valuable clues that although HIV and diabetic polyneuropathies fall under the ‘deafferentation’ phenotype, there are clear differences between the diseases.

Attention patient phenotyping, including detailed questionnaires, has identified a group of patients that may suffer from pain as a result of autoantibodies directed to the voltage-potassium channel complex. A review at the Mayo Clinic identified 50% of patients with these autoantibodies described their pain with neuropathic descriptors such as burning and stabbing, and the pain predominately affected the limbs but also involved the body and face. Intriguingly, the patients did not have evidence of nerve injury, and it is entirely plausible that these antibodies are somehow causing nerve hyperexcitability with subsequent neuropathic pain. Antibodies to the β2 adrenergic receptor and muscarinic-2 receptors have been identified in patients with complex regional pain syndrome, and a small trial of intravenous immunoglobulin reported some pain relief.

Detailed somatosensory phenotyping has revealed that fibromyalgia, a chronic pain condition thought to be purely centrally mediated, has deficits within the peripheral nervous system. When compared to patients with depression and healthy control, fibromyalgia patients demonstrated multiple abnormalities consistent with small fibre dysfunction. Cold and warm detection thresholds, on quantitative sensory testing, were elevated, and pain-evoked potentials were reduced. Most importantly, a reduction in intra-epidermal nerve fibres on skin biopsy was observed, as intra-epidermal nerve fibre assessment is the gold standard in the diagnosis of small fibre structural injury (see below). To further explore small fibre function, recordings were performed using microneurography in patients with fibromyalgia. Microneurography is a neurophysiological method that allows single fibre recordings from human subjects. It allows recordings from small nociceptive and autonomic fibres. Microneurography demonstrated multiple abnormalities from C fibre nociceptors. Many C nociceptors were spontaneously active, generated prolonged firing in response to mechanical stimulation and had a distinctive pattern of activity-dependent slowing of their conduction velocities. Therefore, these series of elegant studies have demonstrated that whatever the fundamental the aetiology of fibromyalgia, there is clear nerve injury both at a structural and at a functional level which may contribute to the pain experience in patients with fibromyalgia.

The histological assessment of small fibre nerve integrity has been a fundamental development in diagnosing small fibre neuropathy. Quantification of intra-epidermal nerve fibre density is the most important advance in small fibre neuropathy diagnostics over the last decade and is probably the most validated technique to diagnose small fibre neuropathy. It involves obtaining a 3-mm punch biopsy 10 cm proximal to the lateral malleolus. There are very few contraindications and has a complication rate of less than 1%. As demonstrated in the fibromyalgia studies and genetics studies of voltage-gated sodium channels, intra-epidermal nerve fibre quantification is a valuable window into the world of small fibre pathology and is a worthwhile investigation for clinicians to consider if faced by a patient with neuropathic pain that cannot be explained.

Neuropathic pain treatment – updated guidelines

Despite fundamental improvements in our understanding of the pathophysiology of neuropathic pain, this has not been translated into improved treatments for patients. A major hurdle is that many patients with neuropathic pain do not receive appropriate treatment. A recent review of the guidelines highlighted that the reasons may include ineffective drugs and lack of knowledge of effective therapies and their appropriate incorporation into clinical practice. Recent guidelines were published by the Special Interest Group on Neuropathic Pain (NeuPSIG) of IASP based on an exhaustive summary of systematic reviews and meta-analyses. Drugs strongly recommended for first-line therapy include gabapentin, gabapentin extended release or enacarbil, pregabalin, the serotonin–noradrenaline reuptake inhibitors duloxetine or venlafaxine, and tricyclic antidepressants. Drugs with weak recommendation for use included capsaicin 8% patches, lidocaine patches and tramadol as second-line agents.

Botulinum toxin A (subcutaneously) and opioids are recommended as third-line agents. Inconclusive recommendations applied to a host of drugs and treatment strategies that included combination therapy and carbamazepine. Weak
Neuropathic pain – an update

Recommendations against the use of cannabinoids and valproate, with strong recommendations against the use of levetiracetam and mexiletine, were adopted. These recommendations are readily accessible and should hopefully be adopted by most clinicians working at primary care level.

Neuropathic pain is a global health problem that needs a sustained and unified front to combat. Mendelian pain disorders are very rare, but they have enhanced our understanding of the molecular mechanisms of nociceptive transmission substantially, and with continued standardisation and systemic investigation of the nervous system in patients with neuropathic pain, a greater pathophysiological understanding will hopefully hold the key for the development of new classes of analgesics.

Acknowledgements
I would like to thank Annina Schmid for her invaluable advice in preparing this article.

References

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How to amend your membership details on our new website?

To check or amend your details, you need to sign-in to your Online Account.

Once signed in, click on My BPS and then My Account. Here you will see Update Details, Change Password and Change Email Preferences.

When you have made your updates, please click Submit.
Bradford Teaching Hospitals NHS Foundation Trust is set within the fourth largest metropolitan district (in terms of population) in England. The district has the largest proportion of people of Pakistani ethnic origin (20.3%) in England. The largest religious group in Bradford is Christian (45.9% of the population). Nearly one-quarter of the population (24.7%) are Muslim.1

Pain management programmes (PMP) are a Westernised concept, covering topics such as self-management, goal setting, pacing, assertiveness and communication.

A PMP with an interpreter takes much longer. Using an interpreter in a group setting often leads to the loss of flow of thought, discussion, meaning and interaction between participants. Given the demographics of Bradford and the background of patients who are referred into the service, the Living with Pain Team have been looking at ways to cater more specifically for the needs of the South Asian pain population.2 The work by Patel et al.3 in Leicestershire, which has similar demographics to Bradford, looking into chronic pain management in primary care, provided an invaluable foundation. Topics such as pacing, compassion and assertiveness are uncommon in the South Asian community.4 The development of a culturally specific PMP was initiated by Mohammad Shoiab, a physiotherapist, and Dr Razia Bhatti Ali, a clinical psychologist, who met up with the Trust’s chaplaincy manager Mohammed Arshad, who has worked within the Trust for the last 15 years. The latter’s input has been invaluable, in helping to dispel cultural and religious myths regarding what persistent pain is.5,6 Dr Asim Suleman, a General Practitioner with Special Interest (GPwSI) in Pain Management also provided incredibly invaluable support. Within the South Asian community, patients often hold doctors in very high esteem, so often have full faith that a doctor will be able to ‘cure’ the pain with medication or an injection.7 Dr Suleman’s role involves a talk about the paradigm shift necessary to move from dependence on pain medication and the concept of self-management that needs to incorporate all the aspects of the PMP into patients’ daily lives.

The Urdu Living with Pain Group Programme runs as a 3.5-hour session for 8 weeks. One of the leaflets produced to educate patients is titled ‘Islam & Chronic Pain Information Leaflet for Muslim Patients’. The use of this leaflet has proved to be extremely successful as it helps patients with often the most important challenge of persistent pain, acceptance, but within their own cultural and religious context.8 Another important tool for the delivery of this PMP is the use of Mr Arshad’s other prize-winning leaflet: ‘Taking Care of Your Health, Islam and Chronic Pain’. The development of this leaflet had previously helped to ensure effective care and treatment for Muslim patients attending the Physiotherapy Department at Bradford Teaching Hospitals NHS Foundation Trust.

Mindfulness techniques are covered during the PMP, in addition to the use of an Urdu relaxation CD that was sourced along with various videos which patients found very helpful. Many members of the South Asian community are unable to read or write in English/Urdu/Punjabi, therefore these audio-visual aids help to provide further support this section of the pain population. Since many patients, particularly females, are often socially isolated and feel depressed,9 it has been useful to be able to put them in touch with their nearest exercise/self-help groups on completion of the PMP, in order to further promote long-term pain self-management in these patients.
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A language-specific and culturally adapted pain management programme

Throughout the 8-week sessions, many tears are shed and patients have defined their experience as a ‘light at end of a tunnel’ as they had previously struggled to come to terms with living with persistent pain or lacked access to language/cultural-specific information. Patients are invited back for a 3-month review, to evaluate progress.

As Maki et al.4 found, having an understanding of a patients’ culture-specific social relationships may help to inform clinicians on how to advise about pacing activities of daily living, communicating pain experience and delegating home or work responsibilities.

References

RCGP One Day Essentials: Pain Management
Jointly organised with BPS Primary Care SIG
Wednesday 27th January 2016
RCGP, Euston Square, London

Topic include:
Headache – Diagnosis & Management for GPs
Opioids in Primary Care
Pain Rehabilitation
Placebo and Central Pain Modulation
Fibromyalgia
Joint examination workshops

Can drawings assist us in understanding children’s pain better?

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Drawings: why are they useful?
The use of children’s drawings for assessment and therapeutic purposes has a long tradition in psychology and education, both in research and in clinical practice. Over the past several decades, research has demonstrated that projective assessment techniques are often used to help children express emotions in the hospital setting, with the use of drawings the simplest of these methods.

The purpose of this article is to present a brief review on the use of children’s drawings in the clinical setting in order to gain a richer understanding of children’s beliefs and experiences in a holistic and child-centred way. In a review, Driessnack found that few methods exist to elicit children’s thoughts. Traditional methods, such as questionnaires, surveys and directed interviews, are often adult-centred, adult-dominated and biased. Drawing, alternatively, is a natural mode by which children may express their feelings and emotions, particularly children with serious medical conditions. Children’s drawings are a form of non-verbal communication, existing as a projection of their personalities, including how they see themselves, their experiences and important people in their lives. In summary, their drawings are a way to see the events suited to effecting a transformation of the unconscious. Indeed, although children often lack the ability to pinpoint the specific effects they experience, drawing is often found to be an accessible language they can use for emotional expression.

Drawing as an assessment of self- and pain-perception in children
Two of the most commonly used projective drawing techniques include person drawing (e.g. Draw-A-Person test and Human Figure Drawing test) and family drawing (e.g. Kinetic Family Drawing). Human figure drawings have been used to assess chronically ill children’s self-perception in view of their illness and are found to generate more descriptive information compared to verbal interviews. Kinetic drawings, as the name implies, are designed to include motion or an activity within the picture. The most popular of these drawings is the Kinetic Family Drawing which asks children to draw their family, including themselves, engaged in an activity. It is believed that this type of drawing displays the interpersonal communication, emotional support and activities characteristic of the family from the child’s perspective.

To summarise these two major tests:

- **Self and other person.** Two drawings are compared to determine the child’s self-representation in terms of organisation, body image and sense of self. For example, there may be no difference in size or organisation between the self and other person drawn, or there may be marked differences between the two.
- **Family.** This drawing provides information about the child’s perception of protection, safety and family support. It may reveal conflicts in the family and may provide an estimate of perceived support available to the child.

Children express their mood through the form and content of their drawings; the use of graphic illustration, the strength and direction of lines, the use of space and the choice of colours all provide clues regarding their current state of mind. It is therefore important that any analysis of a child’s drawing consider such elements in combination. Although drawings have been used to help understand children’s experiences of many forms of illness, this article will consider the use of projective assessment techniques to help children express their cognitive, emotional and contextual experiences of pain specifically.

Unruh et al. were among the first to explore the use of children’s drawings as an expression of their pain experience. Children (aged 5–18 years) who suffered from migraine headaches or...
Can drawings assist us in understanding children's pain better?

These findings were confirmed by Stefanatou and Bowler,\textsuperscript{20} who explored the perception of pain in children (aged 5–9 years) with sickle cell disease. Once again it was found that children's drawings could be categorised by content (site of their pain), colour (dark colours) and size (pain drawings were smaller).

In recent years, there have been attempts to analyse children's drawings more systematically, especially in headache and migraine. For example, Stafstrom et al.\textsuperscript{21} recruited a large sample of 226 children (aged 4–19 years), using their self-depictions of headache to provide valuable insights into their experience of pain and as an aid in the differential diagnosis of headache types. It was concluded that children's headache drawings are a useful adjunct for the diagnosis of headache type and provide valuable insights into the children's experience of pain: the most severe pain was illustrated by exploding heads, lightning bolts, jackhammers and even decapitation. Pain was perceived as coming from either outside or inside the head. This study also affirmed that headache drawings can be used longitudinally to provide additional information concerning clinical course. More recently, Wojaczyn'ska-Stanek et al.\textsuperscript{22} evaluated the usefulness of drawings of the child's headache in the diagnostic process carried out by a paediatrician and a paediatric neurologist. The child was asked, 'Please draw your headache', or 'How do you feel your headache?', without any additional explanations or suggestions. Recruiting a sample of 124 children (aged 5–18 years) with a diagnosis of headache (5–18 years) with a diagnosis of headache, black and red colours were most frequently, which signified severe pain.

Probably the most reliable method to interpret children's drawings is in combination with other information such as that derived from interviews or writing tasks. One of the first studies to adopt this approach was Mares,\textsuperscript{23} who developed a method of verbal–graphic diagnostics with quantitative and qualitative indicators derived from kinetic drawings and written comments of children's experiences with painful interventions in hospital. It was found that for an ill child the painful intervention was less stressful than the circumstances under which it was performed (e.g. inadequate preparation of the child, lack of social support). A further example is that of Woodgate and Kristjanson,\textsuperscript{24} who used semi-structured interviews combined with play or Draw-A-Picture related to children's (aged 2–6 years) pain experience in hospital following surgical intervention. The findings revealed children to experience many different types of pain, and that the most important aspect of care was to have their parent at the hospital.

Recently, qualitative child interviewing and drawings have been used in combination. Korteslouma et al.\textsuperscript{4} compared data from hospitalised children (5–11 years) and healthy controls. The drawings of hospitalised children frequently depicted medical procedures, whereas the drawings of the healthy children depicted more family relations. It was concluded that children's drawings can be a relatively simple yet effective method of determining their pain-related emotions. Twycross and Finley\textsuperscript{25} explored children's and parents' perceptions regarding the quality of postoperative pain management via three different methods: draw-and-write, semi-structured...
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In answering this question, we need to consider the effectiveness of using drawings as a projective technique. Interviews and writing answers to interview questions. Overall, the majority of children reported experiencing severe pain at some point post-surgery, although also reported satisfaction with the care provided. Most recently, Failo and Venuti26 explored how children and adolescents (7–14 years) with chronic disease cope with their pain. Behavioural, cognitive and emotional aspects of pain were assessed via traditional pain assessment scales and questionnaire, interview and observation, and projective drawings (Draw-A-Person,29,30 Child Drawing: Hospital,31 House Tree Person test32,33 and Kinetic Family Drawing15,16) continue to be regularly used as part of a general psychological test battery in many settings.34 Concerning validity and reliability, it may be concluded as Rollins10 suggests that a series of drawings by the same individual demonstrates constant structure and form, although content may vary. Thus, although clothing, details and accessories (content) may change, the size of figures, lines and placement (form) remain stable. Such techniques allow children to freely express their perceptions and experience, unbiased by perceived right or wrong answers and cultural influences. But we have to be careful, as when therapists interpret children’s drawings, they are typically guided by the way they themselves conceive and interpret the world and, especially, the way they believe children to perceive the world.3 Thomas and Jolley35 claim that drawing by itself is inaccurate and unreliable as a personality state assessment, but can nevertheless provide information on children’s emotional attitudes towards a topic and therefore can be very useful when used alongside other techniques.

Conclusion

In conclusion, it is believed that the most effective method of using drawings as a projective technique is via the use of multiple drawings, at different time points of the treatment process, to try and find an internal coherence of the child’s self-perceptions. It is also important to focus on what children say while they draw, which will likely help when assessing the validity of the drawing task. While children can also be interviewed or asked to write what the drawing means to them, care is needed not to unduly lead or influence their responses, which could otherwise undermine the usefulness and uniqueness of the projective drawing technique.

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Informing practice

Social ecology: where politics meets pain

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Background
Kate Pickett and Richard Wilkinson are famous for demonstrating an association between income inequality in a region (countries, US states) and poor social outcomes. This effect has been found in health and wellbeing, educational performance, imprisonment rates, obesity, teen pregnancy, violence and recycling.¹ It is independent of the wealth of the country, so long as the country has passed a certain wealth threshold. Importantly, Pickett and Wilkinson² put forward evidence suggesting the link may be causative. As Bartley³ points out, however, there is considerable debate about this, not least due to the political implications of such work (pp. 116–34).

We have increasing amounts of data on chronic pain inequality within countries, and these data tend to show that there is a gradient in chronic pain prevalence, incidence and severity with poorer people having more pain,⁴,⁵ in adults and children.⁶ To my knowledge, there are no studies which examine the association between income inequality and chronic pain among different countries. In this brief report, I combine data from published datasets to analyse this issue and to discuss some possible explanations.

This is very much a preliminary analysis based on existing data, so I do not propose to draw any conclusions. I hope merely to encourage debate and highlight the macro-social and political issues surrounding chronic pain.

Methods
The first dataset I used is the published data from the widely cited survey of chronic pain in Europe by Breivik et al.⁷ This was a large study conducted in 15 European countries and Israel in 2003 (see Figures 1–3 for the countries studied). It had 46,394 participants aged ≥18, of which 4,839 were further interviewed in depth. In line with other epidemiological studies,⁸ it found a prevalence of moderate to severe chronic pain of 19%, defined as pain which had lasted for at least 6 months, having experienced pain within the last month, having experienced pain at least twice in the last week and having a pain intensity of at least 5/10 on a 1–10 (sic) numerical rating scale the last time they had pain. Unfortunately, data on the socioeconomic status or position of the participants were not collected. I used this particular study because, although now quite old, it has a well-described methodology standardised internationally.

Second, I used data from the Organisation for Economic Co-operation and Development (OECD)⁹ on the Gross Domestic Product (GDP) in 2003 of the countries studied in the pain in Europe survey. The GDP of each country was converted into US Dollars using average exchange rates for 2003, also obtained from the OECD.⁸ I also utilised a commonly used measure of income inequality – the Gini coefficient. This was obtained from the OECD Income Distribution Database.¹⁰ The Gini ranges from 0 (total income equality) to 1 (total income inequality) and can be calculated for any given geopolitical unit. It can also be calculated for before or after taxes and transfers. The coefficients used here are after such redistribution. The OECD does not hold Gini coefficients for all countries for every year. Where a coefficient was not available in 2003, a coefficient from the most proximate year was used. Finally, I obtained benefits expenditure data for each of the countries in 2003 from the...
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OECD.9 I conducted analysis in R with scatter plots, linear regression and Pearson’s correlation coefficient.

Results and discussion

Inequality and prevalence

When we look at the prevalence of chronic pain as defined above, we find that it was not associated with GDP and, rather surprisingly, that it was also not associated with inequality (Figure 1(a) and (b)). However, Breivik et al.7 also provide data on the prevalence of severe chronic pain – the proportion of people who met the above definition but reported pain intensity ≥8 last time they had pain. As expected, this was associated with inequality but not with GDP (Figure 2(a) and (b)).

The finding that moderate to severe chronic pain was not associated with inequality but severe chronic pain was interesting. Kawachi and Subramanian11 note that income inequality has been linked with a ‘promiscuous range of outcomes’ (pp. 138–9), some of which I noted in the introduction. ‘Science would’, they state, ‘be advanced by clearly stating the mechanism and specifying the hypothesised etiologic [sic] period’.

Pain is known to be sensitive to social factors. It is hypothesised that social stressors, such as the stress of adversity and relative deprivation, manifest themselves biologically through, among other mechanisms, the body’s stress response. The incidence of anxiety and depression as well as socially determined lifestyle factors may also be relevant here.1,3,12 These agents, which are distributed according to social position or social status, contribute to the incidence and severity of pain through shared neuro-endocrine-immune pathways.4,13

Could it really be that income inequality is irrelevant for moderate to severe chronic pain? This is unlikely. Other conditions which follow a social gradient within countries have been shown to be sensitive to income inequality between countries.14 Epidemiological studies have consistently found that the lower a person’s socioeconomic position, the more pain they have. We would therefore expect chronic pain to be sensitive to differences in income inequality among countries.

One source of error lies in measurement. Where Gini coefficients were not available for 2003, I used the nearest, which were 1 or 2 years out. This is unlikely to be a significant source of bias, however. The coefficients do change over time, but only gradually. In Germany, for example, the Gini rose from 0.280 in 2002 to 0.282 in 2003 and then to 0.285 in 2004. A more likely source of bias lies in Breivik et al.’s methodology, which used telephone interviews. As they acknowledge, these are much less likely to capture people of lower social status.

A particularly serious flaw is that I have ignored the effects of time and therefore the ‘aetiological period’. The life-course view of health inequalities stipulates that adversity accrues and compounds over time. We know, for example, that childhood adversity predicts chronic pain and depression in adulthood.15 It may therefore be the case that inequality in an earlier period (which I have not examined) is important for risk exposure to chronic pain, whereas contemporaneous inequality (which I have examined) may affect pain experience due to the embodiment of immediate psychosocial stress among those who have developed the disease.

Inequality and healthcare

One theory which explains the income inequality effect is neo-materialism. This theory posits that more unequal societies are less likely to spend on public goods such as quality housing, healthcare, infrastructure and transfers. As a result, public health suffers as everyone needs these goods and services and cannot individually afford them, except perhaps the very rich who are able to cocoon themselves away from the rest of ‘us’.3 The reason that we see an association between severe chronic pain and inequality might be because people who have pain, who are more likely to be poorer and therefore require public services do not have adequate access to them, and this in turn causes stress, anxiety, depression and other health problems, all of which, along with their pain, are not adequately treated.

I can only begin to test the last strand of this argument. Is pain more severe in more unequal countries because healthcare is less adequate there? Breivik et al.7 collected data on how many participants had seen pain specialists and how many had tried physiotherapy, acupuncture or massage.

There was a trend in more unequal countries of being more likely to see a pain specialist, although this was not statistically significant (Figure 3(a)). There was a trend the other way regarding physiotherapy but, again, this was not statistically significant (Figure 3(b)). Income inequality did predict the rate of acupuncture. In more unequal societies, the percentage of people who had tried this treatment was lower (Figure 3(d)). Inequality alone explained 39% of the variance. In summary, the more unequal the country, the higher the prevalence of severe pain (and possibly the more likely it is that people consulted pain specialists), but the lower the rate that people had tried acupuncture, and possibly physiotherapy.

There are at least two possible, fugal explanations. First, more unequal Western societies may be less willing to invest in therapies which are not part of the traditional biomedical model and which are therefore seen as outside the scope of appropriate public remuneration. Second, society’s attitudes to these therapies may be more welcome in more equal countries. People may be more willing to try them and therefore more willing to support their cost publicly or spend money.
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Figure 1. Income inequality, measured using (a) the Gini coefficient and (b) Gross Domestic Product plotted against moderate to severe chronic pain prevalence

BE: Belgium; CH: Switzerland; DE: Germany; DK: Denmark; ES: Spain; FI: Finland; FR: France; IE: Ireland; IL: Israel; IT: Italy; NL: Netherlands; NO: Norway; PL: Poland; SE: Sweden; UK: United Kingdom.

Figure 2. Income inequality, measured using (a) the Gini coefficient and (b) Gross Domestic Product plotted against severe chronic pain prevalence

BE: Belgium; CH: Switzerland; DE: Germany; DK: Denmark; ES: Spain; FI: Finland; FR: France; IE: Ireland; IL: Israel; IT: Italy; NL: Netherlands; NO: Norway; PL: Poland; SE: Sweden; UK: United Kingdom.
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Figure 3. Income inequality plotted against the proportion of patients who reported (a) seeing a pain specialist; or (b) trying physiotherapy, (c) massage or (d) acupuncture.

BE: Belgium; CH: Switzerland; DE: Germany; DK: Denmark; ES: Spain; FI: Finland; FR: France; IE: Ireland; IL: Israel; IT: Italy; NL: Netherlands; NO: Norway; PL: Poland; SE: Sweden; UK: United Kingdom.
themselves (of which people lower down the social hierarchy have more due to stronger redistribution policy – I shall return to this presently).

**Pain and social security**

Benefits cause a certain consternation among clinicians. Getting benefits on the back of one’s pain, the story goes, means that one has to somehow ‘get worse’ and will not recover. This is usually based on the personal views of the clinicians who themselves have never had any real contact with the benefits system and do not understand its rules. It is not evidence-based medicine.

The available data show that rather than being a predictor of poor outcome, receipt of disability-related benefits may in fact improve outcome.16–18 There is a plausible explanation for this. This money can provide much-needed stability in the lives of people who have chronic pain and therefore alleviate sources of stress, anxiety and depression19,20 that can make pain worse. Benefit expenditure data broadly concurs. Figure 4(b) shows the public expenditure on incapacity-related benefits in 2003 as a percentage of total GDP. It shows a borderline significant trend that as benefit expenditure increases, the prevalence of severe chronic pain decreases.

Figure 4(a), however, shows the opposite, borderline significant, trend for moderate to severe chronic pain. This alone, probably, does not tell us much. It would be premature to conclude that as benefit expenditure increases, the prevalence of pain increases because these data tell us nothing about prior experiences and exposure to risk factors for pain. Nor does it tell us anything about the lives of those reporting pain in relation to receipt of benefit income. It could be that in countries where benefits are higher and people with long-term illnesses more financially secure, people may have more control over their lives and their pain. There may be more pain, but those with it may have better control, hence why the rate of severe pain is lower. In countries where benefit expenditure is higher, for example, the proportion of people who have used acupuncture is higher (r=0.51, p=0.04, not shown).

**Closing remarks**

In this article, I have demonstrated a possible link between income inequality and pain. We saw that severe chronic pain prevalence was associated with income inequality. We also saw that inequality is associated with certain

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**Figure 4.** National incapacity-related benefits expenditure as a percentage of total GDP plotted against the prevalence of (a) moderate to severe chronic pain and (b) severe chronic pain

| BE: Belgium; CH: Switzerland; DE: Germany; DK: Denmark; ES: Spain; FI: Finland; FR: France; IE: Ireland; IL: Israel; IT: Italy; NL: Netherlands; NO: Norway; PL: Poland; SE: Sweden; UK: United Kingdom. |
aspects of treatment and that increased benefits expenditure did not necessarily equate to increased pain prevalence. I suggested some possible reasons for these findings rooted in health inequality and social ecology theory.

References
Book review


Pamela E. Macintyre, Stephan A. Schug

Being a practical guide, authors have deliberately avoided filling the book with basic theoretical knowledge of anatomy, pathophysiology and neurobiochemistry in order to maintain its practicality managing acute pain in everyday practice. Furthermore, authors have excluded paediatrics and obstetrics analgesia, thereby focusing mainly on acute pain management within the adult population. However, they have aptly covered surgical and non-surgical acute pain in adult patients, management of complex cases such as the elderly, opioid tolerant patient group and pregnant/lactating patients. Inclusion of a chapter in regards to opioid analgesia after discharge from hospital is particularly informative and answers many questions that a junior doctor may want to know while completing the discharge summary.

This book’s basic theoretical knowledge is confined to 60 pages discussing pain medication pharmacology. In this section, they have covered pharmacology of opioids, local anaesthetic agents, non-opioids and adjuvants covering each drugs’ side effects, warnings and contraindications which are all practice related. Although the basic theory dealt with in this book is not sufficient enough to meet the curriculum for Faculty of Pain Medicine and the Royal College of Anaesthetists fellowship examinations, it certainly meets the requirements of practising clinicians managing pain in acute settings on a daily basis. In our opinion, candidates who are using this book as a guide should have a basic knowledge of anatomy, pathophysiology and pharmacology in pain management in order to better understand this complex and continuously evolving field of medicine. A short chapter about non-pharmacological therapies may not be sufficient for candidates to be able to utilise available techniques; however, it is informative enough to be aware of such adjuncts.

Throughout the book, authors have incorporated various diagrams, guidelines and tables for the administration of opioids via different routes and for troubleshooting while managing acute pain. There are examples of prescribing opioids via various routes, but in practice, each candidate should refer to their local policy. Authors have utilised and combined evidence-based information with an extensive list of references for each chapter.

This book is available in ebook format and a 269-page print on acid-free paper version. It is fascinating to know that acid-free paper provides better durability, reduces yellow discolouration over years and is environment friendly. This book certainly should not be confused as a pocket guide; however, it can be easily carried in a bag for daily use and as a quick reference guide in different clinical circumstances.

Overall, this book is an excellent, simple and practical guide for all doctors, nurses and students within the medical and nursing field and also for those with an interest in pain management.
It's not all in your head

Neil Berry  Consultant Clinical Psychologist in Pain Management, Elected Member on the Council of The British Pain Society
Neil.berry@nhs.net

Those who read my earlier submissions to Pain News – on Improving Access to Psychological Therapies (IAPT) and Diagnostic and Statistical Manual of Mental Disorders–Fifth Edition (DSM-5) – won’t be surprised to learn that, on receiving the September issue, I made a beeline for Sandeep Kapur’s article ‘It’s All in Your Head’. Sandeep’s article was inspired by Suzanne O’Sullivan’s recently published book It’s All in Your Head: True Stories of Imaginary Illness. I too had read the book and had contemplated writing to Pain News. I was in two minds, however – not sure that I wanted to give the book the oxygen of publicity. Unlike Sandeep, I do not ‘commend it highly to anyone working within pain management’. It’s a readable, honest and often compassionate book which expresses the puzzlement and frustration that most clinicians experience when dealing with patients with challenging conditions. But it can also be said to be ‘a Marmite book’ as testified by the bimodally distributed reviews on Amazon.

The book’s title is surely designed to provoke, but it is also likely to offend. I hope that the title was not of Dr O’Sullivan’s choosing. Throughout the book, she reiterated that the patients she is describing were not imagining their suffering imaginary illness. She doubts, however, that their symptoms or suffering imaginary illness are disorders of the imagination.

She cites no research. Rather, she travels back over a century to the founding fathers of psychoanalysis: Charcot, Janet, Breuer and, of course, Freud. Psychological inferences and interpretations are afforded the same status as scientific tests. She does not doubt that if the patient can be helped to gain insight into the causal bonds that ‘must’ connect their (presumed) psychological distress to their physical symptoms, those bonds will be broken and the symptoms will disappear. If not, the symptoms ‘will go on until they are replaced by another expression of distress, another illness’. She cites no evidence to support any of this, however. She does not even provide evidence that her own patients – the patients she has based her book on – have benefitted from her efforts to give them psychological insights and from redirecting them to colleagues in psychiatry and neuropsychiatry.

Dr O’Sullivan demonstrates awareness of functional magnetic resonance imaging (fMRI) scanning and neuroplasticity and she views the move away from brain-mind dualism as ‘the greatest modern advance in thinking about psychosomatic illness’. Clearly, she has been trained in science, but in this book, she leaves science behind. According to Dr O’Sullivan, psychosomatic disorders ‘obey no rules … [they] are disorders of the imagination restricted only by the limits of the imagination’.

Dr O’Sullivan longs for a world in which her own faith in ‘the
It’s not all in your head

End stuff

It’s not all in your head

psychosomatic’ is widely shared both inside and outside medicine. She writes at times with the passion of an evangelist and the zeal of a convert. She clearly believes that psychological explanations hold the key to our understanding of many poorly understood conditions. More than that, she believes that psychological therapies offer the prospect of complete remission for thousands of patients. In that, she undoubtedly echoes the hopes of Freud and Co. more than a century ago – a hundred years in which the evidence to support the thesis could have been assembled. I am not inclined to suggest that we should abandon pain science and biopsychosocial pain management for a thesis based more on faith than on science. Fifteen years spent addressing the psychological distress of patients presenting with intractable medically unexplained pain has shown me that such pains can be rendered more manageable. Almost without exception, however, the pains persist.

References

Erratum
September Editorial which mentioned about Dr Bhadra’s article on Consent for Post Surgical Pain, quoted Dr Bhadra, as ‘he’. It should have been ‘she’.

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## New Members

### New Members ratified since August 2015

<table>
<thead>
<tr>
<th>Name</th>
<th>Post</th>
<th>Place of Work</th>
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<tbody>
<tr>
<td>Mr Yousaf Ahmad</td>
<td>Lead Pharmacist- Pain Services</td>
<td>Ninewells Hospital and Medical School</td>
</tr>
<tr>
<td>Mr Edward Baker</td>
<td>Lecturer Practitioner/ Senior Charge Nurse</td>
<td>King’s College Hospital</td>
</tr>
<tr>
<td>Dr Rav Bhandal</td>
<td>Clinical Psychologist</td>
<td>Royal Hampshire County Hospital</td>
</tr>
<tr>
<td>Mrs Joanne Bishop</td>
<td>Clinical Specialist Physiotherapist - Pain Management</td>
<td>University Hospitals of Leicester NHS Trust</td>
</tr>
<tr>
<td>Dr Christine Bonathan</td>
<td>Clinical Psychologist</td>
<td>Royal Free Hospital</td>
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<tr>
<td>Mr Kerry Booker</td>
<td>Clinical Psychologist</td>
<td>Salford Royal NHS foundation Trust</td>
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<tr>
<td>Ms Paula Bronson</td>
<td>Lead Physiotherapist Persistent Pain Service</td>
<td>Mile End Hospital</td>
</tr>
<tr>
<td>Dr Nicola Buccheri</td>
<td>Clinical Psychologist</td>
<td>Leicester General Hospital</td>
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<tr>
<td>Mrs Catherine Burns</td>
<td>Specialist Physiotherapist in Pain Management</td>
<td>Wythenshawe Hospital</td>
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<tr>
<td>Dr Jo Burrell</td>
<td>Highly Specialist Clinical Psychologist</td>
<td>Queen Elizabeth, Kings Lynn</td>
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<tr>
<td>Mrs Alison Cadman</td>
<td>MSK Outpatients Physiotherapist</td>
<td>Calderdale and Huddersfield Foundation NHS Trust</td>
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<tr>
<td>Professor Bernie Carter</td>
<td>Professor of Children’s Nursing</td>
<td>University of Central Lancashire</td>
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<td>Miss Jill Chanter</td>
<td>Clinical Specialist</td>
<td>Northern General Hospital, Sheffield</td>
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<td>Mrs Caroline Daniels</td>
<td>Sister</td>
<td>Wythenshawe Hospital</td>
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<tr>
<td>Miss Alice Draycott</td>
<td>Pain Physiotherapist</td>
<td>St George’s University Hospitals NHS Foundation Trust</td>
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<tr>
<td>Dr Clare Eldred</td>
<td>Health Psychologist</td>
<td>West Middlesex University Hospital</td>
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<td>Dr Emma Evans</td>
<td>Clinical Psychologist</td>
<td>Churchill Hospital, Oxford</td>
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<tr>
<td>Dr Mark Eveleigh</td>
<td>Anaesthetic Registrar</td>
<td>Bristol Royal Infirmary</td>
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<tr>
<td>Ms Carol Fennell</td>
<td>Physiotherapist</td>
<td>Salford Royal Foundation Trust Pain Centre</td>
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<td>Miss Rebecca Franklin</td>
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<tr>
<td>Mr Daniel Graham</td>
<td>Senior Physiotherapist</td>
<td>Primary Care Rehabilitation Facility</td>
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<tr>
<td>Dr Emma Harrold</td>
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<td>Addenbrooke’s Hospital</td>
</tr>
<tr>
<td>Dr Alison Hunter</td>
<td>GPST3</td>
<td>Tillicoultry Medical Practice</td>
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# New Members

New Members ratified since August 2015

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<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Mrs Helen Jenkins</td>
<td>Specialist Occupational Therapist</td>
<td>Herts Community NHS Trust,</td>
</tr>
<tr>
<td>Professor Suan-Phaik Khoo</td>
<td>Professor, School of Dentistry</td>
<td>International Medical University, Kuala Lumpur</td>
</tr>
<tr>
<td>Dr Susan Kidd</td>
<td>GP with interest in chronic pain</td>
<td>Strathmore Medical Practice</td>
</tr>
<tr>
<td>Dr Indre Kriukelyte</td>
<td>Speciality Doctor</td>
<td>Gwynedd Hospital</td>
</tr>
<tr>
<td>Mrs Joanne Marley</td>
<td>Doctoral Fellow</td>
<td>Ulster University</td>
</tr>
<tr>
<td>Miss Ashley Montgomery</td>
<td>Team Lead/ Advanced Practitioner Physiotherapist</td>
<td>Ulster Hospital Dundonald</td>
</tr>
<tr>
<td>Miss Michelle Morgan</td>
<td>Occupational Therapist</td>
<td>Leicester General Hospital - University Hospitals of Leicester</td>
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<tr>
<td>Dr Senthil Kumar Muthu</td>
<td>Consultant Anaesthetist</td>
<td>Wirral University Teaching Hospital</td>
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<tr>
<td>Dr Suneet Nayee</td>
<td>Locum Bank Anaesthetist</td>
<td>Hillingdon Hospital</td>
</tr>
<tr>
<td>Dr Lucy Nicholson</td>
<td>Clinical Psychologist</td>
<td>Whittington Hospital, London</td>
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<tr>
<td>Dr Louise Robinson</td>
<td>Clinical Psychologist</td>
<td>The Queen Elizabeth Hospital NHS Foundation Trust</td>
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<tr>
<td>Mrs Victoria Robinson</td>
<td>Specialist Physiotherapist</td>
<td>The James Cook University Hospital</td>
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<tr>
<td>Mrs Beth Roughsdale</td>
<td>Clinical Psychologist</td>
<td>Norfolk and Norwich Hospital</td>
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<tr>
<td>Dr Ahmad Saaed</td>
<td>Speciality Doctor</td>
<td>The Hillingdon Hospital NHS Foundation Trust</td>
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<tr>
<td>Dr Mohammed Sajad</td>
<td>ST7 Anaesthesia</td>
<td>The Dudley Group of Hospital</td>
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<tr>
<td>Miss Denise Sangster</td>
<td>Registered General Nurse</td>
<td>HMP Wormwood Scrubs Healthcare</td>
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<tr>
<td>Dr Melanie Smith</td>
<td>Clinical Psychologist</td>
<td>Salford Royal Foundation Trust</td>
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<tr>
<td>Dr Amelia Swift</td>
<td>Senior Lecturer/Clinical Academic Lead</td>
<td>University of Birmingham</td>
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<tr>
<td>Mr Warren Travers</td>
<td>Clinical Specialist Physiotherapist</td>
<td>St Thomas’ Hospital, London</td>
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<tr>
<td>Miss Sareeta Vyas</td>
<td>Assistant Psychologist</td>
<td>Cossham Hospital, Bristol</td>
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<tr>
<td>Dr Paul Watson</td>
<td>CT2b Anaesthetic Trainee</td>
<td>Royal United Hospital, Bath</td>
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<tr>
<td>Miss Angelika Wilczek</td>
<td>Clinical Specialist Physiotherapist</td>
<td>St. Thomas Hospital, London</td>
</tr>
<tr>
<td>Mrs Samantha Williams</td>
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