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British Pain Society Calendar of Events

2012

Commissioning pain services (25th Study Day)
Monday 10th September
Churchill House, London

Interventional Pain Management SIG Conference
Friday 28th September
Radisson Blu Manchester Airport, Manchester

Psychological therapies in the management of pain (26th Study Day)
Friday 23rd November
Churchill House, London

Pain Education SIG – One Day Seminar
Thursday 29th November
Churchill House, London

2013

Pain in Older People (27th Study Day)
Monday 28th January
Churchill House, London

Annual Scientific Meeting
16th – 19th April
Bournemouth International Centre, Bournemouth

More information can be found on our website
http://www.britishpainsociety.org/meet_home.htm
Or email meetings@britishpainsociety.org
It is not the strongest of the species that survives, nor the most intelligent, but rather the one most adaptable to change

Charles Darwin (1809–82)

Thank you very much for all your kind feedback about the last issue of our newsletter. It was really encouraging and motivating to see your responses and comments; it gives us more enthusiasm to work hard once again.

Peter Wemyss-Gorman always helps our newsletter by providing transcripts of the Philosophy and Ethics SIG lectures; in this issue, he has presented Andy Graydon’s talk on Mindfulness. I found this a thought-provoking talk; he states that we don’t live in the present and always want to keep one step ahead of things. We always think that a future moment is more important than the present one; we have got so much to do with so many deadlines. His description of climbing a mountain peak – the fact that each step has its own meaning, not just the last step to the peak – makes us realise the need to pace our life.

I immediately remember The Last Lecture by Randy Pausch (New York Times bestseller in 2008). Randy, a computer science professor in Carnegie Mellon, was diagnosed to have terminal pancreatic cancer when he was invited to give a lecture in the famous ‘Last Lecture Series’ (September 2007). His lecture was about ‘Really achieving your childhood dreams’ and not about dying. It was about the importance of overcoming obstacles, of enabling the dreams of others, and of seizing every moment (as you may suddenly find that you have less time than you think). He stresses that one should have fun in everything they do and should live life to its fullest. He wants us to ask ourselves: ‘Are we spending our time on the right things?’ His lecture on YouTube is one of the most visited and can be accessed at: http://www.youtube.com/watch?v=ji5_MqicxSo

I feel that Andy Graydon’s article in this issue is most appropriate to health care professionals, especially in the present time – and more so to those working in pain clinics. Both the NHS and private providers have significant restrictions to many services that are provided in our pain clinics. Waiting time breaches, commissioning and patient choice, guidelines, outcomes, funding … there are lots of challenges around us that could stress our services and us. Are we aware of them and dealing with them appropriately?

In an article in the British Medical Journal, the proportion of doctors with stress was found to be around 28%, whereas it was only 18% in the general working population. A paper in 1994 stated that two-thirds of women doctors and over half the men said that they had regretted studying medicine. Even recent studies have suggested that the incidence of burnout among consultants in the UK has increased from 32% to 41% between 1994 and 2002. I assume that this should be high in our specialty of pain management, where patients might be anxious, depressed and frustrated. We face lots of emotionally difficult situations in the clinic and witness more suffering among our patients. Patients might feel that their concerns are not adequately addressed to their satisfaction, which can result in disgruntlement and formal complaints. Restricted time availability and an increasing workload can add pressure to this situation. In the pain clinic, these situations could lead to unnecessary investigations and treatments, aiming to satisfy the patients.

False facts are highly injurious to the progress of science, for they often endure long; but false views, if supported by some evidence, do little harm, for everyone takes a salutary pleasure in proving their falseness.

Charles Darwin (The Descent of Man, 1871)

One Canadian study showed that a feeling of loss of control due to numerous government guidelines and protocols could cause significant dissatisfaction among health care professionals. Qualitative studies have shown that work/life conflict, lack of autonomy and emotional exhaustion are associated with stress.

Stress is simply explained as an imbalance between what is asked of us and what we perceive we are able to achieve. Are there ways to avoid stress in pain services?

Physicians, heal thyself!

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Physicians, heal thyself!

It has been proven that better teams have less stressed staff as they are supported by their colleagues; furthermore, they notice when one colleague is performing below par and step in to help. Experts have suggested techniques of engaging in reflection to help avoid stress; for example, acknowledging our emotions about difficult patients or challenging clinical scenarios.

The highest possible stage in moral culture is when we recognise that we ought to control our thoughts.

Charles Darwin (1809–82)

In ‘Rayen’s column’ in this issue, Arasu writes about his own painful experience from the other side; it is eye-opening to see how and what patients feel when they have severe radiating neuropathic pain. More important are the simple facts that are easily missed, like prescribing regular analgesics and ‘starting low and going slow’. These unfortunate events teach us a lot, especially to understand the problems of our patients and to listen to their practical problems. I thank Arasu for discussing this in an open forum in his regular column to help other clinicians treat their patients in a better way.

This issue of our newsletter also has many other interesting articles; I feel very happy to see various patient group articles in this issue, including the articles from Pain UK, CRPS UK as well as the Knitting group. It is timely that we encourage these groups to help our patients self-manage their pain in an appropriate way with adequate support in a friendly manner. The online self-management pain management programme (PMP) course by Charles Pithor is another interesting innovative way of helping patients in persistent pain.

The Chairs and Committee Members of the Special Interest Groups (SIGs) are regularly updating and educating us with regards to their SIGs; I thank them for their regular articles in our newsletter.

Also in this issue, Andy Nicolau, chair of the Pain Patient Pathway implementation group, gives us an update of the most important current project of the British Pain Society. It is interesting to note that more than 80 volunteers have contributed to these five vital pathways, which will soon be published in the Maps of Medicine format. Pain News extends its sincere thanks to all those involved in this project and hopes that it will be a milestone in the evolution of our specialty.

I am happy with the discussions that have arisen with the knitting article written by Betsan Corkhill; no scientific evolution is possible without appropriate discussion. I have learned a lot from these correspondences; I am sure our members will too.

Please continue to write your valuable comments and feedback. Once again, my sincere thanks to you for your kind support. Now, enjoy this issue of our newsletter.

Thanthullu Vasu
Editor

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The British Pain Society Learning in Pain series
Commissioning Pain Services Study Day
Monday 10th September 2012, London

Commissioning Pain Services

Changes to the NHS mean changes to the way in which pain services are to be commissioned. This course will lead the reader through the commissioning process and give practical advice on how proposals can be developed, how they may be judged, and how to understand the commissioning process better. The day will be presented by leading clinicians working in the commissioning of pain services.

CPD points applied for
This year the ‘Fourth of July’ took on additional significance to being Independence Day, commemorating the adoption of the Declaration of Independence on 4 July 1776 in the USA. Wednesday 4 July 2012 was the official launch of ‘Putting pain on the agenda: The report of the First English Pain Summit’. The launch took place at a well-attended reception in the Houses of Parliament hosted by the All Party Parliamentary Group on Chronic Pain, at which Earl Howe, Under-Secretary for Health, and Dr Beverly Collett both spoke.

Earl Howe confirmed the selection of pain for a quality standard and reiterated its significance. You will recall that the Pain Summit itself was led by the CPPC in partnership with the British Pain Society (BPS), FPM, Royal College of General Practitioners (RCGP) and patient organisations, and took place in Westminster in November 2011.

The summary report is now available to download from http://www.painsummit.org.uk/news/articles/final-report-pain-summit-launched

Key Recommendations

A Clear standards and criteria must be agreed and implemented nationally for the identification, assessment and initial management of problematic pain.

B An awareness campaign should be run to explain the nature, extent, impact, prevention and treatment of chronic pain to the wider general and NHS community.

C Nationally agreed commissioning guidance must be developed and agreed, describing best-value care in chronic pain to reduce unwarranted variation.

D A data strategy for chronic pain should be agreed through the creation of an epidemiology of a chronic pain working group.

Each of the four main organisations will lead on one project, with the BPS responsible for the recommendation D, with these specific aims:

• Bring together national epidemiologists and public health specialists with an interest in chronic pain and its impact.
• Define core data items and sources, including the chronic pain data produced by the Health Survey for England 2011, to enable ongoing surveillance of the extent, severity and impact of chronic pain.
• Generate an accurate burden of disease calculation, including identification of the groups most affected and characterising unmet need and those most likely to benefit from interventions.

• Involve close working with Public Health England (PHE) and the Quality Observatories (including the evidence and intelligence function) to agree and review key national data sources relevant to this area. PHE and the Quality Observatories could focus on the development and interpretation of such data sets to produce and promote a clear and workable methodology for local public health teams to gather relevant information to systematically include the extent and impact of chronic pain on the local population routinely as part of the Joint Strategic Needs Assessment.
• Further develop the scope of the National Pain Audit to support this work.

Northern Ireland Pain Summit

This year witnessed an equally exciting landmark event for pain medicine and people living with pain in Northern Ireland. Their Pain Summit was staged on Tuesday 15 May 2012 in the Stormont Hotel, Belfast by the Pain Alliance of Northern Ireland (PANI) under the chairmanship of Dr Pamela Bell, in partnership with the Patient and Client Council. Speakers and attendees included patients who gave particularly moving accounts of their experiences, health care professionals, policymakers and politicians.

Northern Ireland Minister for Health, Social Service and Public Safety, Edwin Poots MLA, noted that Northern Ireland has ‘the highest prevalence of chronic pain in the UK with almost one in five people suffering. It is the main contributor to the annual cost of medically related benefits and
Professor Richard Langford

long-term sick leave in Northern Ireland’ and ‘the importance of health professionals working together to improve services for those living with chronic pain’. In the final session, Pamela Bell outlined the ‘road map’ for action to follow on from the Pain Summit, and Northern Ireland’s Chief Medical Officer, Dr Michael McBride, made the closing and highly supportive remarks.

Pain Patient Pathways
The development of our own BPS Pain Patient Pathways is now into the final stage, with all five pathways submitted to Map of Medicine for its pre-publication processes. If all goes smoothly, these examples of endorsed, evidence-based, best practice patient care pathways should be sequentially published through August and early September and hence available to underpin your local commissioning and service design discussions. You may also be interested in our ‘Learning in Pain’ study day on Monday 10 September 2012, on commissioning pain services.

As I mentioned in the previous edition, Andy Nicolaou is leading the programme of ‘Dissemination and implementation’, about which you will hear much more over the next six months.

BUPA
On 27 April, BUPA circulated revised guidance, which raised serious concerns as they not only severely restricted spinal procedures, but also stated that anaesthesia-based pain medicine specialists could only conduct such procedures ‘where the treatment has been agreed by a clinician from another approved specialty’.

In a joint strategy, we (William Harrop-Griffiths, President Elect of the Association of Anaesthetists of Great Britain and Ireland (AAGBI), David Rowbotham, Dean of the Faculty of Pain Medicine of the Royal College of Anaesthetists, Stephen Ward, Andrew Baranowski and I) met senior BUPA executives at the AAGBI offices on 12 June. I am pleased to say that BUPA agreed to restore its recognition of pain medicine, and has issued a statement saying that consultants who are fellows of the Faculty of Pain Medicine of the Royal College of Anaesthetists or Fellows of the Faculty of Pain Medicine of the College of Anaesthetists of Ireland may carry out spinal injections (i.e. without requiring the authorisation of another approved specialty).

With kindest regards,

Pain Education Special Interest Group
http://www.britishpainsociety.org/members_sigs_education.htm

Improving patient education: making a difference
An interactive study day exploring strategies for enhancing patient education about pain and self-management

29th November 2012, Churchill House, Red Lion Square, London

Keynote Workshop
Principles of patient education: the challenges, innovations and practical tips
- Supporting self-care in people with long term pain
Dr Frances Cole, GP and Pain Rehabilitation Specialist and Pete Moore, Co-author of The Pain Toolkit and Trainer

Interactive sessions
Using learning styles to your advantage
Motivational interviewing in education
Barriers to education in the clinic and the classroom
Patient education: work of the Patient Liaison Committee

To apply for this meeting or for more details please visit the website or email kenobbard@britishpainsociety.org
Some people may be thinking of the impending World Pain Congress and the exciting opportunities that it will bring to network with colleagues around the world and to hear of new developments in the field of pain research and practice. It is also a good time to reflect upon the work of the British Pain Society (BPS) that continues to be carried out, often behind the scenes by council members and the executive officers. You will probably have noted that the new editor of Pain News has begun to make his mark on the publication and I hope that it will encourage you to write some papers for him. Also, the British Journal of Pain has been launched this year and again this is looking very impressive. Both reflect well upon the work of the BPS.

**Membership**

At the time of writing this report, membership stands at 1,462 and is represented by 701 anaesthetists, 252 nurses, 97 psychologists and 85 physiotherapists, with other disciplines accounting for 327 members. Other disciplines include occupational therapists, rheumatologists, neurologists, pharmacists, general practitioners and basic scientists. Information on joining can be found at [http://www.britishpainsociety.org/join_home.htm](http://www.britishpainsociety.org/join_home.htm) and the benefits of joining are many.

**Special Interest Groups**

We have a number of special interest groups (SIGs) that reflect the diversity of our members’ interests. These groups are incorporated into the BPS and are therefore not independent of the society. But they often lead on publications, specialist advice and study days related to their areas of interest. All of the groups met together recently to discuss ways of collaborating in the future and hopefully we will see the results of these discussions very soon. All of the SIGs can be viewed on our website and if you have not yet signed up to any, just download the application form and submit it to the secretariat. If you are thinking about setting up a SIG, take a look at the website where there is guidance on what you need to do. You will also notice that the SIGs are submitting an article to Pain News to update you on their activities. If you want to get involved in a SIG, just get in touch with Ken Obbard in the Secretariat or the SIG chair.

Finally the Learning in Pain Series continues with study days on commissioning pain services due to run in September, psychological therapies in November and pain in older adults in January. Check out the website for the dates and programmes and make sure you have these in your diary: [http://www.britishpainsociety.org/meet_bps_study_days.htm](http://www.britishpainsociety.org/meet_bps_study_days.htm)

**Updates**

On a personal note, I wanted to let you know that our Pain Management Guidelines for Older Adults will be available soon, so please recommend to your colleagues that they take a look at them. Thanks to all colleagues who were involved in developing or reviewing them. If you are interested in writing a publication, take a look on the website. There is an application form that needs to be completed and submitted to the Communications Committee.
The Pain Patient Pathways Maps of Medicine Project: update and next phase

Dr Andrew Nicolaou Chair, PPP Implementation Group

The Pain Patient Pathways have been a major undertaking for the British Pain Society (BPS). I am pleased to report that the pathways themselves are all now completed and submitted; we have imminent roll-out over summer on the chosen Maps of Medicine platform.

There are five pain pathways: (1) the primary pathway of initial pain assessment and early treatment, which leads on to the next four specific pathways; (2) spinal pain; (3) other musculoskeletal pain (non-inflammatory); (4) neuropathic pain; and (5) pelvic pain (male and female).

The pathways will be sequentially published on the Maps of Medicine platform – the website being very familiar to many especially in primary care and open to those with an NHS email and also our patients.

Most of us will be aware of the considerable time and effort that has gone into this project from its inception in 2010 to the present day. The workload has been onerous; thanks and praise are due to all those involved from the pathways development executive group, the chairs of the five pathway groups and the groups themselves with secretariat support. The groups reflect our Society well with a true multidisciplinary character. Representation includes that from patients, primary care, secondary care, nursing, physiotherapy, chiropractors and psychology, among others. All areas of pain medicine are represented across the spectrum of interventional to non-interventional practice. If you include the secretariat support of the BPS, members and co-optees, there are over 80 people contributing – clearly too many to individually mention. We are also grateful for the support of partner groups and organisations such as the Faculty of Pain Medicine (FPM), Royal College of General Practitioners (RCGP) and the Chronic Pain Policy Coalition (CPPC) in such a major project.

I will just recap further some of the background to the pain pathways before outlining the next phase. At the time of writing, we await final sign-off of the pathways in the Maps of Medicine internal process. This has taken longer than anticipated and we are grateful for your forbearance. However, it will produce a robustly reviewed set of guidance that we hope, we hope, be thought of as groundbreaking in the field of pain management.

The Chief Medical Officer’s report of 2008 highlighted pain as a clinical priority and the need for consensus on best practice pathways and to improve pain education. In 2010, the NHS White Paper, Equity and Excellence: Liberating the NHS, set out a vision of unprecedented change in all aspects of health care and particularly with the commissioning of services, in the context of severe financial challenges within the NHS. The phasing out of primary care trusts (PCTs) and the introduction of clinical commissioning groups (CCGs) (due to go live in April 2013) leads us into uncharted territory and with this comes threats but also opportunities. The need of an overarching strategy to put pain on the agenda and preserve and improve pain services for the good of our patients was very much needed. BPS personnel met with Sir Bruce Keogh, the medical director of the NHS of England, and senior figures in the Department of Health (DoH) and the National Institute for Health and Clinical Excellence (NICE). All agreed that there was merit in developing BPS-endorsed pathways to inform guidelines and a quality standard. This would have influence throughout the NHS and would also complement elements of the DoH Spinal Taskforce work. Inherent in the pathways is a design to underpin commissioning and then develop educational material for both the primary and community setting and secondary care. The pathways aim to form the basis of quality standards to feature in the new NHS Quality and Outcomes Framework (QOF) for pain – which in itself is an important development.

There was no real precedent for this project so it has been achieved from a standing start, so to speak, and it represents a real achievement of being the best there is ‘out there’ in terms of a consensus for best practice that is evidence based (or as near as you can get to that in the real world).

As the recently appointed chair of the Pain Pathways Implementation and Dissemination Group, my role is to coordinate the four strands of this group:

1. Commissioning, led by Ollie Hart – with RCGP.
2. Primary and Community Care, led by Martin Johnson – with RCGP.
An early ‘Mind Map’ of the Pain Pathways Implementation and Dissemination Group
The Pain Patient Pathways Maps of Medicine Project: update and next phase

3. Patients and the Public, supported by the Patients Liaison Committee and Ann Taylor, CPPC and Pain UK.
4. BPS membership, led by Nick Allcock.

Clearly there is overlap of target audiences – in particular, with commissioning and primary care, and the contribution of the patients’ work stream is integral and interwoven in all of the others at every level. Patients will have a better understanding of what forms best practice and what to expect from clinicians; this empowerment is key as implementation and dissemination cannot be just a top-down process. Patient educational materials will flow from this.

For commissioning there is ongoing work to develop consistent commissioning support materials for providers, including how to engage with and influence commissioners, and for the commissioner’s information on pathway costings. Their agenda may well include maximising value in health gain, reducing variation in care with multiple referrals across a number of services, drug budgets and so on. A series of national/regional workshops will help disseminate this, with a BPS study day on commissioning on 10th September 2012 being the first of these.

For primary and community care, there is collaboration with the RCGP – with pain embedded in its clinical priority programme. Educational material will take many forms and includes linking into the FPM e-learning project for pain announced at the end of last year. The recent edition of British Journal of Pain emphasised the importance of education in improving pain management.

For the BPS membership, there will be a number of forthcoming publications and web links to all members to disseminate the pathways and commissioning materials plus the series of national/regional workshops. With the CCGs going live in April 2013, the need for our members to understand the language and process of commissioning and be empowered to influence and negotiate will be important.

Psychological therapies in the management of pain

Much of the clinical work in pain management involves using psychological approaches either directly or indirectly. A plethora of psychological research means more is understood about applying different psychological principles at different points in the patient pathway. This study day will inform on the issues of screening for the development of chronic incapacity, how to train non-specialists to manage selected patients and will help the attendee understand different psychological interventions currently used in the management of those with chronic pain.

Competition

Have you received an interesting Christmas gift or letter from your patient?

What was the best one you received?

Would you be willing to write a few lines for our competition?

Pain News has five vouchers of twenty pounds each to be given to lucky winners.

Even if you don’t win, it could be published in our next issue.

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BPS Research and Audit Report: results of second survey

Prof David Rowbotham  Dean, Faculty of Pain Medicine
Dr Mick Serpell  Chair of Science and Research Committee, British Pain Society

Thanks to all who participated in the second Research and Audit Survey, which aimed to identify the themed topics that the British Pain Society (BPS) should prioritise in the future. The survey revealed that ‘Prevention of acute to chronic pain transition’ was the clear front-runner of the eight different domains offered. This was followed closely by other topics including ‘Opioid use for non-cancer pain’, ‘Primary care aspects’, ‘Pain service delivery’ and ‘Education of pain’.

**Question 8. Please rank the priority for research/audit activity from the following eight domains**

The Science and Research Committee has suggested several specific topics to the NIRH (National Institute for Health Research) Evaluation, Trials and Studies Coordinating Centre (NETSCC) from within the favoured theme, for the development of evidence, population, intervention, comparison, outcome, time stamp (EPICOT), a process to develop a theme into a specific research or audit question. These have been taken from a mix of the best responses from our first survey and the committee’s own thoughts. We hope to develop specific research topics that can compete for external research funding (see below). However, having now identified a priority theme, our next step is to announce an early call for members to consider projects based on this theme, in order to submit them for the next round of the Clulow Grant (deadline May 2013). As previously explained, the theme is broad based and is applicable to a range of disciplines from basic to clinical sciences, including all relevant clinical disciplines.

**Research Forum**

We wish to alert members to the fact that there will be a pain research meeting on 1st November 2012 in Churchill House. This meeting will be hosted by the Faculty of Pain Medicine (FPM), National Institute of Academic Anaesthesia (NIAA) and the BPS. We hope to mimic the very successful results of the peri-operative research network, set up by the Royal College of Anaesthetists and NIAA. We plan to bring together all parties interested in pain research in order to develop a network of researchers who can identify common research themes and deliver the required activity. Competition for research grants is fierce in the current economic climate, so by combining resources and expertise, we hope to establish our network as a serious contender among the other research organisations.

All BPS members, and especially those from the BPS survey who have registered to be entered into the research/audit database, will be invited to attend this meeting. We hope this meeting, and the Clulow Grant, acts as a catalyst for motivating the whole Society into providing the evidence-based medicine that we all demand, to improve the care we provide to our patients. We hope to see you all there.
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The Pain in Developing Countries SIG workshop entitled "Practical analgesia in the developing world: Making a silk purse," took place at the British Pain Society (BPS) Annual Scientific Meeting (ASM) in Liverpool. We had two incredibly interesting and inspiring presentations starting with David Snell (Anaesthetic Registrar, Northern Deanery) who shared his experiences of working in Uganda as an anaesthetist and managing acute pain issues, and concluding with Karen Frame (Consultant in Palliative Medicine, St Mary’s Hospital, Imperial Healthcare NHS Trust) detailing some of her work managing pain in a palliative care setting in Africa. Both concluded that pain management in developing countries is often grossly inadequate due to multiple factors including inadequate resources, notably insufficient access to strong opioids and a lack of education. They emphasised the need for targeted, culturally sensitive training to empower local health care professionals and to improve sustainability by coordinating with local communities, government organisations and non-governmental organisations (NGOs).

Following on from the workshop, the lunchtime meeting led to many positive suggestions for our future direction. As well as discussing broad issues such as advocacy for access to pain management across the globe, more specific aims were also outlined. As a result, it was decided that the SIG could act as an intermediary to facilitate matching the diverse resources of interested members within the BPS (e.g., educational tools, time working abroad, mentorship, fundraising, etc.) to established organisations working in and with developing countries.

The importance of a ‘bottom-up’ approach was emphasised so that we can tailor our support effectively and sustainably. We are also working towards collaboration with related organisations such as the International Association for the Study of Pain (IASP).

We have recently completed a ‘pilot’ survey of the Pain in Developing Countries SIG. The primary aim was to identify what links exist between members and pain services in resource-poor settings and to discover details of professionals’ experiences of working overseas. We are extremely grateful for the 22 responses. These largely consisted of doctors (91%), with 68% having had some experience of working within the developing/resource-poor world. Countries visited included Uganda, India, Pakistan and Palestine. Work was most often hospital based (36%), but educational links were also common (32%). Clinical work was largely spread across cancer (17%), acute (17%) and chronic pain (17%). Fifty percent of the group who specifically answered said that they had pain guidelines available in various formats. Only 57% of these felt they were able to fully implement these guidelines, the commonest obstacle being a lack of medication, in particular opiates.

The survey has begun a useful exercise in providing key links with organisations that our members feel we should collaborate with in the future. It has also served to re-emphasise the ongoing issue of opioid availability (and likely education and regulation barriers) in providing equitable pain control globally. We are aiming to extend this survey to the wider BPS membership over the coming months to gain a more comprehensive view of potential resources and links.
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CARDIFF
Putting Pain on the Agenda

Report of the First English Pain Summit

The report of the First English Pain Summit was officially launched on Wednesday 4th July 2012; the report is available to download from http://www.painsummit.org.uk/news/articles/final-report-pain-summit-launched

In November 2011, the British Pain Society, Chronic Pain Policy Coalition, Faculty of Pain Medicine and Royal College of General Practitioners came together to produce the First National Pain Summit for England. Following this, stakeholder consultations and engagements led to formulating the following priorities:

A: Clear standards and criteria must be agreed and implemented nationally for the identification, assessment, and initial management of problematic pain

B: An awareness campaign should be run to explain the nature, extent, impact, prevention and treatment of chronic pain to the wider general and NHS community

C: Nationally-agreed commissioning guidance must be developed and agreed, describing best value care in chronic pain to reduce unwarranted variation

D: A data strategy for chronic pain should be agreed through creation of an epidemiology of chronic pain working group

New members

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Institution</th>
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<tbody>
<tr>
<td>Dr Yvette Coldicott</td>
<td>Advance Pain Training Fellow</td>
<td>Ashford &amp; St Peter's Hospital NHS Foundation Trust</td>
</tr>
<tr>
<td>Dr Satish Kumar Gopa Narasimhula</td>
<td>ST5 Anaesthetics</td>
<td>Aberdeen Royal Infirmary</td>
</tr>
<tr>
<td>Dr Niraj Gopinath</td>
<td>Consultant - Anaesthetics &amp; Pain Management</td>
<td>Leicester General Hospital</td>
</tr>
<tr>
<td>Dr Nofil Mulla</td>
<td>ST5 Registrar in Anaesthetics</td>
<td>Warwick Hospital</td>
</tr>
<tr>
<td>Dr Ravi Gopal Nagaraja</td>
<td>Advanced Pain Trainee</td>
<td>Whipps Cross University Hospital, London</td>
</tr>
<tr>
<td>Mrs Georgina Ann Robertson Oldfield</td>
<td>Private Practitioner - Physiotherapist</td>
<td>The Pain Relief Centre, Huddersfield</td>
</tr>
<tr>
<td>Mr Chris Seenan</td>
<td>Lecturer in Physiotherapy</td>
<td>Glasgow Caledonian University</td>
</tr>
<tr>
<td>Dr Catherine Stack</td>
<td>Pain Fellow, SpR 5 Anaesthetics</td>
<td>Medway Maritime Hospital, Gillingham</td>
</tr>
<tr>
<td>Miss Faye Louise Travis</td>
<td>Pain Management Sister</td>
<td>James Cook University Hospital, Middlesbrough</td>
</tr>
<tr>
<td>Dr Jean Laurent Vonsy</td>
<td>Medical Liaison Neuroscience (Scientist)</td>
<td>Eli Lilly &amp; Co</td>
</tr>
<tr>
<td>Miss Kirsty Bromage</td>
<td>Medical Student</td>
<td>University of Bristol</td>
</tr>
<tr>
<td>Dr Benson Adebowale Ikuesan</td>
<td>Clinical Psychologist</td>
<td>The Mind, Body and Soul, Colchester</td>
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The Department of Health and Social Services in Northern Ireland first recognised chronic pain as a ‘entity in its own right’ in 2005; it made a series of recommendations aimed at ensuring that Health and Social Care Boards reviewed the extent and quality of their services for patients with long-term pain, developed guidance for ‘non-expert’ practitioners in the management of pain, and offered enhanced training in pain management for clinicians.

Work taken forward from this included a comprehensive review of primary and secondary care services throughout the province in 2006, the establishment of a multi-professional Master’s degree in the science and practice of pain at the Queen’s University of Belfast and the publication of the CREST guidelines for the management of neuropathic pain in 2008.

Since then, progress towards more accessible pain services, particularly in the community, has been hampered by successive reorganisations and major restructuring of health and social care. So why hold a Northern Ireland Pain Summit? And why hold it now?

First, a comprehensive review of health and social care in Northern Ireland (Transforming your Care, DHSS+PS NI 2011) highlighted that the current service was not sustainable or affordable and that more care, particularly for long-term conditions, should be delivered in primary and community care. Second, the Department published its strategy for the management of long-term conditions (again more care delivered in the community and patient self-management to be prioritised) and the general practitioner (GP)-led local commissioning groups indicated that they planned to move chronic pain services into the community. Finally, the appointment of a clinical champion for chronic pain by the Royal College of General Practitioners and the English Pain Summit in November 2011 gave support to the idea that it was timely to hold our own summit.

The overarching aims of the summit were to:

- Raise awareness of the extent of the problem of people living with chronic pain
- Raise awareness of the cost of chronic pain to the Northern Ireland economy
- Highlight to decision-makers key opportunities to develop prevention strategies and services for people with chronic pain
- Begin to develop consensus around the interventions and service models that offer the best strategies for people with chronic pain
- Engage local organisations, leading providers and commissioners in these actions

Recognising that it is challenging to engage the interest of Members of the Legislative Assembly (MLAs), including the Minister for Health and his deputy, MLAs were invited to sign up to a road map for chronic pain in Northern Ireland. The seven key points included enhancing education in pain management (including self-management), the appointment of a lead clinician, recognition for GPs undertaking pain management (through the Quality and Outcomes Framework (QOF)) and including an indicator focused on patients’ experiences of their pain as part of the national outcome measures.

The summit itself was opened by the Minister for Health, Social Services and Public Safety, Mr Edwin Poots MLA. He acknowledged the importance of health professionals working together to improve services for those living with chronic pain, indicating that his department recognised the burden that chronic pain places on sufferers and their families and that it places a significant economic burden on families and individuals, the health service and on society at large. In line with the strategic direction of Transforming your Care and the recent report on long-term conditions, he said:

We have an opportunity, through the implementation of a number of key policies which are highly relevant to chronic pain, to deliver improvements. I hope that today’s summit will be a driver for change and I look forward to seeing this happen.
Northern Ireland Pain Summit

The opening session of the summit looked at the impact of pain on individuals and society with presentations from patients, voluntary sector organisations and the workplace director of Business in the Community, who reported on how good understanding of the impact of pain on employees and taking steps to accommodate their needs can improve profitability of businesses.

It is sometimes said that the extent of chronic pain is unknown; so in the second session (Scoping the Problem) Mr Steve Barron of the All Ireland Institute of Public Health presented his research on the population prevalence of musculoskeletal pain in Ireland (14% suffer from arthritis and 35% suffer back pain). Dr William Campbell presented the results of an audit of pain services indicating that there has been a modest improvement since the 2006 review but capacity and resources still fall significantly behind those of the rest of the UK.

With this in mind, the third session looked at two examples of best practice, one from Dr Jim McMullan, GP with Special Interest, and Dr Paul McConaghy, who runs a secondary care-based multi-professional pain service in the Southern Health and Social Care Trust. Mrs Maeve Hully, Chief Executive of the PCC, also announced the launch of its audit of patient experience of services for chronic pain, which she hopes will be completed later this year.

In the final session of the morning, Prof Richard Langford introduced the audience to the concept of pathways for the management of pain as envisaged for the Map of Medicine and Dr Martin Johnson discussed the role of the Royal College of General Practitioners (RCGP) clinical champion. Dr Steve Gilbert, lead clinician for pain in Scotland, spoke of the progress made towards enhancing pain services there and Dr Alan Stout GP discussed how changes might be implemented locally.

In the afternoon, the delegates drawn from patient, voluntary sector and community organisations, health care professionals from primary and secondary care, commissioners and public health, joined one of three workshops on education, public health and commissioning. I hope to report on these in the autumn.

After brief feedback form these workshops and an outline of the next steps to be taken, the summit was closed by the Chief Medical Officer for Northern Ireland, Dr Michael McBride, who commended the organising committee saying:

This event is very timely and provides an opportunity, at a time of significant change in health and social care in Northern Ireland, to ensure that we all work in partnership to raise professional knowledge and work together to improve the quality of services for people living with chronic pain.

Extensive coverage of the event in press, broadcast and online media has helped the summit to achieve its aims of raising awareness in society. Further work is needed to ensure that the outcomes of the workshops and the key aims of the road map are taken forward.
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News from the Pain in Children Special Interest Group

Dr Alison Bliss  Leeds General Infirmary, Secretary, Pain in Children SIG, The British Pain Society
Dr Gwen Porter  Norfolk and Norwich University Hospital, Chair, Pain in Children SIG, The British Pain Society

The British Pain Society (BPS) Pain in Children Special Interest Group (PICSIG) provides a forum for a diverse range of professionals, including medical, nursing, therapeutic and research backgrounds, to share knowledge and practical experience of preventing and treating pain in children. The remit is large, covering acute, chronic and complex pain, within an age spectrum from the earliest premature neonates, barely through their second term of gestation, to those young people making the awkward transition from teenager to fully fledged adult. The relative paucity of high-quality research in children with pain, compounded by the variations in physiology and pharmacokinetics seen within paediatric practice, makes evidence-based pain management a difficult goal to achieve without the support of a collective such as the PICSIG – an assorted group of clinical practitioners and scientists linked by a desire to alleviate pain in children.

So, children feel pain too! Why should that bother me?

Well, it should ‘bother’ just about everyone. For those of us who treat children in pain as part of our day-to-day practice, providing the most efficacious analgesic regimes we can is a part of our raison d’être. One of the rights encompassed within the United Nations (UN) Convention on the Rights of the Child is the right to effective pain management by informed and competent practitioners,¹ and within our well-resourced pharmacologically replete first world countries, that includes not just nociceptive and neuropathic pain but pain driven and maintained by the fears, anxieties and emotions of children.

Some of these areas were addressed in this year’s PICSIG workshop at the Annual Scientific Meeting (ASM) in Liverpool. The first part of the workshop covered the difficulty of pain management in child victims and refugees of abuse and torture, presented by Lynne Fordyce and Mishu Fell, of Solace – ‘Surviving Exile and Persecution’. The second part looked at the role of gangs, peers and groups in enhancing effective therapy during the emotional turbulence of adolescence in a presentation by Dr Ruth Drake, Consultant Clinical Psychologist at University College Hospital.

For our junior colleagues just beginning their journeys into the world of pain, whether they will make those day-to-day encounters is not yet certain, but the knowledge required to manage them is included within the curriculum² for the examinations admitting Fellowship of the Faculty of Pain Medicine of the Royal College of Anaesthetists – and that is always an incentive to learn more about the subject. With this in mind, the PICSIG is planning a specific training day in the autumn to address topics from the paediatric pain curriculum.

What about our senior colleagues well established in their completely adult-based practice? Do they need to know or care?

Well, they should be watching with vested interest the efforts of those of us dealing with both acute and chronic pain in the paediatric population. Our success or lack of it may determine the population base of the PICISG – an assorted group of clinical practitioners and scientists linked by a desire to alleviate pain in children.

Within the world of pain, as in most other paediatric specialities, paediatric practitioners are the magpies, watching the adult practice for those innovations and ideas that lend themselves to ‘stealing’ and reshaping into a workable child-appropriate version. Join us at the 2013 ASM for a combined PICSIG and Acute Pain Special Interest Group (APSIG) workshop on doing just that – exploring the potential for analgesia within enhanced recovery programmes in children and adolescents, the roles of pre-hospital pain relief. Better still, join the PICSIG – you never know, by joining us in improving what we know and what we can deliver to treat pain in children, your future workload may ease and you might even be able to magpie a few tasty morsels for your own practice too.

As Nelson Mandela said:

There can be no keener revelation of a society’s soul, than the way in which it treats its children.

For any enquires, including information on membership and study days, please contact alison.bliss@leedsth.nhs.uk

References

Rayen’s column

The ‘other side’

Arasu Rayen  Birmingham

Alarm woke me up at 6.00 am. It was my usual wake-up time. But, that morning I felt a bit lazy, might be Monday morning blues! Silenced the alarm for 10 minutes and snoozed. Alarm went off again and I woke up at 6.10 am.

It was the Monday of the 2012 Annual Scientific Meeting (ASM) of the British Pain Society (BPS). I had a busy full-day anaesthetic list that day; meeting in the evening; another meeting on Tuesday afternoon after the morning anaesthetic list; had to drive to Liverpool the next day for the BPS ASM; had to do a presentation in the Departmental Clinical Governance meeting on Friday. Thinking about this entire week’s schedule, I started brushing my teeth not knowing that in a minute not only this week’s schedule, but also a few weeks’ schedules were going to come to halt.

Listening to Kenny G’s saxophone, I was brushing my teeth. Suddenly I felt an excruciating, shooting pain, starting on the left side of the neck, then shooting around the left shoulder blade, back of the left arm up to my left thumb, index and middle fingers. At first I thought it was just ‘one of those odd pains’ and tried to shrug it off. But it kept shooting again and again. To make matters worse, I started having severe spasms in the muscles of my neck, shoulder, forearm and arm. One point, rather than intermittent, the pain and spasms became permanent.

With the muscle spasms, my head turned and fixed to left side – I had torticollis; left shoulder rotated inwards, elbows and wrists flexed. As the pain and spasms were so intense, I felt sweaty and faint. To prevent me from fainting, I tried to lie down – but couldn’t because of the position of my head, shoulder and hand. Somehow I managed to go into ‘jackknife’ position. I was there on the floor for at least 45 minutes hoping that the pain would settle. Instead, the pain and the spasms intensified. I shuffled painfully and slowly towards the bedroom and got on to the bed and told my wife what had happened. Even with my clouded mental ability, I was trying to think of the diagnosis for the pain, but I didn’t have a clue. The pain was such a powerful ‘mental blocker’; I couldn’t think clearly. The one thing I remembered was rolling in the bed in pain, holding my left hand.

Looking at my state, my daughter, as she was getting ready to go to school, asked me: ‘Can I do anything to help you, Daddy?’

I did not know what to do. The first thing that came to mind was work. I didn’t think I was able to go to work. I called my colleague to inform him that I wouldn’t be able to come in. He was the one who asked me what I was going to do about the pain. After a few minutes of debate, we decided that he would call the orthopaedic surgeons to ask their advice about the situation and probably about the need for investigations.

In the meantime, I was thinking how to get to hospital – get an ambulance or go in the car? As I was still in a lot of pain, going by car at that time was unthinkable. But at the same time I felt that I shouldn’t dramatise the situation by going in the ambulance. I shouldn’t waste precious ambulance time. It can be used to save someone’s life. There might be someone who needed the ambulance more than me. So I decided to think about ways to reduce the pain so that I could go by car. I wanted to take some analgesics. Because of the pain, the muscle spasm and torticollis, I was not able to take the medicines in the usual way. With a lot of difficulty, I managed to take ibuprofen and paracetamol with the help of water that I sipped with a straw.

After an hour, ibuprofen 400 mg and paracetamol 1 gm reduced the pain and spasms slightly. So I decided to go by car. Getting up from the bed, getting out of my pyjamas and into my trousers, coming down the stairs and getting in the car were all extremely painful and slow. I felt ashamed that I could not even do the basic activities. I needed my wife’s help even for simple activities! She also took me to the hospital.

I had to go to the magnetic resonance imaging (MRI) suite to have cervical and shoulder scans as suggested by the orthopaedic surgeons. Getting into the MRI scan was a mammoth task. Lying still in the scanner for 30 minutes without moving when in pain was exhausting. By this time I started feeling the intense pain and spasms again. Somehow I managed the MRI with great difficulty. When I got up from the scanner, I had...
another severe bout of pain and spasms. The pain became intolerable to the extent that I had a vasovagal attack. I had to ask for a wheelchair to go from the scanner up to the waiting room. After waiting for 20 minutes in the waiting room in the wheelchair, my feeling of “fainting” did not settle. In fact it was getting worse. At that point I asked for the trolley to lie down on, so that at least I would feel normal without feeling faint. By this time the orthopaedic surgeons had come to see me. When they saw the state of me, they decided to admit me to the hospital ward. I was wheeled from the MRI department up to the ward. I felt ashamed again to be wheeled in my hospital. I wanted to hide my face; I did not want my colleagues to see me being wheeled around.

The MRI showed a lateral disc prolapse with nerve root irritation at C6/7. After admission, I had one more dose of ibuprofen, paracetamol with 300 mg gabapentin and 2 mg diazepam. This settled the pain and spasms to a tolerable level. With this concoction, I had a good sleep and woke up with less pain.

As I had less pain I decided that rather than wasting a precious hospital bed, I could go home and take it easy. I had persuaded the admitting team to discharge me so went down to the lobby and was waiting for my wife to bring the car. Luckily I was with my colleague; while I was talking to him I had another bout of pain and spasms with which I fainted. When I regained consciousness, we decided that I would stay overnight in the hospital.

Staying in the hospital bed for one night was an experience. It was a busy surgical admissions unit. Throughout the night, there were continuous admissions with associated noise from the trolley, patients, porters, nurses and doctors. My pain and this noise did not allow me to sleep. The prescription of my analgesics on the ‘as required’ (PRN) section of the drug chart did not help either (please see below).

Next day when the pain was better, I discharged myself and went home. I had to be on gabapentin 300 mg, diazepam and diclofenac for a few days. Later, gabapentin was changed to pregabalin 150 mg bd because of the side effects. I had a neurosurgical consultation; as I expected, the advice was to continue what I was doing and be reviewed in a month’s time. Car journeys in the first three weeks were very painful; I could not even sit in the car and go for more than a few hundred yards as the pain became more intense. I could not even go to the hospital to do my physiotherapy because of the pain. Luckily, I had a physiotherapy friend who came to my home and helped me.

Three weeks following my discharge was another saga. I could not sleep properly as lying down and turning over in bed was painful. I had to sleep in a sitting position for so many nights. I hardly had one to two hours sleep at night and I couldn’t sleep during the daytime. I had to resort to diazepam if I felt that I needed some sleep. During the night I had to read books to kill the time and managed to finish Steve Jobs’ biography in a week. If I had moderate sleep at night I had relatively less pain the next day. Daytime TV became my favourite pastime and I became an expert in all the daytime television programmes.

It took nearly six weeks before I could be more or less back to where I was. I was off sick for six weeks and this journey gave me an insight into various aspects of patient care, pain, medications and side effects, and the paid sick leave system. I thought I could share my thoughts with you:

- Acute severe muscle spasms associated with acute neuropathic radiculopathy is very intense and intolerable.
- Gabapentin produced more side effects that pregabalin (at least in my case). In my case, the effective dose of pregabalin without side effects was 50 mg at night and 25 mg in the morning. A few pain management consultants also told me that this is
the dose they usually use in their patients.
• Do not treat yourself! Let the expert – even if he/she is from your own speciality – treat you. Pain and emotions can cloud your judgement about the severity of the problem and treatment.
• If you are an anaesthetist and writing painkillers for post-operative or any other pain, please write some analgesics in the regular medications section of the drug chart. I realised this when I was admitted in the hospital. The orthopaedic registrar wrote all the analgesics in the PRN section of the drug chart. I had to wake up, ask for the analgesics and wait for a considerable time before I was given the medications.
• I had personal experience on how pain can control your life. When I was in pain, I couldn’t think about anything else other than the pain. I also felt tired just thinking about the pain. I could very well understand how chronic pain patients suffer with unrelenting pain 24/7. I always had sympathy towards my chronic pain patients; after this incident, I have more empathy as well.
• I came to know that it is common for the South East Asian population to have a low vitamin D level if they are living in western countries (my vitamin D level was low). A low vitamin D level has been incriminated for generalised muscle aches and pains. Even though vitamin D is important in maintaining calcium level in the blood, it is also shown to be very important in muscle function.1–3 If you have another Asian patient with ‘whole body pain’, please think of vitamin D levels.
• The treatment for low vitamin D level is to supplement the diet with cholecalciferol or ergocholecalciferol. There is no consensus on which is the best way to treat this. Literature advice is very confusing – doses from 20,000 to 50,000 IU have been recommended. Even small dose of vitamin D maintenance can interfere with laboratory testing of the serum cholesterol level. Daily intake of vitamin D gives rise to a spuriously high level of serum cholesterol. So if a patient is on cholecalciferol or ergocholecalciferol, he/she has to stop taking it for a few days before checking the serum cholesterol level.4,5
• The analgesic duration of an analgesic may depend on the intensity of the pain. I was on diclofenac 50 mg three times a day. In the initial period, when my pain was intense, 50 mg gave me pain relief of just two to three hours. It took nearly two hours to work and gave a mere two hours of pain relief. When I had this experience, I realised that what my patients were telling was true. I don’t know if you have had a similar experience, but quite a few of my patients tell me that analgesics never work for more than a few hours. On the contrary, when my pain improved,
The interdisciplinary nature of PMPs – how do we get there?

Dr Dee Burrows, with contributions from the PMP SIG Committee 2011–12

The September 2011 Pain Management Programmes (PMP) Conference in Bath included discussion on the contribution of doctors, nurses, occupational therapists, physiotherapists and psychologists to the process, delivery and evaluation of PMPs. Each discipline had a one-hour structured, unidisciplinary meeting to define the roles of that discipline within a PMP. This work was then presented formally to the whole conference (around 250 delegates) to stimulate further discussion. A summary of this interesting and productive debate is presented.

There was considerable variation in the represented programme and the breadth of comment reflects this. They do not necessarily represent the views of the British Pain Society (BPS), the PMP Special Interest Group (PMP SIG), or of the wider PMP audience. While the PMP SIG committee aims to report the discussion as accurately as possible, the summary is our interpretation. The committee would be grateful for readers’ contributions to the debate of how discreet disciplines play a part in working towards interdisciplinary PMPs. Our contact details are at the end of this article.

The kind of themes that emerged from the discussions are outlined in Table 1. These are not an exhaustive list of the ideas that were contributed. Rather, they are illustrative and their purpose is to open the debate, not to define the contribution.

Conclusion

The term interdisciplinary refers to the involvement of two or more scientific disciplines coming together in new ways. PMPs are described as being interdisciplinary in nature with a variety of health care disciplines contributing from their unique perspective. Some disciplines find it easier to express their unique contribution than others.
### Table 1.

<table>
<thead>
<tr>
<th>Profession</th>
<th>Contribution – potential key themes</th>
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| **Doctors**         | • Consider the overall health needs of an individual with pain  
|                     | • Guide individuals with any medical diagnosis they have including understanding the condition and how it might affect them  
|                     | • Manage new medical problems that emerge  
|                     | • Manage the individuals’ journey through complex health care systems  
|                     | • Help individuals manage their expectations and help bring about closure of treatments (medicines, injections and other treatments)  
|                     | • Explain neurophysiology and medicines management  
|                     | • Provide messages to keep individuals on track towards acceptance and improved quality of life  
|                     | • Steer people towards PMPs  
|                     | • Encourage and facilitate the measurement of medical-rated outcomes such as medicine usage  
| **Nurses**          | • Bridge between biomedical and psychosocial aspects of pain management  
|                     | • GP and other medical liaison and referral management  
|                     | • Trust liaison including development and implementation of policies and guidelines such as medication management and infection control  
|                     | • Assessment and formulation  
|                     | • Programme organisation  
|                     | • Using the principles of cognitive behavioural therapy (CBT) or acceptance and commitment therapy (ACT) enabling individuals to understand pain mechanisms, managing medication and side effects, sleep and stress management, relationships, relaxation, and flare-up planning  
|                     | • Healthy living promotion  
|                     | • Family/carer involvement  
|                     | • Clinical supervision  
|                     | • Educating other health professionals regarding rehabilitative pain management  
|                     | • Contributing to research and audit  
| **Occupational therapists** | • Assessment of the impact of chronic pain on occupational performance in the areas of self-care, leisure and productivity  
|                     | • Use of occupation-specific standardised outcome measures  
|                     | • Reassessment of change in occupational performance following PMP intervention  
|                     | • Assimilation of physical and psychological skills into specific activities  
|                     | • Teaching of activity management strategies to initiate and maintain engagement in meaningful activity  
|                     | • Promoting awareness of the workability of activity management strategies and providing opportunities to practise alternative approaches  
|                     | • Commitment to goal-orientated action and value-driven targets  
|                     | • Advice regarding work retention with patients in employment, including liaison with employers  
|                     | • Facilitate return to work interventions and signposting/liaison with appropriate agencies  
|                     | • Analysis and interventions to optimise the balance between work, rest and leisure  
|                     | • Promotion of skills development including problem solving  
|                     | • Provide advice on the appropriate use of environmental adaptations  
|                     | • Delivery of interventions that promote relaxation and stress management in daily life  

Professional perspectives

The interdisciplinary nature of PMPs – how do we get there?

As might be expected there was considerable consistency in the initial discussions at the PMP Conference regarding how the contribution of each discipline is interpreted in practice to support the interdisciplinary nature of PMPs. Having different disciplines coming from different perspectives towards a common goal was seen as a strength for the complex management of individuals with pain.

Table 1.

<table>
<thead>
<tr>
<th>Profession</th>
<th>Contribution – potential key themes</th>
</tr>
</thead>
</table>
| Physiotherapists | • Determine whether physiotherapy alone or PMP is appropriate  
                      • Identify PMP exclusion factors including low functional level, medical instability and lack of readiness to change, including willingness to exercise  
                      • Deliver the exercise component within a psychological model and facilitate interdisciplinary contribution to this component  
                      • Assess when specific exercises are required in the case of certain pathologies and prescribe appropriate programme  
                      • Identify and challenge barriers to exercise and rehabilitation through appropriate communication and exercise exposure  
                      • Apply fear avoidance models, motivational techniques and educational models  
                      • Education regarding pain mechanisms  
                      • Ongoing assessment of changes in physical conditioning, function and activity  
                      • Group supervision  
                      • Outcome measurement including administration of self-report questionnaires, physical function tests, video feedback, and values-specific measures, monitoring of health care and medication use |
| Psychologists | • Interpretation and application of therapeutic models including CBT, ACT and motivational techniques  
                      • Facilitating multidisciplinary working – consultancy, supervision, formulation and conceptualisation, understanding of systems and groups, facilitating reflection, cohesion  
                      • Psychopathology and psychology of normal functioning  
                      • Organisation, assessment and treatment  
                      • Patient experience perspectives  
                      • Skills including group dynamics, CBT, change, development and culture  
                      • Risk management  
                      • Research and audit  
                      • Using evaluation to support service change |

This may be related to practice contexts and settings.

Notes

1. The revised BPS draft guidelines for PMPs will be published later in 2012.
2. Guidelines related to training for competencies in pain management physiotherapy have recently been published by the Physiotherapy Pain Management Association: http://www.csp.org.uk/sites/files/csp/secure/generic_competencies-guidance.doc
3. PMP SIG Committee 2011–12: Doctors – Dr Frances Cole and Dr Paul Wilkinson; Nurses – Sara Brookes and Dr Dee Burrows; Occupational therapists – Emma Wheatley and Louise Haynes; Physiotherapists – Eve Jenner and Leela Heelas; Psychologists – Dr Sue Peacock and Dr Kerry Matthews; BPS council member - Suzy Williams.
4. The PMP SIG Committee can be contacted via Dr Paul Wilkinson, chair of the committee, at p.r.wilkinson@ncl.ac.uk or via Ken Obbard, events and membership officer, BPS Secretariat at KenObbard@britishpainsociety.org
My interest in online courses for patients started when a few years ago I saw a paper demonstrating the efficacy of an online cognitive behavioural therapy (CBT) programme for depression. Two thoughts struck me: the first was to be amazed that you could achieve results by interaction with a piece of software; if CBT could be done by a computer, the change was clearly something relating to the process that the patient was engaged with, aside from the magic and skill of the therapist.

This was news to me because I had always thought there was an element of charisma and persuasion involved. I had worked with a number of really impressive psychologists who seemed to get great results, and less good folk who got moderate results. (In addition, I recall a whole issue of The Psychologist focusing on the subject that nobody dared mention: the importance of the therapist in outcome. The conclusion confirmed that the therapist mattered.) But here were data suggesting that it could all be done by a software program – very interesting!

The second thought that struck me was that if online treatment worked for depression, where CBT had been shown to be effective in general terms, then why couldn’t it work for chronic pain management, where there was similarly convincing data?

Working with Wellmind Media, a publisher of online health programmes, the possibilities of an online approach suggested many potential advantages. Here was an opportunity to properly educate patients about the complexities of chronic pain. We could use technology to prompt and nudge, we could measure outcome using various validated computerised tools, and there was the possibility of the provision of access for those not able to attend groups or therapists face to face. So why not develop an online course encompassing the best elements of our conventional programmes in a package delivered through the internet?

The naysayers immediately came up with a number of problems and pitfalls, mostly related to the percentage of patients with access to the internet who would have the necessary skills to negotiate their way around such a package, but working on the basis that even if it was a small percentage of folk who could access the course, it would still be worthwhile.

The conversion of this roughly hewn idea to a working and sophisticated online course is thanks to the hard work, ideas and experience of Wellmind Media. As the development started, what rapidly became clear was that my own ideas of how we might translate the complex and comprehensive components of a pain management programme (PMP) into a usable format, were based on an outmoded scientific educational experience that just would not suffice for an online package aimed at a general public of mixed educational attainment, and who needed to be kept interested if they were going to complete the whole course. In addition, it became clear that the user interface had to be totally bullet proof; it had to work with one click, and never lead you up a blind cul-de-sac.

The eventual format of 24 short video-based modules of about 20 minutes each, felt very different from the traditional medical learning paradigm of my studenthood, but we were able to include many other aspects that I considered crucial, such as inclusion of whiteboard teaching on pain mechanisms, ideas about acceptance and a diary facility to jot down thoughts and feelings as part of the cognitive modules. We also included a series of guided audio meditations for relaxation.
and mindfulness, which had already proved their value with Macmillan Cancer Support and its online community. The guided meditations have proved very popular with participants and seem to be used predominantly to self-manage during pain flare-ups and help with stress and sleep problems.

The area that caused us the most angst was how to deliver the stretch and exercise programme. Our concerns were getting the balance right between the person who could cope with the Mr Motivator-style TV exercise regime, versus the person severely disabled and barely able to get to the general practitioner (GP) surgery. In the end, we kept it really simple, focusing on the general not the specific.

The technology development team also designed fantastic VAS ‘sliders’ that give the participant the opportunity of scoring their pain along with a number of other modalities whenever they login. This enables participants to track any improvements while they progress through the course and to consider what aspects of pain management are working especially for them.

After a year of work, and a great deal of glitch sorting, we finally started recruiting volunteers over the internet to pilot the programme, provide feedback and help us to make improvements.

Even from the earliest days it emerged that people really did engage with the online course. Patients (if they are that) like it, and if they start it, on balance they complete it, taking on average of two months (perfect!). They slide the sliders, press the buttons, do the tasks and write heartfelt comments in their pain diary, and most importantly give things a try in their daily lives. Maybe this is a key advantage of an online course: it is accessed by people while in the reality of a typical day and so gets them practising pain management in the here and now. It seems that they really do feel that they have a relationship with a trusted friend and experienced counsel, and many report those same ‘Ah ha!’ moments we know from our face-to-face experience.

We have discovered that the best way for the online course to be delivered is within the auspices of a multidisciplinary pain clinic. This is not surprising. Look at how much you get from your online Etruscan ceramics distance-learning programme, then add in supervision, chat and a regular call from your tutor and you will do better. Anchoring the course within a specific clinic not only allows us to personalise it with screens specific to the unit, but also allows the course to be integrated into the other modalities of the treatment package.

The marvellous feature from our perspective is that the program generates its own outcome data. Once a user completes the course, we have data from numerous self-evaluation questionnaires measuring changes in various domains. No need for postal questionnaires, face-to-face follow-up, or that tricky telephone call; we have the data, which is shared with the participant and their clinical referrer.

We now know that those completing the online course make, on average, a 20%–30% improvement in health, mood, confidence and general function. What is more extraordinary is that participants’ physical function and walking distance also improves. Completion rates are above 60% (which, believe me, is good for this type of protocol), with many more people than not making a worthwhile change.

But the real point is this: it costs less than £150 per person, less than the monthly cost of few medications. We can agonise over treatment efficacy and ponder about whether the person is ready for change, but at such a low price it just might be the most cost-effective treatment that can be offered to a chronic pain patient.

For the future we need to know more about who can get most from the course, as well as more fine-tuning of the course content, but that an online course can help those with persistent pain to make key changes to their mood and function is now not in doubt.
Feedback from participants

Deborah King, Participant
As a sufferer of chronic pain for over 20 years I began the online Pathway through Pain program with great scepticism. Doctors and so-called health specialists had always promised so much and disappointed so often. How could an online course help? The Pathway through Pain program helps you by changing your long-held views about pain and by teaching you to help yourself.

In the first week, I was still a sceptic; as each health specialist presented a short video on the programme, I always looked up their profile on the internet to check out their credentials, but soon began to realise how fortunate I was to be given help and advice by such a range of well-qualified, respected consultants, doctors, physiotherapists and so on.

I had always thought that ‘there is no simple cure’ to back pain and strangely this is why I really believed in the health care specialists I was introduced to on the programme – they agreed with me! However, while they do not offer a cure, they do offer practical advice that is easy to follow, simple to fit into your day-to-day life and realistic.

As you can only complete so many steps of the course at a time you have time to practice each exercise you have covered that day. This could be a psychological exercise like relaxation or a physical one like gentle stretching. All these methods and exercises I had tried before but it was only when I changed my beliefs about pain and put all the tools the program offers together, that I began to see positive, lasting results. By the middle of the course I was eagerly awaiting the time when I could access the next steps of the program.

For the course to be successful, you will need to have an open mind and be prepared to try all the suggestions and see if they work for you; even if you don’t think they will work, they may!

By the end of the online course I had really changed my way of thinking and this helped me to change my life. I still have some pain but I have now joined a gym, go swimming regularly, go for long walks and have planned a long flight to see my son in America, all things I couldn’t have even hoped for last year.

Elizabeth Dutton, Participant
Two years ago, I had a fall skiing and fractured a vertebra. Although X-rays and MRI scans showed the fracture had healed, from that point on I suffered from chronic back pain. None of the interventions I tried had any noticeable effect on the pain and increasingly I began to feel like a ‘victim’. The pain, which intensified during the day, had a negative impact on my working and domestic life and increasingly restricted social activity.

I had more or less given up hope of ever getting to grips with my pain when I discovered the Pathway through Pain course. Doing an online course did not immediately appeal to me because I, probably like most people, was used to a more hands-on approach. How wrong I was! On the contrary, the course is designed in a way that is accessible, supportive and, most importantly, motivating. Having started it, I was hooked!

The online course has given me practical tools for dealing with my pain including exercises, relaxation techniques and meditation. These, combined with new knowledge and perspectives about pain and pain management, have empowered me to take greater control over my life. This means that although I still have occasional pain, I have the confidence to deal with it.

Being liberated from pain in this way, I have a much more positive outlook. My husband says I’m a lot easier to live with and I have even taken up gardening again. One of the key lessons I have learned is pacing myself, particularly in relation to work. I am self-employed and need to spend long periods of time sitting at a computer. Whereas in the past I used to sit for hours writing reports, I now take regular breaks, away from my desk, often using these breaks to take short walks or do stretching exercises.

For more information about the online course please visit: http://www.pathwaythroughpain.com
Pain UK – Establishing an alliance of pain charities

Christine Hughes

Umbrella organisations for pain have been tried in the past and failed, so why did we establish Pain UK in 2011? Most people who suffer pain say that they are rarely asked about it. Pain UK wants to change that; we want to work as a collective voice to move pain up the political and public agenda. We want to ensure that at every consultation patients and users will be asked: ‘Does it hurt?’ We want employers to understand the needs of people living with chronic pain. We want society to recognise the economic and societal costs of pain if left under-treated. We want to work alongside the organisations that represent health professionals and other interested parties such as the British Pain Society (BPS), the Royal College of General Practitioners (RCGP), the Chronic Pain Policy Coalition (CPPC) and the Royal College of Nursing (RCN) to strongly influence the way pain is dealt with within the NHS and to ensure that the patient’s voice is heard.

Patients generally want to help themselves but are often not listened to or told about patient or support organisations. In coming together to form Pain UK, smaller voluntary organisations can work with those that are better established to create a stronger voice representing those living with chronic pain. Working together, this alliance will speak for people in pain, using the specialist knowledge and experience of patients and their families, thus increasing the potential to invoke change in health and social care as well as in the community and society as a whole.

Most good ideas have lots of small beginnings and there was a groundswell running in 2011 in favour of this one. Many pain charities are very small, run by volunteers and struggling to promote their particular condition and the needs of their members. At a number of meetings they made their feelings known. At a round table discussion on patient information hosted by the Patients Association in March 2011, one of the most significant recommendations was that there should be a pain federation, probably online, that would facilitate better information spread. At the Societal Impact of Pain (SIP) Conference in Brussels in May, Mary Baker, from the European Federation of Neurological Associations (EFNA), chaired a group of interested European patient pain charities with a view to starting a European Alliance. The British charities that attended realised the need to come together if we were going to be effective in this new organisation and it was agreed that we should try to form a coalition.

At the end of May 2011, Pfizer provided a facilitator for an interested group of charities to look at the possibility of setting up a UK group. In the facilitated session, it was agreed that we needed to be an independent group, funded by more than one source, able to work together on common goals and able to represent the pain charities both in the UK and in the European group. To this end ARMA hosted a meeting in June and a steering group of representatives from BackCare, Pain Concern, Migraine Trust, Trigeminal Neuralgia Association, Pelvic Pain Support Network, Pain Association Scotland, Fibromyalgia Association UK, ARMA and the CPPC was established. From this meeting the alliance has grown and developed. Pain UK was formally established at an inaugural meeting on 1 November 2011 and launched at the Pain Summit three weeks later where the chair, Sean McDougall, talked about the charity’s aims and ambitions. In a nutshell, our aims are to improve the efficiency and effectiveness of charities providing support to people living with pain, to work with others to ensure that pain is seen as an issue in its own right, and to provide support to people living with pain where that service is not already provided.

What have we achieved thus far? We are well on target to meet our first-year aims and objectives. We have been funded for our first year by Pfizer, Grunenthal and Medtronics; we are a registered charity; we have established ourselves as a brand with a striking new logo; we have a temporary website, with a new more exciting version about to be
launched; we provide a regular newsletter to our members; and we have begun to establish ourselves as a significant voice in the pain world. We have a trustee on the Patients in NICE group, and another is a member of the Specialised Commissioning Clinical Reference Group. We had a table at the BPS Annual Scientific Meeting and attended the Northern Ireland Pain Summit and the SIP Symposium in Denmark. We had two articles in the press related to SIP and one mention, and so have a sense that we are beginning to gain attraction.

We have been very conscious that the most important thing is to attract new members and to find out what our members would like us to do. To date 23 organisations have signed up as members – 19 full member charities and four associates, which include the BPS and the CPPC. Our newest recruit is the Limbless Association, which is anxious to promote the plight of its members and to get much better information to patients and medical professionals about post-operative pain and phantom limb pain than appears to be available at the moment. For the Limbless Association, like most of our member charities, it is an uphill task and we hope we can help by lobbying for better pain services in general and by helping the association to link to other useful organisations and interested bodies.

To discover more about what our charities want, we are also launching a survey of our members and hope in three months’ time to have a much clearer idea of the areas they need help with and what they would like to see us do. As a group of five volunteers who also work for other charities, we feel we have made a good start. But we also realise that we have a long way to go. We need more and different funding and we need at least one permanent staff member and more trustees. We see this as a two-year project to establish whether a pain alliance can work. So far, we have been very well supported by significant organisations and people; we hope we can justify their faith in us and make a difference.
CRPS UK – Inaugural Conference

Rosalind Leeming

17 and 18 May 2012 saw the first Complex Regional Pain Syndrome (CRPS) UK Conference and it was a resounding success. Sixty delegates, many of them severely disabled by this debilitating condition, gathered at the Hilton Hotel in Bath to listen to experts at the cutting edge of research and treatment. The event was hugely important for everyone; for the first time many people were able to meet others with this extraordinarily rare condition, and ask questions to the experts and specialists who had given up their time to attend.

CRPS UK is the organisation uniting, representing and supporting those with an interest in CRPS across the UK. The groundbreaking CRPS guidelines, to be published this year by the Royal College of Physicians (RCP), were presented to the conference by Dr Jenny Lewis (clinical research occupational therapist) who was party to their development. The guidelines have been developed for the diagnosis and management of CRPS in the context of primary and secondary care, and a shortened version is already available on the RCP website.

Particular highlights of the event included lectures from Dr Andreas Goebel (senior consultant at The Walton Centre, Liverpool), who specialises in the role of immunology in CRPS; Dr Richard Haigh (consultant in rheumatology, Royal Devon and Exeter Hospital), who spoke on the potential mechanisms for CRPS; and Dr Alex Green (consultant neurosurgeon from John Radcliffe Hospital), who spoke on the role of spinal cord stimulators and deep brain stimulation.

Taking much of his inspiration from the latest findings of world-renowned Professor Lorimer Moseley, an engaging session was also delivered by specialist pain physiotherapist Richmond Stace, and Sarah Wilson of the CRPS unit at Bath discussed issues of adolescents with CRPS. Additionally, patients had a unique opportunity to directly pose questions to a panel of experts, including Professor Candy McCabe (professor of nursing and pain sciences), Dr Peter Brook (consultant in anaesthesia and pain management), Karen Coales (clinical specialist occupational therapist) and Dr Karen Rodham (senior lecturer health psychology), all of whom are part of the team at the internationally renowned Bath Centre for Pain Services.

CRPS UK is led by a handful of volunteers, for whom the next big step is application for charity status. If you want to know more about this exciting organisation, or want to get involved, please visit http://www.crpsuk.org
Cluster headaches are severe primary neurovascular unilateral headaches that can vary in duration from 15 minutes to a few hours. Typically they last 30–45 minutes and can be completely symptom free in the intervals. The attack frequency varies between one and 15 in 48 hours. It can be accompanied by craniofacial parasympathetic features. The onset of symptoms is rapid without any premonitory signs. Patients describe the pain behind the eye or periorbital with radiation to neck or shoulder. It is also accompanied by autonomic symptoms, ptosis, miosis, conjunctival congestion, lacrimation, facial swelling or sweating, all appearing at the same side of the face. It is also associated with restlessness, with the sufferer pacing up and down the room or rocking back and forth. In contrast to migraine, it is about five times more common in men than woman. Absence of warning signs also differentiates it from migraine. It is also to be differentiated from trigeminal neuralgia, which is a lancinating pain mainly around the face. Alcoholic products and tobacco can trigger attacks. Other triggers include hot weather, watching television, stress, allergic rhinitis and sexual activity.

The underlying pathophysiology of cluster headaches is not well understood. The periodicity of attacks in cluster headache suggests the involvement of the biological clock within the hypothalamus. The posterior hypothalamus grey matter is identified as a key trigger area by neuroimaging. There are mainly two types of cluster headache:

1. Episodic – this is more common. The patient might get two to three episodes per day for approximately two months and will be symptom free for the rest of the year.
2. Chronic – Persistent headaches without any sustained period of relief.

Although the mainstay of management is pharmacological, interventions and surgical approaches are well described. Pharmacological management of cluster headache can be classified as abortive/symptom management and prophylactic/preventive.
Pharmacological management
Due to the fleeting short-lived nature of the attacks, prophylactic drugs are considered as the mainstay in their management.

1. High flow oxygen. Inhalation of high-concentration oxygen is highly effective as a prophylactic approach, although its precise mode of action is not known; 6–8 L 100% oxygen by face mask is given for no more than 15 minutes. It can be mainly used as an adjunct in an emergency setting, but is impractical in an outpatient clinic.

2. Triptans. Selective serotonin (5HT1) agonists cause vasoconstriction of cranial vessels and can reduce the severity of cluster headaches within 15 minutes of subcutaneous injection. Intranasal preparations are recently available in the USA eliminating the need for self-injections.
   - Sumatriptan 6 mg SC followed by a second injection after one hour if ineffective, not to exceed two injections over a 24-hour period. It is also available as an intranasal preparation.
   - Zolmitriptan 2.5–5 mg PO, dose to be repeated after two hours if ineffective, not to exceed 10 mg in 24 hours.
   - Naratriptan 1–2.5 mg, dose to be repeated after four hours not to exceed 5 mg in 24 hours.

Interventional and surgical approaches
1. Greater occipital nerve block can be effective in aborting headache.6
2. Deep brain stimulation with electrodes being implanted under stereotactic guidance in to ipsilateral posterior hypothalamus has emerged as a potential option for patients with chronic cluster headache refractory to pharmacologic management.7
3. Sphenopalatine ganglion radiofrequency ablation has been effective in select groups of patients.8 We would like to share our experience and invite thoughts about our management of a case of intractable chronic cluster headache.

Case history
A 68-year-old male patient presented to our pain clinic in a district general hospital setting with an approximately 20-year history of cluster headache. He was initially managed at a specialist neurological institute with conventional drugs including methysergide, sumatriptan, verapamil, steroids and oxygen therapy. He derived initial benefit from subcutaneous sumatriptan injections and later three to four months’ relief from greater occipital nerve block. Unfortunately the duration of benefit was becoming progressively shorter. He did not notice any difference with oxygen therapy and steroids gave him depressive side effects. In desperation, the patient resorted to intramuscular injections over a 24-hour period. It is available in strengths of 100, 200, 300, 400, 600 and 800 µg.

Discussion
Different types of short-acting fentanyl preparations had previously been used in treating intractable cluster headache. This includes flavoured lollipops of fentanyl citrate as well as effervescent buccal preparations of fentanyl. Unfortunately, compliance could potentially be an issue; during an episode, patients can feel quite detached from the surroundings. Although sublingual fentanyl is primarily licensed for breakthrough cancer pain in opioid-tolerant patients, the pharmacokinetic profile of sublingual fentanyl is ideal for managing similar situations. The key advantages are the rapid onset of action, duration that fits into the symptoms and offset of the drug effect once the symptoms are successfully resolved. Sublingual fentanyl is available in strengths of 100, 200, 300, 400, 600 and 800 µg.

References
2 Capobianco DJ, Dodick DW. Diagnosis and treatment of cluster headache. Seminars in Neurology 2006; 26: 242–59
Study day report: Therapeutic knitting to facilitate change

Betsan Corkhill  Stitchlinks, Bath

Bath’s Royal Scientific and Literary Institution was a fitting venue for the world’s first conference on therapeutic knitting on 15th June 2012. The event, hosted by Professor Paul Dieppe of Exeter University and organised by Betsan Corkhill of Stitchlinks, attracted a large amount of interest from across the UK and beyond.

Sixty clinicians, academics, patient representatives and group facilitators enjoyed a packed day with many others requesting a copy of a post-conference manuscript. Requests have been received from as far afield as Chile, the USA, South Africa and Australia. There was a tangible buzz about the room as Professor Dieppe outlined the aims of the day:

- To establish a core team of clinicians, academics and group facilitators interested in helping develop a network of therapeutic knitting groups and measure their outcomes.
- To gather a group of like-minded individuals interested in exploring low-cost, sustainable alternatives to managing well-being, stress, social isolation and long-term medical conditions.
- To establish ideas for potential research.
- To formulate a basis for a communication network.
- To formulate an action plan.

Delegates included specialists in areas ranging from pain and mental health to dementia, multiple sclerosis, clinical and research psychologists, psychotherapists, occupational therapists, nurses, physiotherapists, knitting and textile artists to EMDR, EEG and fMRI experts. It was recognised that despite coming from diverse backgrounds, all those present shared a common goal – to facilitate a positive change in the people they encountered, be that a change in the course of an illness, lifestyle or their social support network.

It was also recognised that the current model of health care is unsustainable, particularly for long-term conditions, and that more research is needed to find ways of tapping into the body’s own healing mechanisms. In the words of occupational therapist Grace Main: ‘The practice of supporting people to improve their well-being and actively engage them in actions to self-manage symptoms and causes would appear to be the foundation of sustainable health care in
Informing practice

Study day report: Therapeutic knitting to facilitate change

In support of these comments delegates heard how addicts can use knitting as a self-soothing tool for affect management to enable them to partake in group activity.

In more specialist areas, delegates heard how therapeutic knitting is being used to manage the experience of pain from Betsan Corkhill, mental health from Grace Main, dementia from psychologist Hilary Jones and Methodist Homes resource centre manager, Teresa McNulty, and addiction from Betsan Corkhill on behalf of clinical nurse specialist Andy Falconer. Groups are easily tailored to meet the specific needs and challenges of these different specialities at low cost. They promote purpose, creativity, success, reward and enjoyment, which is particularly important for individuals who have no experience of these in other aspects of their lives. In addition to the group benefits, the importance of context and having a portable ‘take-home’ tool was also stressed.

During discussions, consultant physiotherapist Eve Jenner and clinical psychologist Patrick Hill from East Birmingham Community Pain Services, showed the audience photographs of a magnificent knitted garden created by the local community knitting group with contributions of some patients from one of their pain management programmes (PMP). Eve Jenner said:

Several of our PMP patients were involved in the production of the garden, which was organised by the local community knitting group. We have started introducing knitting about halfway through the PMP as a pain management technique to those who are interested, and at the same time ask the local knitting group leader to talk and bring some examples of what they do. Happily a number of patients have gone on to join, which is great as it helps embed people into their community from which they have

a growing population experiencing dramatic demographic changes.’

The first half of the day entailed learning about the multidimensional benefits of knitting from possible biological and physiological changes through to social and behavioural; the use of knitting as a creative tool to manage symptoms and emotions and the use of therapeutic knitting groups to tackle loneliness and isolation. Clinicians heard how they could use therapeutic knitting as a means of educating, supporting, monitoring and motivating people over the longer term at low cost in an unintrusive way that does not necessitate patients to focus on problems, thus reinforcing the refocusing of attention on to more positive experiences.

When asked whether it was the activity or the group that was beneficial, Grace Main and Betsan Corkhill commented that it was the activity that enabled the group. There appeared to be a synergistic relationship; the combination of the self-soothing knitting activity and safe social contact can enable successful therapeutic groups and successful group therapy, and actively engage the patient in the recovery/management process.

This garden was knitted by Creative Moments Community Craft Group from Perry Common, Birmingham with participation from local residents, junior school and some patients from the local PMP – an intergenerational, whole community project; thanks to the organiser Phillipa England.
Study day report: Therapeutic knitting to facilitate change

usually been pretty isolated. The group does lots of projects – this one was for Gardeners’ World Live at the NEC in June, but the great thing, I think, is that the projects include knitting for all levels of ability.

The second half of the day focused on the structure of the proposed network, measurement, evaluation and research potential. It was proposed that community groups be at the heart of the Stitchlinks network, which will focus on tackling social isolation, loneliness and stress. Their aim would be to strengthen local communities to ameliorate wellness and positive living.

Linked to these groups will be the groups based in general practitioner (GP) surgeries and hospitals run by clinicians for people who need additional support. The network will also include speciality groups for particular conditions such as pain, addiction, dementia and mental health where specific education and treatment can take place through the groups. These groups will provide GPs and other clinicians with options for early intervention in a community environment. Group members and facilitators will be supported through an online communication network and the Stitchlinks website.

Research occupational therapist Dr Jill Riley reported on findings of an international survey of over 3,500 knitters carried out by Stitchlinks and Cardiff University, while Professor Dieppe discussed the question of establishing an evidence base for such a complex intervention. This poses significant challenges in terms of the complexity of the intervention and gaining funding for what is seen as a ‘non-scientific’ approach, while at the same time recognising the dangers of ‘medicalising’, and thereby changing, the nature of the intervention. It was also recognised that obtaining funding for a knitting study has been difficult simply because of the word ‘knitting’ and the particular connotations it evokes.

The research workshop run by reader in pain Ann Taylor took this discussion further and advocated developing a proposal for the use of knitting with dementia sufferers since there is more money available in this area of research. With larger numbers of elderly people living longer and developing dementia, the prospect of a low-cost health care tool that enables mental engagement and social interaction as managing symptoms of pain or depression could be extremely attractive.

Other workshops discussed the setting up of a therapeutic knitting group: a network of groups and communication pathways plus an evaluation and dissemination group that looked at who needs to be convinced and what evidence we need to convince them. These were led by Dr Jill Riley, nurse practitioner Carol Davidson and change management consultant Steve Corkhill.

The day closed with feedback from workshop facilitators and the formulation of an action plan lead by Professor Dieppe. Grace Main said: ‘The level of energy in the room to try and put this on an evidence-based foundation was inspiring.’ Outside the main lecture area, exhibits included a series of remarkable posters entitled ‘Pictures of Pain’ (fresh from the Neurodynamics and Neuromatrix Conference in Adelaide, Australia) by communication artist Molly Van der Weij and a range of knitted walking-stick cosies provided by Dr Felicity Ford.

Group facilitator for Age Concern Natalie McCulloch said: ‘It was a wonderful and motivating experience, which I feel privileged to be part of.’

Leisa Grey, community development manager for Manchester Art Gallery, said: ‘Thanks for a wonderfully stimulating, informative and inspiring day. It was the best conference I’ve been to for ages!’

Within a week of the conference, the communication network was up and running and many of those who attended were already actively engaged in making things happen, which is really exciting and refreshing. A manuscript of the day’s talks and proceedings is being published. For a copy please email Betsan Corkhill (Betsan@stitchlinks.com).

Reference

1 Velenzuela M. Brain power; why using it helps stop losing it. The Conversation. Available online at http://www.thecommunication.eu.edu.au (accessed July 2012)
I am not going to give you any more stuff for your heads – you’ve had enough this week. I want to appeal more to your hearts. You won’t need to write anything down – perhaps you won’t even have to think much. Just let things ride for a little bit. That’s what ‘presence’ is all about.

If I started with a roll call, you might all answer ‘present’ … but perhaps you’re not present? Your body is here but your mind might be somewhere else. Already I’ve seen people getting ready to go and thinking of taxis and all that stuff they’ve got to do when they get back; your minds are moving on somewhere. We’re not always really present. That is a big problem in our society today: we want to keep one step ahead of things; we feel we’d never get anything done otherwise. And if it is not preparing for the future, we find ourselves kind of being pulled back into the past … I should have done it that way, I could have done it better, I’ll have to sort that out …

So very little goes on in the present. In our insane society, we think it is normal to think that a future moment is more important than a present one. We are so stretched – I’ve got so much to do, so many deadlines, so much to prepare for, the next patient is waiting, I’ve got to get rid of this one – and the past problems are stretching in the opposite direction; and it hurts! But people get so used to it and they take it for granted that this is how we should be. People even start feeling guilty if they don’t feel stressed: I’m not doing my job properly; people will think I’m lazy.

I used to work in a secure mental hospital. There was a newly appointed modern matron whose job was to attend meetings. I was at a meeting at which he arrived late and rather breathlessly apologised that he had just come from another important meeting – and left half an hour early because he had another one to go to! So the meeting he was coming from and the meeting he had to get to was always more important than the one he was at. He was never really present at any meeting; the guy had a breakdown two years later.

So I want to offer you a few simple ways to get into this presence. The first is walking; we think of walking as a means of getting from A to B. But some people never seem to walk anywhere; they never feel the earth under their feet. People say: ‘I’m so busy my feet hardly touch the ground!’ No wonder they can’t be present. So I’m suggesting walking for no other purpose but for walking. It might seem a bit slow … thinking of every step … one step at a time … but remember the first step climbing the mountain is as important as the last at the top. Each step has its own meaning, helping you to become present.

The second thing to think about is nature. We have got so much beauty around here; I see people walking around just taking it all in. Sometimes, when we do appreciate nature, when we see a beautiful scene, we just stop in awe. We don’t think – it’s just … ohhh … And for a moment you are totally present; almost at one with that. But soon you will be back into your daily life. But, wherever we are, nature is around us in every sense; just feel the wind in your face – even rain – be present to it, don’t be wishing this bloody rain would stop; when it’s cold don’t be wishing it were summer again. Be at one; be at peace with it. Just take it on board for what it is. Nature is what we call “pre-mind” – it just is. And when we are giving presence to nature we are actually giving something back. It is like what we have
been talking about: transactional communication with each other. You are adding something to nature when you become present to it, because you are not separate; when you appreciate the trees and the scenery, you are actually enabling nature to express itself. Some people get so busy that they can go round in circles trying to get things done and never be at peace with nature. Jesus said: ‘Look at the flowers in the field and the birds in the air’; some translations say ‘consider’ – think about – but they don’t need thinking about; just look! – notice – see.

Pets, too, can be a great help to us. My dog used to be my spiritual director. He just seemed to accept me as I am. When I came home late he wouldn’t say: ‘Where the hell have you been – where’s my food?’ – he’d just love me. It’s the one moment of true presence they have in their day. There is a lovely prayer: ‘Dear God, help me to become the sort of person my dog thinks I am.’

The third way of finding presence is simple actions. A Zen master was asked: ‘What is Zen all about?’ His reply was: ‘Chopping wood and fetching water.’ ‘And if I do this for a long time what does it lead to?’ ‘Chopping wood and fetching water.’ Now we just turn a tap for water or press a button for warmth, but yet simple actions is where it’s at: discovering the extraordinary in the ordinary. Most of the time, we want to escape the ordinary; I’ll get the simple actions out of the way and do something more interesting. There’s no presence in that. When food has been cooked without presence it doesn’t taste as good. Another Zen saying is: ‘Do one thing at a time.’ Putting your foot into your shoe and tying the laces or buttoning up your shirt is just as important as going off to do something else. To think that there is a more important future act to prepare for than the present moment is ludicrous. But it is so normal to us; if you get this done then you can get that done. So be attentive to each new moment, seeing it as deeper and fresher.

Amazing things can happen. You are widening a field of presence around you, and this leads into other people. They have got something to teach us. It affects our relationships; bringing presence into other people can only bring presence into our lives. Couples doing a lot of shouting and talking at each other are hardly ever present. Minds are meeting but nothing else.

Real presence between people involves attentiveness and real listening.

We constantly want to change things in our lives, addictions; too much food, alcohol, cigarettes. None of them can be changed just by willpower. It might work for a while but if you don’t bring presence into it, it won’t last. There is a sort of primordial instinct to want more and more: more stuff, more information, and more interest. Being present opens a field of energy; instead of eating that sandwich and being cross with yourself, just be aware of that impulse – be present to it. In the end it won’t matter whether you fail or not, because presence has been alerted, and it will widen to make a difference.

That is what presence is – in the centre of all the stuff we are doing; we can have presence, and we can begin to bring it into everything we do. We may never get into it totally – at least not until death, but why wait till then when we can enjoy so much in the present moment?
Informing practice

Reductionism revisited

Diana Brighouse  Consultant in pain medicine (retired) and psychotherapist

This is a lecture from a Philosophy and Ethics SIG meeting, reproduced by Peter Wemyss-Gorman. These are neither the views of Pain News nor the British Pain Society. Please bear with us if there have been any omissions or errors during the transcription process.

Eleven years have elapsed since I gave a talk at the very first meeting in 2001; a lot has happened in this time, both in the world of medicine and in my world. I want to reflect both on my journey and on the political journey of the health service and look at them through a reductionist lens. My very simplistic definition of reductionism is an understanding that the nature of complex things can be understood by reducing them to more fundamental things, or a philosophical position that a complex system is only the sum of its parts.

Giles Fraser, the canon chancellor of St Paul’s Cathedral, wrote, the day after the Royal Wedding:

The night before I got married I went out for a drink with a mate. I tried to make a rational analysis of reasons for and reasons against getting married. But it was a stupid exercise because no equation of reasons could begin to describe the situation. How is love to be reduced to a series of propositions? In truth what binds people together as a couple or as society always exceeds the reach of a purely rational analysis.

I would ask how can medicine, and certainly pain medicine and mental health medicine (which in my experience are often intertwined), be reduced to a series of propositions?

On the other hand, an economist was quoted in the Observer as saying: ‘Capitalism wishes to see the maximum return from its investments. To that extent it exerts great pressure to turn both human beings and nature into commodities. Viewing people as commodities promotes hierarchies of worth and discourages communication.’ We had a tendency in medicine in the last decade or so to turn human beings into commodities. An article in the British Journal of Psychiatry 2009 proposed that:

Reductionist policies have impoverished the health services. Providing high-quality care is reduced to meeting targets (this applies in large part to chronic pain, and indeed most chronic conditions). Professionalism is reduced to competences. Diagnostic assessment is reduced to assessing needs and risk. Clinician-patient relationships are reduced to an assembly line model where functional teams provide “client-centred” but fragmented and impersonal care. The current emphasis on health rather than illness and on recovery rather than treatment represents magical thinking (a lot of this in chronic pain) in attempts to deny the existence of madness (chronic pain). These manoeuvres also help to tidy away the suffering and emotional pain of mentally ill persons (chronic pain patient).

Lean and NICE

Evidence-based medicine [EBM] appeals strongly to managers, health service economists and people who want to measure things and deliver reports. Lean is a model of care which originated with Henry Ford and has been adopted by the DoH [Department of Health] as a model of efficiency: if you can streamline and become more efficient and save money you can improve outcome. NICE [National Institute for Health and Clinical Excellence] ‘works with the experts as well as the carers’. They claim to make ‘independent decisions in an open and transparent way, based on the best available evidence and including input from experts and interested parties. The first step for EBM is to translate an uncertainty into an answerable question’
Reductionism revisited

Informing practice

Research: Quantitative Vs Qualitative

Simplistically, quantitative research is about numbers; discrete entities and variables. Qualitative research is about continuous variables and less numerically measurable things. The null hypothesis is an essential part of any research design. Alternative terms for the traditional research paradigm are quantitative, scientific, experimental, hard, reductionist, prescriptive and psychometric. Traditional research paradigms rely on quantitative data and mathematical treatment of that data. The ‘truth’ is real and incontestable because it has been tested by numbers and is grounded in mathematical logic. This is absolutely fundamental to the reductionist paradigm in medicine. Patricia Greenhalgh, writing in the BMJ [British Medical Journal] in 1997 observed that ‘most of us are happy to accept uncritically simplified, reductionist and blatantly incorrect statements so long as they contain at least one number.’

Qualitative research aims to gather an indepth understanding of human behaviour, and the reasons that govern such behaviour. In quantitative research, the possibility of a researcher taking a neutral position is seen as normal; whereas in qualitative research we accept that the phenomenon of the observed and the observer changing one another means that there is really no such thing as a neutral position for the researcher. A reductionist approach isolates variables and establishes relationships between them. A qualitative method starts to look at systems which cannot be understood by looking only at the sum of its parts.

In the latest edition of the MRC’s [Medical Research Council’s] good practice guide there is not one mention of qualitative research, but:

There is ample evidence that the legitimacy and usefulness of qualitative research is no longer questioned by most prominent scholars in administrative and organisational science.

Stanford University School of Education, January 2011

Researchers who use qualitative methods look for a deeper truth. They attempt to make sense of the meanings people bring to them, adapting a holistic perspective which preserves the complexities of human behaviour.

Patricia Greenhalgh, BMJ 1997

In chronic pain we have long abandoned the simplistic notion that we can abolish pain by cutting nerves etc. We try and make sense of what is happening in terms of the meanings our patients bring to us.

Qualitative researchers aim to gather an in-depth understanding of human behaviour and the reasons that govern human behaviour. Various aspects of behaviour could be based on deeply held values, personal perspectives, experiences and conceptual circumstances.

John Hopkins School of Medicine

We all know this. So why is it not getting out there? Guidelines issued by the College of Emergency Medicine raise a series of enlightened questions such as: ‘Should we allow relatives to witness emergency resuscitation?’ They continue: ‘These questions cannot be answered very satisfactorily by our familiar quantitative methods. They require a deeper understanding of attitudes, experiences and behaviour. Therefore we have to use a different research methodology.’ The Pain Faculty of the Royal College of Anaesthetists has said nothing comparable: nothing! Perhaps we might think of doing something similar for our trainees?

Positivism and Reductionism

Although they are not the same, I would like to equate positivism and reductionism – for our present purposes, they are near enough. Positivism, then, is the view that all true knowledge is scientific and that all things are ultimately measurable. It avers that the entities of one kind are reducible to another, and processes are reducible to physiological, physical and chemical events. There is a strong strand in psychiatric research that all mental health problems will be reducible
Reductionism revisited

Informing practice

Reductionism revisited

to biological events. Social questions are said to be reducible to relations between and actions of individuals. So when we differentiate between qualitative and quantitative research, are we talking about the philosophical difference between reductionism and anti-reductionism or constructivism? These are some of the differences:

- Positivism as a single tangible reality broken up into variables, versus constructivism which involves multiple constructed realities.
- The idea that with reductionism you can separate the observer and the observed versus the recognition that they are inseparable.
- The implication of reductionism that cause and action are described by one another versus the constructivist perception that they are interlinked.
- Most importantly, the positivist belief that inquiry is value free – the Holy Grail of evidence-based medicine – versus the understanding that it should be value bound.

Positivists argue that if you cannot measure, then it is not worth studying. The problem is that if it is so simplified it’s probably not ‘It’. In a paper in April’s BMJ on qualitative research, Paley and Lindfield say: ‘It is impossible without further inquiry to rely on what people say about themselves.’ So when your patient comes to the pain clinic and tells you something, you don’t believe them until you have made your own inquiries. The assumption is that there is a single verifiable truth – if you gather enough versions you will find the truth. That is highly reductionist.

Understanding the context in which people live is essential. Qualitative researchers need to identify and understand how their own views and beliefs may influence the interactions they have with participants. People understand the world differently, and that informs their beliefs and their intentions. Understanding these differences is sometimes a matter of listening rather than counting, which is why history-taking is still so important. Fitness to work is a reductionist paradigm, as a result of which (as revealed in a recent BMJ article) many people with serious health problems including MS [multiple sclerosis], terminal cancer, bipolar disorder, serious depression and agoraphobia have been found fit to work; because the questions that are asked are highly circumscribed and if you have managed to book an appointment and walk up the stairs then you are fit to work!

The comfort of reductionism
So what is the comfort of reductionism? Certainty offers security; that is part of the human condition. As doctors we like to have some illusion of truth: we might accept our short-fallings and admit to patients that we cannot quite get there but we can send them to someone who might find that absolute truth. This is particularly a problem in chronic pain where patients are passed from one doctor to another in the hope that the next one will have the answer, and we still hope that one day we will know ‘It’ all and will have all the answers. Descartes said: ‘Divide each difficulty into as many parts as is feasible and necessary to resolve it.’ But I would prefer Aristotle: ‘The whole is more than the sum of its parts.’ And Edmund Simpson: ‘The love of complexity without reductionism makes art. The love of complexity with reductionism makes science.’

The slides including carefully chosen artworks that accompanied this talk can be obtained on request from the speaker at dbrighouse@aol.com
The perception of pain: is one person’s agony merely another person’s irritation?

Cllr Stephanie M Stokes  Chair, Community First New Forest; retired Open University lecturer in neuroscience

‘Ouch!’ you cry as the nurse inserts the cannula for the pre-med while you lie on the bed half-reading a boring book. She moves on to her next patient who is watching Manchester United play Chelsea on TV. She inserts the cannula and barely gets a murmur. Why is there such a difference in response to the same stimulus of a skin-piercing prick?

The perception of pain is the subject of this essay. I will argue that pain is perceived differently by individuals in accordance with their level of consciousness and with respect to their culture.

When examined biologically, pain appears to be merely a physiological response to a stimulus. The circuit consists of a nociceptive sense cell responding to a stimulus (e.g. needle prick) and the stimulus electrochemical information travelling in afferent pathways to the brain for processing. If the stimulus is harmful (you touch a hot stove) then information is passed along the efferent pathways to a muscle that responds by contracting and moving your hand. However should you wish to do so, you could consciously keep your hand on the hot stove, by force of will. This conscious control is essentially what Swamis do when they walk on, for example, beds of nails – seemingly without pain.¹

At some level they are consciously controlling their pain perception. Indeed in 1969, Swami Rama and Jack Schwartz, in an empirical experiment conducted by Dr Elmer Green, demonstrated that it is possible to control a number of physiological and other responses by mind control alone. Schwartz even managed to insert a darning needle into his arm and control the bleeding. This seems bizarre, but has been recorded as fact.

This ability to control the perception of pain is seemingly a medical conundrum and is known as the ‘mind–body’ problem – or the issue of consciousness. It is our level of consciousness or awareness that plays a large role in our perception of pain. The patient in my scenario above who was watching football was less conscious of the needle’s sharpness than the book reader. But what is this concept called consciousness and how does it play into our perceptions? Let us digress to consider it.

Daniel Dennet in his book Consciousness Explained² discusses the matter at length, attempting to formulate a theory in which he argues against Cartesian dualism (mind separate from the body) and for the mind as a part of a fully functioning brain machine. If we take our initial scenario and apply Dennet’s thesis to it, then it is within the brain that consciousness is located and thus the needle prick’s pain intensity must be perceived on some level of conscious understanding within the brain – that is, the person experiencing the percept does so by means of processing in the brain of stimuli located outside the brain. Exactly where these ‘neural correlates of consciousness’ lie is as yet unknown. Scientists have been grappling with the problem for many years, but in the last 30 years, some understanding is emerging. In 1987 Jackendorf,³ whose research concentrates on vision and linguistics, postulated the concept of the phenomenological mind and the computational mind – two brain ‘domains’ working in synchrony to bring about an understanding of mental representations of phenomena (qualia) such as a visual stimulus. It is well known among physicists and cognitive scientists that while the visual image received by the retina is veridical, the perceived image is correctly orientated. In some way the brain ‘knows’ unconsciously that the veridical image is the wrong way up.
The perception of pain: is one person’s agony merely another person’s irritation?

This synchronicity may well play into the perception of pain too; it is a stimulus received outside the brain, but how it is perceived by the individual is processed in the brain. However, how can scientists look for the neural correlates of ‘pain’?

If processing occurs within the brain – probably deep within the cortex – it is difficult to study any mental ‘representations’ in situ. With the brain encased in a rigid bony skull, research has to largely concentrate on comparing reports from experimental participants with healthy brains and those from participants with known lesions. Today we are able to look at the brain’s functioning under given stimuli via scanning techniques. The usage of functional magnetic resonance imaging (fMRI) in particular is transforming the process of comparing sensory input with memory. In short, we will remember that if we put our hand on a hot stove it hurts, so we do not do so again, or if we do then we remember that it will hurt.

Returning to our hospitalisation scenario, evidence suggests that focussed attention, as in meditation, distracts one from our affective states.6 This would accord with our patient watching the football match. He may not be practising meditation, but he is certainly clearly focussed on something other than the needle and he is less aware of his affective state than the bored book reader. Consequently he perceives the needle prick less painfully. There is evidence too that men and women perceive pain differently, possibly because different regions of the brain are activated.7

There are other factors that may impact upon perception, not always immediately appreciated, and one of these is culture. Callister8 argues that pain perception is culturally bound and differences and cultural norms, the patient’s perceptual experience of their pain should be integral to planning a treatment protocol. Patient education is essential too, which should help a patient to understand the pain that they feel and enable them to put this experience into context.

References
1 http://www.neilslade.com/Papers/Rama.html
8 Callister LC. Cultural influences on pain perception and behaviours. Home Health Care Management 


Reviewed by YGM Coldicott
Ashford and St Peter’s NHS Foundation Trust

This book follows the structure of the well-known Oxford Handbook series, and is therefore pocket-sized and concise. The primary aim stated in the editors’ preface is to provide a practical handbook about interventions performed for pain management. It does not attempt to discuss pathology, assessment or treatment plans but rather provides detail in the areas of anatomy, imaging, indications and contraindications, techniques, complications and tips from the authors.

The chapters are written by UK consultants and specialist registrars specialising in pain management, with each chapter having at least one consultant contributor. The target readers are specialists and trainees who perform procedures, as well as those preparing for the exams. It may also appeal to members of the multidisciplinary pain team and palliative care physicians who are involved in the comprehensive management of patients undergoing interventions as part of their wider treatment.

The book is presented as 14 chapters, each covering a broad group of interventions based on anatomical location. These are further subdivided into small sections of a few pages that describe each intervention in turn.

The general format of each section is the same, with subtitles such as anatomy, indications, contraindications, positioning, technique, fluoroscopy, complications, and tips/pearls of wisdom. Suggestions for further reading are also provided at the end of each chapter. The text is widely illustrated with diagrams and X-ray images that complement the bullet-point text and ensure that the practical advice is easy to follow.

The first few chapters cover anatomy, imaging and drugs and the more commonly performed procedures including lumbar, cervical and thoracic spine procedures. There then follow chapters on less day-to-day procedures including disc procedures, vertebroplasty and kyphoplasty, spinal cord stimulators, intrathecal drug delivery, autonomic blocks and head and neck interventions. The final chapter is about medicolegal issues. Patient selection, examination and complications will be of interest to all health care professionals seeing patients in pain clinics who may be asked about suitability for interventions.

Where different techniques are recognised for a specific procedure, these are discussed in the text. For example, a variety of techniques for sacroiliac joint denervation are described including newer techniques such as SInergy cooled radiofrequency and Simplicity.

Although the book does not attempt to provide evidence for specific interventions, reference is made to relevant studies and trials, which are useful in ascertaining the benefit that patients could expect following a procedure. In addition, extensive reference is made to UK and US guidelines including those from the Faculty of Pain Medicine of the Royal College of Anaesthetists, the British Pain Society and the International Spine Intervention Society. I found this pocket-sized book a useful reference prior to performing pain-management interventions, and also an interesting introduction to some of the more specialised, less widely performed procedures. The text covers much detail, especially for a book of this size, and the excellent illustrations demonstrate common fluoroscopic images as well as regional anatomy.

In summary, I would recommend this book to all members of the multidisciplinary team and in particular to trainees and pain fellows who are learning interventional procedures as well as possibly preparing for the exams.
Face Pain: A Guide for Patients and Carers

Reviewed by Dorothy Helme
Lay Member, Patient Liaison Committee

Facial pain is often a diagnosis by exclusion and therefore patients frequently report a long journey of investigations, consultations and in some cases unnecessary operations before getting any pain relief and strategies for coping with their condition. This clear and concise booklet on the different sorts of facial pain and what treatment is available is a welcome guide for patients and carers.

Inevitably, over half of the booklet is dedicated to trigeminal neuralgia since this is one type of facial pain for which there are possible surgical solutions. The explanations are clear and the use of medical terminology with bracketed lay translations is very helpful for the patient’s understanding and for future consultations for which the patient’s clinician may not so easily lapse into lay language. The various surgical procedures are explained in good detail with the percentage risks given for each one. I would strongly recommend such patients to take this booklet with them to any surgical consultation.

The other types of facial pain considered in the second half of the booklet are glossopharyngeal neuralgia, post-herpetic neuralgia, temporomandibular disorders, chronic idiopathic facial pain, atypical odontalgia and burning mouth syndrome. Each is given good, clear descriptions and the bottom line on treatment for all of these conditions is spelled out at the foot of the final page in this section: that there is no surgical treatment. The authors state that treatments used are medication and developing ways to manage the pain. This is a significant message for patients and clinicians alike and one that is difficult to face, for we all want a cure and it is important for patients in this group to realise that surgery is not an option and for dentists to hold back on fruitless extractions. The message from the authors is emphatic and they then dedicate the last three pages to possible medications and pain management strategies.

Psychological therapies are dealt with positively and succinctly, and the suggestion that the patient talks to their general practitioner about availability is helpful for us, the patients, are often unaware of what specialist services exist for us. There is a short list of useful contacts, including the British Pain Society, at the back of the booklet. The booklet can be downloaded from the Brain & Spine Foundation website (http://www.brainandspine.org.uk) or requested free of charge by post. It is nicely laid out and clearly printed with good illustrations and I would recommend it to any patient experiencing facial pain and suggest that every clinician who may see these patients has a copy in his/her desk drawer.

Erratum

The Editor apologises for missing the credentials of Alison Bliss in her article in our last issue. She works in Leeds General Infirmary and is the Secretary of the Pain in Children Special Interest Group of the British Pain Society.
Letters to the Editor

Un-picking knitting
Dr Derek Jones  Senior lecturer,  Northumbria University
Ms Suzy Williams  Council member,  British Pain Society
Louise Haynes  Senior occupational therapist,  Walton Centre Pain Management Programme

Sir,

It was interesting to read Betsan Corkhill’s piece in the March 2012 edition of Pain News highlighting the value of engaging in knitting. This prompted our response to highlight the knowledge and skills that occupational therapists (OTs) have been applying for many years regarding the promotion of valued and meaningful activity as a therapeutic medium.

The concept of ‘occupation’ as used by the profession refers to socially recognised and named undertakings. Occupations can be categorised into three (not mutually exclusive) domains: self-care, productivity and leisure. ‘Activity’ typically refers to a specific example of an occupation: for example, taking a shower, working on a production line, baking an apple pie. It is a basic tenet of the profession that doing value-driven tasks that are important and meaningful to the individual (and that may include knitting) promote health and well-being (whether you have an identified condition or not).

The practice of occupational therapy is deceptively simple with its focus on the ‘doing’ of everyday activity. Its complexity lies in the understanding of the factors that influence ‘doing’ and in identifying activity-focused interventions that enable individuals to achieve their goals.¹

So where does that leave us in relation to knitting and in particular Betsan’s article? As OTs, we would say that it is not just knitting per se that is therapeutic but the fact that it is meaningful to the participants. Moreover, we would challenge Betsan’s claim in her article to the unique value of knitting as a leisure activity. An activity analysis of leisure pursuits with an individual might highlight the therapeutic potential of a range of activities. For example, replace knitting with bread making or pottery and you can achieve therapeutic benefits as both involve bilateral activity, can be done alone or in a group, facilitate social interaction and have potential for grading and creativity.²³

The sense of fulfilment and ‘flow’ that Betsan highlights can only be achieved if the right skill level is matched to the right challenge. If this is not the case, an activity can lead to boredom and/or apathy.⁴ Emerson⁵ also highlights that flow is achieved when an activity is rewarding and there is a sense of control and has meaning to the individual. Therefore a ‘one-size-fits-all approach’ to the prescription of activity is as inappropriate as prescribing everyone the same medication or exercise.

The suggestion in the article that patients should be encouraged to focus on rewarding rather than purposeful occupations is also misleading. It seems here that a distinction is actually being made between occupations under the domain of ‘Leisure/the things one likes to do’ and ‘Productivity or the things one has to do’. To suggest that a rewarding activity does not have to be purposeful is in fact contradictory as Betsan goes on to highlight some of the purposes of knitting, for example chemo hats and socks for soldiers.

We are not disputing Betsan’s claims regarding the potential impact of knitting on neuronal activity and on the well-being of her particular patients, but the article does highlight the need for further research to test the knitting phenomenon on other creative activity to ensure the optimal holistic effect. This is suggested on the Stitchlinks website but it is not clear in the article.

The value of group activity is also highlighted in Betsan’s piece. The fact that most pain management programmes are run as groups endorses this, and psychologists, psychiatrists and OTs have been employing group therapy for many years and well understand the power of this social environment. However, as with all things, it is as well to be aware of the risks as well as the benefits. Betsan tells us that having a group activity to focus on allows people to become social at their own pace, to have eye contact as and when, talking and chatting as they get more comfortable. Conversely, knitting can also allow the person to avoid eye contact and conversation and to remain isolated within a group.

There is no doubt that knitting has some pragmatic advantages as cited by Betsan (cost, venue flexibility, material recycling), but then all activities have their advantages and disadvantages that need to be weighed up. This includes an awareness of risks as well as benefits, for example the need to consider ergonomic and biomechanical factors. (Think of the consequences to some musicians of the repetitive action of playing – and consequently repetitive strain injury; poor technique may lead to muscle tension or joint protection issues for people with rheumatoid arthritis, and neck, shoulder and hand pain may all be exacerbated by the static posture and repetitive actions involved in knitting.) Again, Betsan does raise these issues on her website, but they were not evident in her article.

So our take-home message is:

- Encouraging engagement in an activity such as knitting or any other craft activity is not a new phenomenon.
It may be enjoyable for some, but maximising its therapeutic potential (and safe performance) requires:

a) That it is meaningful and purposeful to the individual.

b) Consideration of the outcomes of an activity analysis, which will then contribute to the formulation of appropriate delivery of this potentially powerful intervention.

There is a need for OTs to promote the positive impact of person-centred valued occupations on the chronic pain experience and for further research into its more specific effects.

References

Response from the author: Picking up the thread
Betsan Corkhill, Stitchlinks, Bath

I’m pleased my article has stimulated this discussion.

We may well find the letter writers are correct. However, we have identified a combination of benefits in the activity of knitting that appears to be unique. This merits investigation in a fully multidisciplinary fashion and it would only be to our patients’ advantage if we could find other activities with the same range and mix of benefits.

The benefits that we have identified in knitting centre around the combination of the nature of the actual movements, creative development and portability. In group work this enables the knitter to overcome problems with managing emotions to ensure that they feel in control; so there appears to be a synergistic relationship that enables the groups to be therapeutic groups but also enables group therapy. The portable, accessible nature of knitting enables this synergy to extend into the home where projects can be worked on to bring into the group in anticipation of praise.

Enabling eye contact, or not, plays an important part in the success of the group. The knowledge that they can come to a group and sit and knit quietly and not have to fully participate all of the time is extremely important. It encourages them to come to the group even on days when they don’t feel great. Far from being isolating, we have identified that it is important for people to have moments of time when they can ‘just be’ in the relaxed company of others without feeling pressure to contribute.

Knitting’s portability enables it to be used to manage pain spasms or panic and anxiety attacks when out and about. It can be taken on to public transport or to a café, or pub to encourage socialisation with friends. It can be done in front of the TV at night to curb addictive habits such as binge eating, smoking or self-harm.

The opportunity for ongoing skill acquisition ensures the sense of fulfilment and ‘flow’ is maintained – boredom and apathy aren’t issues; on the contrary, it inspires. Reward, meaning and control remain in the knitter’s hands. Those who use it as a tool learn to enjoy the meditative, calming state of mind it enables, and continue with the activity for the enjoyment of this experience rather than that of producing an end product.

In terms of rewarding versus purposeful occupation, we are making a distinction between the things one likes to do and the things one has to do. We have never said rewarding occupations shouldn’t be purposeful; in fact the ‘reward’ itself may be the purpose. We are, however, questioning whether all purposeful occupation is rewarding. Housework is purposeful but many don’t enjoy it. Many fill their days with dutiful, purposeful occupations rather than rewarding, beneficial ones.

As far as problems with potential repetitive strain injury are concerned, we provide postural and pacing advice and advice on choosing appropriate materials that enable patients to move and exercise safely. Indeed, those with hand and wrist problems are reporting significant improvement in symptoms because of the movement, which we teach them to manage appropriately.

In addition to our group work we have collected over 600 narratives from across the world. Findings are also supported by a survey of over 3,500 knitters carried out by Stitchlinks and research occupational therapists at Cardiff University. This is ongoing work.

Chronic pain is multidimensional, involving a complex interaction between biological processes, a dynamic nervous system, psychological and social issues. It’s time our treatments reflected this.