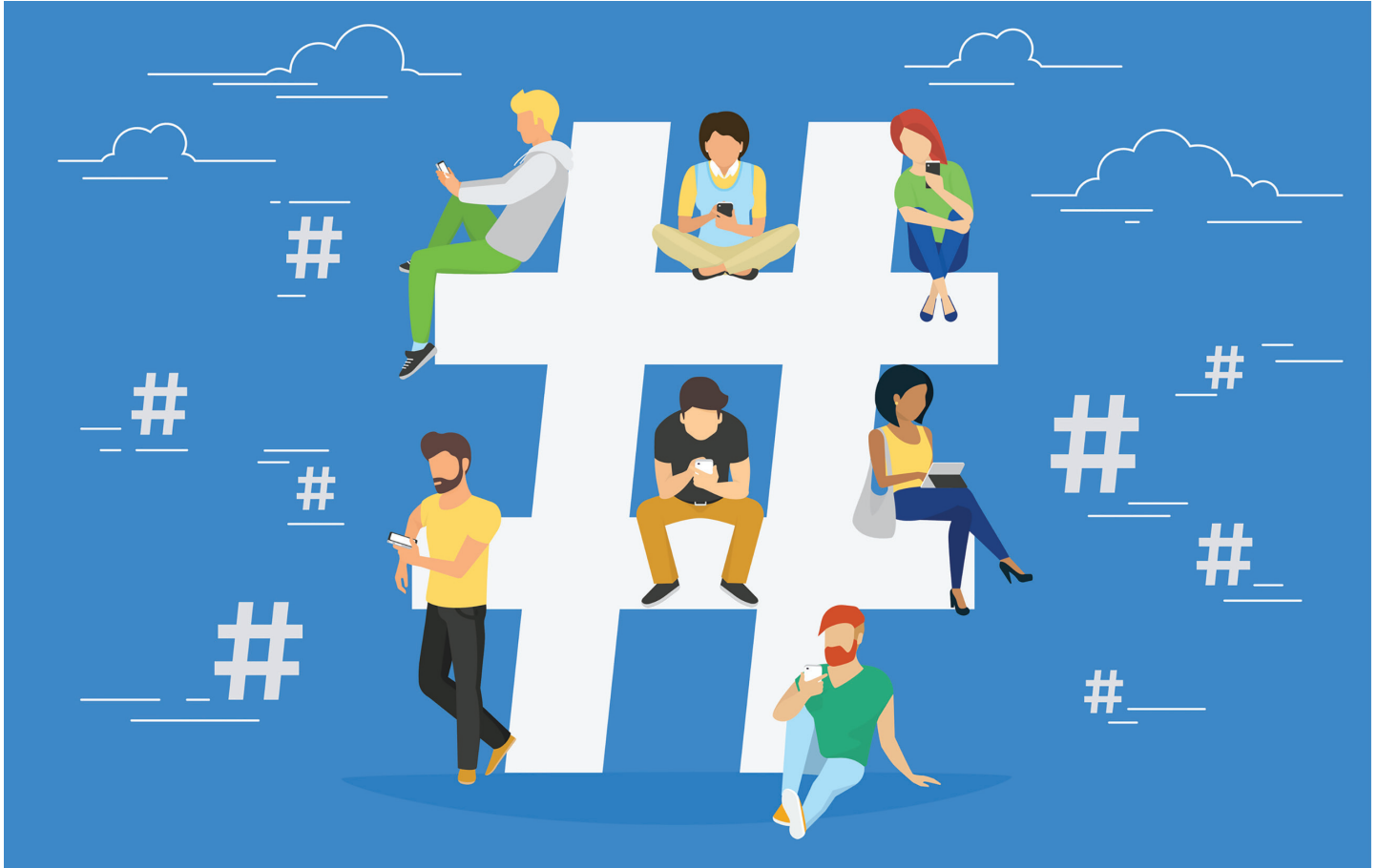


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PAIN NEWS

A PUBLICATION OF THE BRITISH PAIN SOCIETY



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Twitterchat as educational tool

Estimating other's pain intensity, to what extent do clinicians rely on nonverbal behaviours?

Anaesthetists' views of managing children's pain post-surgery

ISSN 2050-4497





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THE BRITISH PAIN SOCIETY
PAIN NEWS

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

Next submission deadline : 5th January 2018

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



British Pain Society Calendar of Events

To attend any of the below events, simply book online at:

www.britishpainsociety.org/mediacentre/events/



**THE BRITISH
PAIN SOCIETY**
EXPERTISE WHERE IT MATTERS

2018

Trainee Study Day

7th February 2018

Churchill House, London

This is an excellent opportunity for those who have an interest in Perioperative Anaesthesia and Management of patients with Chronic Pain. Speakers -experts in their field will cover:

- Neurobiology of the transition of acute on chronic pain
- Perioperative management of the chronic pain patient,
- Management of patients on long-term opioids, and the
- Role of regional anaesthesia

Pain in Military Veterans & Pain in Torture Survivors Study Day

26th February 2018

Churchill House, London

Treating pain in people with post-traumatic stress symptoms: survivors of torture and of war

This day will be run in two halves, and participants are welcome to sign up for either or both. The morning will cover medical, psychological and physiotherapeutic principles and practices of treating chronic pain in military veterans, from an experienced team at the King Edward VII Hospital. The afternoon will cover medical, psychological and physiotherapeutic principles and practices for treating chronic pain in survivors of torture, in a pain clinic, with teaching from clinicians from a variety of settings.

Annual Scientific Meeting

1st & 2nd May 2018

Hilton Brighton Metropole

The British Pain Society would like to invite all healthcare professionals to attend its 2018 Annual Scientific Meeting (ASM), which will be held in Brighton at the Hilton Brighton Metropole.

The Plenary lectures include;

Pain in Mice and Man: Ironie Adventures in Translation

Chronic pain – what's it like? Patient and Professional perspectives

A Gut Feeling About Brain Function: Microbiome as a Key Regulator of Visceral Pain

Leaning on the wind: reducing patient, professional and organisational barriers to pain management through education

What can sociologists contribute towards the understanding of pain?

Pain after torture: progress, setbacks, and prospects

Chronic pain epidemiology: from population health to health policy

Further details for all our meetings can be found on our events listing page:

www.britishpainsociety.org/mediacentre/events/

Dr Arasu Rayen



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What a year 2017 has been for the British Pain Society (BPS). BPS celebrated its 50th ASM which was undoubtedly successful. As you can read from

the President's message, the BPS has several exciting projects to take forward in to 2018.

As ever, our editorial team has produced a wonderful and interesting *Pain News*. I would like to point out that this issue has a few articles on

acute pain. In the News section, there is an article on the success of this year's National Symposium on Acute Pain. In the Professional Perspective section, Dr David Clarke and Dr Samina Ishaq detail how to manage acute pain following rib fractures. Like management of any acute pain problems, they advise a stepwise multimodal approach. In their article, they detail three local anaesthetic regional block techniques, namely paravertebral block, thoracic epidural and serratus anterior block. There is another article on 'Anaesthetists' views of managing children's pain post-surgery'. The e-survey, consisting of 25 questions, was developed to examine anaesthetists' views, confidence, knowledge, training and use of pain assessment tools with children

following surgery. Even though anaesthetists use several tools to assess pain in a child, the survey found out that, in case of uncertainty, anaesthetists ask the parents and nurse looking after the child.

In the previous issues of *Pain News*, Arun Bhaskar et al. discussed social media and its impact in medical sphere. Continuing with the similar theme of social networking, Amelia Swift, Kate Thompson and Alison Twycross discuss twitter as a tool for educational purpose in their article 'Twitter Chats as an educational tool for pain'. In that article they also provide tips for successful TwitterChats.

We are almost nearing end of the year. Christmas is upon us. New Year is around the corner. Happy Christmas and Very Happy New year to you all.

Dr Andrew Baranowski



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Your society needs you!

Over the past 3 years, the British Pain Society (BPS) has seen significant change that we instigated to try and ensure that the Society

meets both your current needs and the needs of the future.

The Changes

As you are aware, if you have been following the events, we invested time and effort in developing a **mission statement: enable best pain management for all** and a **vision: stop suffering from pain**.

We went on to develop our values as a Society:

- **SUPPORT EFFECTIVE PARTNERSHIPS:** So health and social care professional's work together to provide comprehensive support.
- **MAKE PAIN VISIBLE:** So pain and its consequences are on the national health agenda.
- **INFORM PROFESSIONAL EXCELLENCE:** So professional standards are elevated through research, audit and education.
- **INVEST FOR THE FUTURE:** So we have sustainable financial growth to invest in our mission.
- **ENABLE BEST PATIENT CARE:** So people in pain live their lives to the fullest.

Our committees

Each of our *committees* is now tasked with honouring and promoting one of the values listed above. For instance, the Patient Liaison Committee is associated with enabling best patient care and the Communication Committee with making pain visible. Council is continuing to review our Committees and how they work and will look at ensuring they meet your needs and the needs of the Society. It is exciting when we see the Committees fully embracing change and particularly to see them taking ownership of their activities.

The brand

We went on to rebrand our Society, modernised the font of our Heraldic crest, adding EXPERTISE WHERE IT MATTERS as a strapline, as well as modernising the format and content of all our activities but especially the Annual Scientific Meeting.

A more business approach

We have developed a business plan approach to try and ensure that our committees and our Special Interest Groups (SIGs) are focused, cost-effective and produce agreed outcomes. We have tried to ensure that SIGs appreciate the importance of working with the core Society on business plans and finances as we meet some very difficult financial circumstances. Our business arm is well-established and meets regulations around trading. We are reaching out to new Trustees and Ambassadors.

Proactive and not reactive

We have tried to move away from being reactive towards being proactive. To facilitate this, we have developed our media and social media teams as well as to develop a working relationship with NICE, the Faculty of Pain Medicine, The Chronic Pain Policy Coalition (CPPC) and other professional agencies such as nursing, psychology and physiotherapy. With the Faculty and CPPC, we attended a Parliamentary Reception at Westminster to celebrate our birthdays as agencies and to raise concerns about resources and clinic closures.

Involving members and the public

We set up a *Charitable Aims sub-Committee* which has led on our *National Awareness Campaign*. In July, we had the official launch when we released our first poster through Twitter, Facebook and our newly designed website. We have many other posters lined up! The aim is to link this work with other national events, such as in October, when the team coincided the launch with the United Nations (UN) International Day of Older Persons and the BPS highlighted the challenges of managing pain in an ever increasingly older population.

Stating our case

Our *investment prospectus* is now complete and has seen the light of day in several discussions with parties that could potentially work with the Society in the future. A copy is available on the website under the National Awareness Campaign button. If you have contacts that are interested in the activities of the

BPS, who would like to know more and possibly work with us, please direct them to this document.

Art and pain

Discussions around a *National Arts Competition* (NArTC) have been ongoing with eminent artists, sponsors and high profile media. We are now working on developing the concept. One key suggestion is that as well as professional judges, there should be a 'people's panel' judging the submissions. We are fortunate in having a very effective Patient Liaison Committee to support us in engaging patients for that panel.

The survival of pain medicine as a speciality

All the above and more are aimed at promoting the BPS as the Society that represents and supports the Multidisciplinary Approach to Pain Management. It is key to the survival of pain medicine that we have a single unified body that represents the medical doctors, psychologists, physiotherapists and others with overlapping skills (we now have chiropractors, osteopaths, hands on and hands off experts), as well as nurses, occupational therapists and many others. The teams span primary and community care through specialist services to highly specialised services. Other professional bodies look to the BPS to provide that MDT overview. And of course, we have the support and input of around 400 patients through the patient reference group and the Patient Liaison Committee.

So, a lot is going on.

Your society needs you!?

There are three main issues we face:

1. Getting the message out that the MDT approach is crucial
2. Financial stability for the Society
3. Manpower

These issues are linked and we cannot solve either of them alone.

Getting the message out

I had hoped that when we launched the posters, all members would grasp the opportunity to share and to get their friends to share. Of my friends, however hard I tried, only a few did share. I told them that pain services are under threat, that there was a 50:50 chance they would develop chronic pain, but still a limited response. It appears to have been the case for quite a few people that they did not share. The *Charitable Aims sub-Committee* will review the impact of the campaign as we go forward. **However, at the very least can all members engage and share the posters through social media, print off the posters for their clinics.**

Financial stability for the Society

We are heading for a significant financial deficit. At the end of the day, the biggest issue has been with lack of investment by industry. For that reason, we have looked towards other areas for fundraising. The National Awareness Campaign with its prospectus and the National Art Competition are a part of that. We have cut back expenses to the core and now we need new money.

How you can help, please read and share our prospectus. We are looking for donations, sponsorships and endowments. If there are opportunities to engage individuals, societies, business in the concept of supporting the BPS, please raise the possibility with them. And of course, you now know where to find the prospectus.

Manpower

Please work with your Society. There will always be other agencies organising meetings but please remember that the BPS is a not for profit Charity. Please denote time and effort to making our Society and meetings successful. Consider applying for Council. The President Elect role will be advertised in February – do you have the skills to take the BPS forward, if you think that you do, please apply. We are always looking for new blood for Committees and to support activities, if you have a skill, contact an Exec, a Council member or Chair of a committee or SIG and highlight your interest.

In the end

There is a small group of extremely hard workers that are doing an amazing amount on your behalf and on behalf of the Society. We need as much support as possible and every member can do something. At a minimum share and re-share the posters. If you have the energy to be a part of an active and exciting future for the BPS, please speak to us to explore how we can work together.

Professor Roger Knaggs



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This is YOUR Society.

Perhaps you may be reading this issue of *Pain News* over your well-earned festive break or maybe you are considering making some

resolutions for the New Year.

We are very grateful to the many members who contribute to the ongoing work of the Society, whether it is contributing to one of the many Special Interest Groups, the Committees that undertake much of the regular work of the Society, regular contributions to *Pain News* or publishing your research in the *British Journal of Pain*.

Over the first few months in 2018, we will be members regarding several positions in the British Pain Society (BPS) that will become vacant. This is your Society. Do consider if you have the vision and enthusiasm to help support

the direction of the Society over the next few years. If you would like further information about what is expected for any of these roles then do get in touch, and I am sure that current or previous post holders or Council members will be prepared to offer advice and further information about the roles and responsibilities.

The positions that will become available are:

- President elect;
- Honorary Secretary elect;
- Honorary Treasurer elect;
- Council members (up to four vacancies)

Nominations for the executive positions (President Elect, Honorary Secretary elect and Honorary Treasurer elect) must be for an Ordinary or Honorary Member of the BPS who is a past or present member of the Councils of the Society, European Federation of IASP Chapters (EFIC) or International Association for the Study of Pain (IASP). However, if there are no

nominations for people who fall within these eligibility categories, Council may consider a candidate or candidates from the Ordinary and Honorary Members. More details regarding the eligibility for each of these positions may be in the Regulations of the Society available on the Society's website.

To be eligible for election as an Ordinary Council Member, a person must be an Ordinary or Honorary Member. Hence, members from other categories (including International, Retired, Contributing or Associate Members) are unable to stand for election as Ordinary Council Members.

Some of the positions are elected by the membership (President elect and Council members), and the results are announced at the Annual General Meeting at the Annual Scientific Meeting in Brighton in early May 2018, while the Honorary Secretary and Honorary Treasurer elect are elected by the current Council.

If you not feel that it is the right time to stand for one of these positions, then do take the time to vote in the elections.

Spotlight— Dr Fran Toye

The width and breadth of BPS membership is testimony to the diversity within the organisation and in the pain world. The Editorial Board would like to acknowledge this richness by shining a spotlight on some of our members. In this edition, we speak to Dr Fran Toye.



Dr Fran Toye

1. What first brought you in contact with the BPS?

Professor Kate Seers.

2. What is your role in the BPS? What excites you about this role?

My role is to explore peoples' experience of healthcare and talk simply about qualitative research methods.ⁱ This is exciting as qualitative research can encourage self-reflection and open our eyes to new possibilities.

3. What are/were you best known for professionally?

Trying to pin down jellyⁱⁱ and changing my mind (and other people's minds).

4. How do you think the BPS has changed from when you first became a member to now?

I have now met more than one other anthropologist (Rachael Gooberman-Hill) at the Annual Scientific Meeting (ASM).

5. If you were President of the BPS for a day, what would you do?

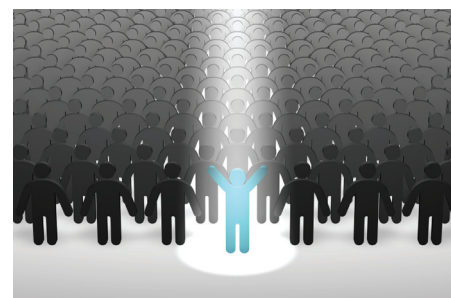
Invite Emeritus Professor Arthur Frank to give a plenary lecture at the ASM.

6. Where can we find you in your spare time? What is your favourite way to spend a weekend or a Sunday afternoon?

Oxfordshire County Music Service Adult Flute Group.

7. What would be impossible for you to give up?

Dr Who.



8. Any life achievements you are particularly proud of?

Grade 8 Flute 2016.

9. Anything else you would like to tell people about yourself?

Delia Smith once broke up a fight between me and my sisters in my dad's restaurant (she used to wash up for my dad in the 1960s in the 'Singing Chef').

Notes

- i. <http://www.evidentlycochrane.net/qualitative-research-patient-care/>
- ii. <https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-13-46>

Have your say and contribute to *Pain News* today

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

Do you have a news item to share?

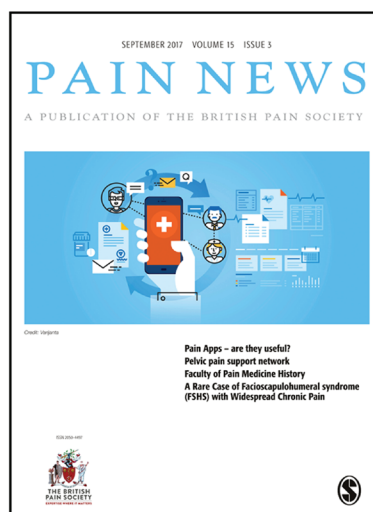
Perhaps a professional perspective, or informing practice piece?

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

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

Upcoming submission deadlines:

Issue	Copy deadline
March 2018	5 th January 2018
June 2018	3 rd April 2018
September 2018	15 th June 2018
December 2018	28 th September 2018



Royal Society of Medicine educational event report. Pain in difficult cases

Felicia Cox *FRCN*

This evening event, developed and chaired by Dr Anthony Ordman, President of the Pain Medicine Section of the Royal Society of Medicine (RSM), aimed to promote the knowledge and competence of healthcare professionals who care for patients with acute pain in the hospital setting, particularly after surgery and trauma. The three speakers with differing professional backgrounds will be well-known by British Pain Society (BPS) members.

The first speaker, Dr Zoey Malpus, Consultant Clinical Psychologist at Central Manchester University Hospital NHS Foundation Trust, described how iatrogenic distress could be harmful to patients. The audience learnt the optimum ways of communicating with patients in pain and how to determine appropriate ways of managing their pain. Zoey also described how to avoid

harmful miscommunication with patients when assessing and managing their pain.

Following Zoey, Dr Gill Chumbley, Consultant Nurse at Imperial Healthcare NHS Trust, outlined how to use ketamine to treat pain safely and effectively in patients with pain refractory to conventional approaches. Gill described how to use test doses of ketamine to determine if the patient had an active *N*-methyl-D-aspartate (NMDA) receptor and the pros and cons of oral and intravenous ketamine for acute pain.

The final speaker was Dr Jane Quinlan, Consultant in Anaesthesia and Pain Management at Oxford University Hospitals NHS Foundation Trust. Jane's presentation covered the perioperative management of acute pain in patients with opioid tolerance – patients with pain taking opioids as well as substance

misusers.¹ Both groups can experience opioid-induced hypersensitivity which leads to a heightened pain response, requiring more analgesia but that this can prove less effective due to opioid tolerance. She also described the management of patients taking opioid substitution therapy, that opioid-dependent patients are particularly vulnerable to stress and that discharge planning needs to start before or on admission.

The audience actively contributed to the expert panel discussion chaired by Anthony. Congratulations to him for organising this well-evaluated event.

Reference

1. Quinlan J, and Cox F. Acute pain management in patients with drug dependence syndrome IASP pain clinical update, pain reports, 2017. Available online at: <http://journals.lww.com/painrpts/> (accessible 20 November 2017).



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27th National Acute Pain Symposium

Dr Chandran Jepegnanam

14–15 September 2017

Harrogate Convention Centre

It was another successful symposium, for what is probably one of the biggest pain symposia in the United Kingdom and Europe, dedicated to acute pain. The symposium was well attended with over 200 delegates and speakers. As always, the programme was stacked with an international faculty of experts, and this year, we had an afternoon dedicated to workshops.

The plenary lecture on 'Transition from acute to chronic pain after surgery' was delivered by *Patricia Lavand'homme, MD, PhD, Professor of Anesthesiology and Head of the Acute Postoperative Pain Service at the Catholic University of Louvain, Brussels, Belgium. Professor Ian Power, Professor Emeritus of the University of Edinburgh*, ably chaired the session.

The programme reflected the inclusive multidisciplinary ethos of the symposium. Mr Sanchit Mehendale, Consultant Trauma and Orthopaedic Surgeon at the University Hospitals Bristol NHS Foundation Trust, presented his experience with persistent post-surgical pain after joint replacement surgery. Michelle Angus, Consultant Physiotherapist at Salford Royal NHS Foundation Trust, outlined a physiotherapist-led initiative to reduce acute back pain admissions via the emergency department as part of a collaborative approach.

A lively topical debate relating to epidurals was lead by Consultant Nurse Debbie Hunter (York) and Pain Consultant Doctor Nick Flatt (Wigan). Other presentations included the initial diagnosis



and management of complex regional pain syndrome (CRPS; Dr Richard Makin, Salford) and management of acute pain in patients with substance abuse disorders (Dr Jane Quinlan, Oxford).

We were honoured to welcome back Dr Naveen Eipe, from Canada, who presented on both days of the symposium.



More than 50 posters were submitted for peer review, with four accepted for publication in the *British Journal of Pain*. The poster reviewers, Professor Ian Power and Dr Ruth Day, commented that all submissions were of a high standard and represented the excellent work that is going on in NHS Acute Pain Teams. The first three prize winners presented

27th National Acute Pain Symposium



their work to the symposium at the Friday morning session.

The first National Acute Pain Awards were launched at a drinks reception on the Thursday after the symposium proceedings were concluded. Dr Jeremy Cashman awarded the prizes for the Best Acute Pain Nurse – Chris Sinclair from South Tees Hospitals NHS Foundation Trust, Best Acute Pain Team – Bolton NHS Foundation Trust and Best Acute Pain Consultant – Dr Andy Uet Meng Ng from Blackpool Teaching Hospitals NHS Foundation Trust. These awards were in recognition of their

contribution to acute pain management and the teams in their hospitals. All nominations were judged by the organising committee.

One of the primary aims of the symposium is to provide an opportunity for all health professionals interested in acute pain to form networks and make new contacts to share knowledge and experience, and this one did not disappoint.

The symposium was ably supported by trade exhibitors and the organising committee would like to express our gratitude for their continued support.

Organising a symposium of this scale would not be possible without the support of Paula, Janet and their team at Cloud 9 Event Management.

Plans are already afoot for the next symposium: dates and details will be on the website soon (<http://www.napsuk.co.uk/>), and we hope to see many of you there next year. We are always looking for new topics, speakers and ideas for workshops. We also welcome contributions from any teams that want to share their work and spread their good practice with a national and international audience. Please get in touch with us (Dr Chandran Jepegnanam at NAPSymp@yahoo.co.uk) with your thoughts and ideas.

Organising committee

Dr Jane Quinlan is a Consultant in Anaesthesia and Pain Management at the Oxford University Hospitals Trust.

Dr Chandran Jepegnanam is a Consultant in Anaesthesia and In-Patient Pain Management at the Central Manchester University Hospitals NHS Foundation Trust.

Sr Angela Leonard, Specialist Pain Nurse, Salford Royal NHS Foundation Trust.

British Pain Society Annual Scientific Meeting, Hilton Brighton Metropole, 1–2 May 2018

Professor David Walsh

Save the date for the British Pain Society's 51st Annual Scientific Meeting (ASM) that will take place in Brighton on Tuesday and Wednesday, 1st and 2nd May 2018. The Scientific Programme Committee (SPC) is hugely grateful for the work being done behind the scenes by the Society's membership and Secretariat. Together we can make this yet again the highlight of the year, for clinicians, researchers, commercial entities and charities with a shared interest in improving the lot of the millions of people who suffer from chronic pain. It's another step towards a 'pain-less' world. The 2018 ASM will bring the usual cutting edge science from world leaders selected from across the multidisciplinary pain landscape, as well as opportunities to keep appraised of current best clinical practice, opportunities for the future, connecting with colleagues and, of course, a red hot social programme.

This year we are developing our '2 + 1' model, with the 2 days of the ASM preceded on Monday 30th April by one day of more specialist meetings. Participants will register for one or both meetings. In fact, as an added bonus, we are currently planning two specialist meetings (one on Pain Education and one on Neuromodulation). Even if you're not able to attend either of the meetings on the Monday, you might want to consider getting down for the Monday evening to catch up with friends who will be staying over.

Several people have asked how the SPC selects proposals for inclusion in

the programme from those put forward by the membership. Indeed this is a difficult task, particularly given the high quality and number of proposals that are submitted. Our primary concern is to produce a programme which meets the needs of the Society's membership; it needs to appeal to different disciplines, be up to date and present rigorous science. We have included sessions offering hands on training, as well as thought-provoking discussions. We take particular notice of the views of the Society's Special Interest Groups (SIGs), which, after all, reflect its special interests! We try to further the aims of the Society to be multidisciplinary. We aim to maximise training opportunities. We try to put together a programme that is varied, topical, exciting and sometimes controversial. We apologise if we cannot always succeed, and particularly to those whose proposals have not made it onto the 2018 programme, but we do hope that on 2nd May you will leave Brighton feeling enthused and informed.

The year 2018 will be the International Association for the Study of Pain (IASP) Global Year for Excellence in Pain Education (<https://www.iasp-pain.org/SIG/Education?navItemNumber=5272>). Our 2018 ASM provides opportunities to further advance pain education through its scientific content, plenary sessions and workshops on education. It is an opportunity for trainees from all disciplines to develop their professional skills in critical appraisal, incorporating new knowledge into their practice, and

harnessing the potential of peer and expert networks to support their lifelong learning. Presentation at the Society's Annual General Meeting (AGM) is recognised not only as an achievement on a trainee's *curriculum vitae* but also rewarded by opportunities for podium presentation and prizes. Eloise Carr has kindly agreed to deliver a plenary lecture on how to harness the potential of education to reduce barriers (patient, professional and organisational) that can sometimes frustrate all of us who attempt to promote effective pain management. More detailed exploration of pain education in clinical and university settings will be offered in a workshop environment. Hands on workshops will be targeted at trainees to help them get more involved in pain research and make the most of their training time.

Other highlights of the 2018 ASM's scientific programme include the Pat Wall lecture from Jeffrey Mogil from the Department of Psychology at McGill University, who most of us would regard as world leader in the genetics of pain. Blair Smith, Professor of Population Science at Dundee University will be delivering the British Pain Society lecture, drawing on his extensive understanding to explain how pain epidemiology has and should shape changes in policy and practice on pain. Additional plenary speakers already confirmed include Amanda C de C Williams, Kate Sears and David Armstrong covering topics as diverse as torture, beliefs and sociology. Parallel sessions will address addiction,

British Pain Society Annual Scientific Meeting, Hilton Brighton Metropole, 1–2 May 2018

pain in children, healthcare delivery, trauma, medicolegal aspects, neuropathic pain, headaches, ageing, cancer and end of life. A key workshop will address interventional management of radicular pain, and a practical workshop will introduce participants to self-hypnosis.

One plenary session will comprise presentations of the top 5 submitted poster abstracts. The SPC is looking forward to reviewing in January 2018 what we anticipate will be a continuation of the year on year increases in number and quality of submitted abstracts. Remember, the deadline for online abstract submission will be 12 noon on 11th December 2017. In addition to offers of podium presentations to the top 5 submitted abstracts, prizes will be awarded for each of the top 5 poster presentations. This will be adjudicated by members of the SPC, with due regard given in order to give credit to those at the earlier stages of their careers.

The scientific programme is, of course, only one part of our annual ASM. During 2017, the SPC worked with the Society's membership and other stakeholders to define what aspects of the ASM are most valued. Keeping up to date and horizon scanning are certainly key to the meeting's success. Networking and professional development are also essential. It might be possible to keep up to date while sitting at home with a computer. Face-to-face contact in a conducive environment can more effectively develop our understanding, placing our own practice in the context of what is happening elsewhere, learning new skills and meeting like-minded people who together can help us continually improve things for the future. We are confident that Brighton is just the right environment! Brighton is a thriving

University town, with healthy sea airs on the edge of rolling downs, food outlets to suit all tastes and pockets, and ample accommodation. Brighton critically offers conferencing facilities that can accommodate our needs while, we hope, not pushing the budget beyond credibility. This year's networking opportunities include the ASM Party Night, which will be on the Tuesday, 1st May at The Mesmerist bar (<http://www.mesmerist.pub/>). Tickets will be £20. Bursaries will again be available to support British Pain Society members to attend the ASM (details at <https://www.britishpainsociety.org/2018-asm-brighton/bursary-applications/>).

The British Pain Society ASM also provides interaction and contributions from other stakeholders in pain management. Our commercial partnerships continue to grow, and commercial displays and satellite

symposia help balance the high hopes for the future offered by basic research, with opportunities to discuss with experts those treatments that are already available. The charitable sector will be again present in force, and patients and carers make important contributions both in the organisation and by participation in the meeting. Together we can achieve much more than any of us alone, and creating that synergy remains a key aim of our ASM.

The British Pain Society ASM remains a unique opportunity to help us make pain management in the United Kingdom the envy of the world. The Society looks forward to meeting by the sea everyone, both current members and possible members of the future. We've come a long way since Turner's time (see picture), and even over the last few years, and we hope that you will be inspired to go even further.



Credit: Royal Pavilion & Museums, Brighton & Hove.

EFIC Congress Copenhagen 2017 ...

The times, they are a changing

Peter Moore

Last year, Dr Chris Wells, the then President of European Pain Federation (EFIC), suggested I write a proposal to have a workshop at the 2017 EFIC Congress Copenhagen.

My first thoughts were WHAT ... me present at the EFIC Congress, but this is only for medics. But as Bob Dylan once sang, *times, they are a changing*. I went ahead and wrote a proposal to have a workshop about pain self-management, and to my surprise, they accepted it, and on 6 September of this year, we ran the workshop.

My other presenters were Dr Tim Williams a GP from Sheffield and my very good friend Dr Reinhard Sittl who is a Pain Doctor from Germany, who is a specialist in pain self-management.

So, there we were on 6 September, myself, Dr Tim, Dr Reinhard and Dr Chris Wells at 10.20 a.m. and in the room with about 40 or so healthcare

professionals who were attending the workshop. The workshop was starting at 10.30 a.m. and we thought we would only get around this number attend. Well to our surprise and by 10.30 a.m., the room was full with over 100 attending and it soon became standing room only at the back.

I was the first presenter and Dr Chris Wells introduced me. He also told the audience that the organising committee said few would attend because there was a patient presenting and no one would attend. Well I guess the numbers proved this wasn't going to be the case.

All three of us spoke about self-management and giving those who attended the workshop some handy tips that when they returned to work, they could use with their patients.

During the workshop, there was a hitch with Reinhard's PPT, so an ideal time for me to do some stretching with

the audience. Pain Doctor Arun Bhaskar filmed on his phone.

At the end of the workshop, many healthcare professionals stayed behind asking for more information, which we all gladly did.

Did we make a difference? Here is an email I received from an Australian Pain Doctor the next day '... I really enjoyed your presentation yesterday, and will be changing to a more patient lead consultation from now on. It has been the highlight of the conference for me' (J.W. Australia).

Yes, times there are a changing. At the opening ceremony, the new EFIC President Bart Morlion said patients need to be more involved with pain and the management of it.

I would personally like to thank Dr Chris Wells, Dr Reinhard Sittl and Dr Tim Williams and of course EFIC for allowing us to spread the word about pain self-management.

Pain and female genital mutilation

Richa Dhar *Winner of the 2017 Royal Society of Medicine Andrew Lawson essay prize*

Female genital mutilation (FGM) is defined by the World Health Organisation (WHO) 'as any procedure that involves the partial or complete removal of the external female genitalia or any other injury to the female genital organ for non-medical reasons'.

FGM poses a great problem, not only in Africa, where 29 countries still have legalised FGM, but also in the United Kingdom and Western society, where women still present with infibulation. There are three main types of FGM recognised by the WHO:

Type 1: clitoridectomy – which involves the removal of all or part of the clitoris.

Type 2: excision – removal of the clitoris and part of the labia minora.

Type 3: total infibulation – involves removal of the clitoris and labia minora. The labia majora is cut and stitched together to cover the entrance to the urethra and vaginal entrance leaving a small gap at the inferior side to allow passage of urine and menstruation.

Although many countries which practice the procedure have given it religious connotations, it predates the religions of today. Those who practice the procedure have thought it to prevent health problems and in some cases to prevent anatomical abnormalities. However, when compared with male circumcision, which has shown to decrease levels of

infections, there is no medical benefit in female circumcision.

The resulting pain associated with this procedure is severe and encompasses psychological, physical and economic aspects. Women who have not had the procedure are seen to be 'unclean' and are often ostracised by society. With some sects depending on village funding, this isolation can cause these families receiving little to no money. The procedure is often performed by a village priest; the age at which the procedure is performed can vary from 6 to 15 years old. This means that not only is the procedure painful, but women can present with post-traumatic stress disorder. Lack of analgesia and anaesthesia, means girls are held down with catgut being used when stitches are not available. Furthermore, infection is common, but rarely treated due to a taboo of FGM in this culture. Women often cope with the pain and infection encountered with this.

There are two other aspects of pain associated with FGM as described by Johanssen (2002). These are the times of first intercourse and when giving birth; these two milestones can be very difficult. The psychosexual impact of this is also severe. Women have described screaming and being held down during their first sexual intercourse. At childbirth, a deinfibulation operation is required, although this is not always performed. This can result in stillbirth, vesicovaginal fistulas and in severe cases maternal death.

As knowledge of FGM increases, many countries are now medicalising



the procedure, in a poor attempt to keep the procedure legal. However, even with the change of laws, there is no change in attitude towards the procedure. In those women who have had the worst experiences, they still claim to want the procedure for their children due to societal pressures. Any change in this attitude would require education to religious leaders and directly to people.

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Prescribing exercise for patients with chronic musculoskeletal pain



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SAGE

Cormac Ryan *Reader in Physiotherapy, Teesside University*



Cormac Ryan

Chronic musculoskeletal pain, which includes conditions like chronic back pain, affects around one in five people. For some, the condition is mild and has only a

minor impact upon their daily life; for others, the impact can be extremely significant with negative effects right across the physical, psychological and social domains. Chronic musculoskeletal pain is a leading cause of disability and work absence and the economic consequences of the condition are considerable.

There are many different approaches for its management – arguably, exercise is one of the most attractive. There is a strong body of research to show that exercise is safe and can be clinically effective for people with chronic musculoskeletal pain for their pain and function, as well as their general health and well-being.

Despite this wealth of scientific knowledge around exercise for people with chronic musculoskeletal pain, there is very little evidence to guide clinicians on the components of exercise that should be prescribed. Exercise can be prescribed using the FITT principles of Frequency, Intensity, Time and Type. Frequency refers to how often exercise should be carried out (e.g. three times per week). Intensity refers to the effort level involved (e.g. moderate to

vigorous). Time refers to how long an individual session/activity should last (e.g. 30 minutes) and type refers to the exercise mode (e.g. cycling). The FITT principles can be used to adapt exercise for people of all shapes and sizes.

To date, there are very few studies which compare the effectiveness of different FITT principle regimes for people with chronic musculoskeletal pain. There are a small number of studies that compare different types of exercise, for example, general aerobic-based exercise compared to Pilates-based exercise, but there are very few which look at the principles of frequency, intensity or time. As such, despite knowing that exercise is good for patients with chronic musculoskeletal pain and being confident about recommending it, the lack of specific guidance for clinicians may be a considerable barrier to prescribing it appropriately in a way that patients can follow and will help them to gradually become regular exercisers.

Clinically, it is common to hear recommendations such as *you should start engaging in gentle exercise*. The key word here, in my opinion, is *gentle*. This can mean different things to different people and have different connotations. The clinician may well use the term *gentle* to make it seem less daunting to the patient, thus increasing the likelihood of exercise adoption. This may well be the case but I wonder if it might also be related to clinicians' misguided fear that exercise more intense than mild might actually damage/injure the patient and so they are encouraging them to be cautious? If the reason is to encourage a more

gradual increase in activity, then this should be clarified. While gradual increase in exercise levels is recommended, increasing patients fear about the potential damaging consequences of exercise is not. Using such terms as *gentle* may make the patient believe that their musculoskeletal system is fragile and anything beyond a very low intensity could be harmful. This could create such a barrier in itself that the patient decides not to exercise at all. Or it could create such fear and hypervigilance that at the first elevation of pain the patient ceases exercise, believing it to be damaging, and reduces the chance they will engage in exercise again.

Alternatively, even if they do engage in *gentle* exercise, are we confident that low-intensity exercise will be of any benefit – perhaps there is a threshold below which the benefits to musculoskeletal health are minimal? In a literature review, I found one study which has examined the role of exercise intensity in respect to prevalence of musculoskeletal pain. In that study, a U-shaped curve was identified where those engaging in the lowest amounts of activity, for example, least often and at low intensities, and those individuals who engage in the highest amounts of exercise, for example, most often and at high intensities, were at increased risk of having musculoskeletal pain compared to those doing more moderate levels of physical activity. While this seems intuitively sensible, a key limitation of the work was that exercise was measured using self-report which is notoriously inaccurate.

Given these limitations and a lack of clear clinical guidelines, my colleagues and I at Teesside University set out to explore the question – what intensity of exercise should be recommended for people with chronic musculoskeletal pain?

Using publicly available data from the 2008 Health Survey for England, where over 4,000 adults had their physical activity levels measured using accelerometers over 1 week, we used a novel form of statistical analysis, called isothermal analysis, to explore this question. Isothermal analysis is a useful method to model the effects of replacing one behaviour with another. In this case, we investigated what would be the effect on musculoskeletal pain prevalence of replacing 10 minutes of sedentary

behaviour with either 10 minutes of light physical activity (LPA) or 10 minutes of moderate-to-vigorous physical activity (MVPA).

We found there was no effect of replacing sedentary behaviour with 10 minutes of LPA, but there was a small protective effect (11% relative reduction) against musculoskeletal pain of MVPA. In a subsequent analysis, replacement of 30 minutes of sedentary behaviour with 30 minutes of MVPA, as per public health guidelines, resulted in a marked reduction (29% relative reduction) in musculoskeletal pain prevalence.¹

Our findings imply that the intensity of exercise clinicians recommend to chronic musculoskeletal pain patients is important. It may not be enough to

recommend *gentle* exercise and more moderate-to-vigorous activity may be warranted. Furthermore, our findings emphasise the importance of current physical activity guidelines when prescribing exercise for musculoskeletal patients. In answer to the question – what intensity of exercise should be recommended for people with chronic musculoskeletal pain? – our advice is to start with current physical activity guidelines and go from there.

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Pain and ventricular assist devices (VADs) from a healthcare professional perspective



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SAGE

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Background

While the number of patients awaiting heart transplant has nearly doubled in recent years, the number of available donor organs has simultaneously dropped by one-third.¹ As a result, more than 30% of listed heart transplant patients require assistance via a mechanical circulatory device such as the ventricular assist device (VAD).¹ While VADs have been shown to increase longevity and improve the quality of life for individuals awaiting transplantation,^{2–4} the dually internal–external nature of the device presents a unique host of potential medical and psychosocial implications for VAD patients.^{2,5–8} Adverse medical events associated with VAD treatment include frequent or recurring infection, bleeding and stroke.³ Anecdotal observations of post-operative neuropathic pain in VAD patients also raise concern regarding the physiological pain status of individuals assisted by these devices.⁹

Concerns regarding the psychological well-being of VAD patients have been expressed following the publication of research which suggests that the introduction of an external medical device can alter patient perceptions of self and affect willingness to care for the device.² Psychosocial alterations noted among the family members and partners of individuals with VADs have also been speculated to negatively impact patient outcome.^{8,10,11} Furthermore, some note

ethical concerns surrounding the rising utilisation of VADs as a more permanent solution or ‘destination therapy’ (DT) for end-stage heart failure patients who are not candidates for transplantation.⁶

Aims

As part of an effort by the Royal Brompton & Harefield NHS Trust to better understand and improve the pain experience of VAD patients, Harefield Hospital, a joint pioneer in VAD development,¹² conducted a focus group session among health professionals. The aim of the session was to cultivate a comprehensive model of the physical and psychological pain experienced by VAD patients from the perspective of the healthcare professionals who work closely with them. The session was conducted also to encourage multidisciplinary approaches to pain management within the Trust.

Methods

After gaining institutional approval, 20 members of staff were approved to contribute to this project, 16 of whom participated in the focus group session. Focus group participants included two nurses and one student from the pain management service, three physiotherapists, three pharmacists, three nurses and two doctors from the transplant unit and two nurses from the VAD team. Among participants was one

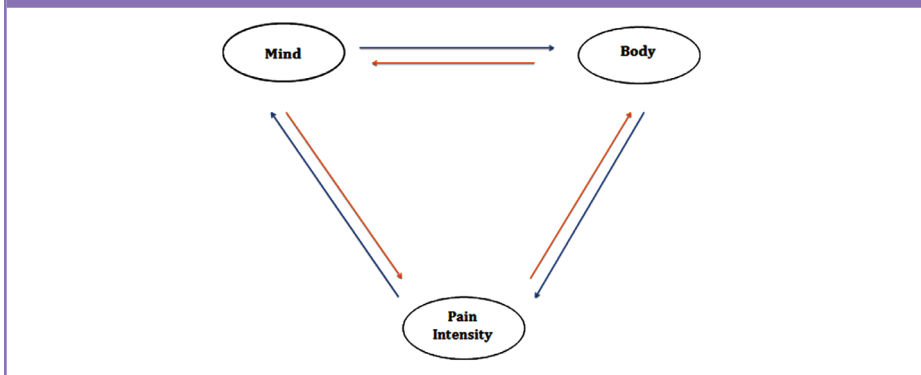
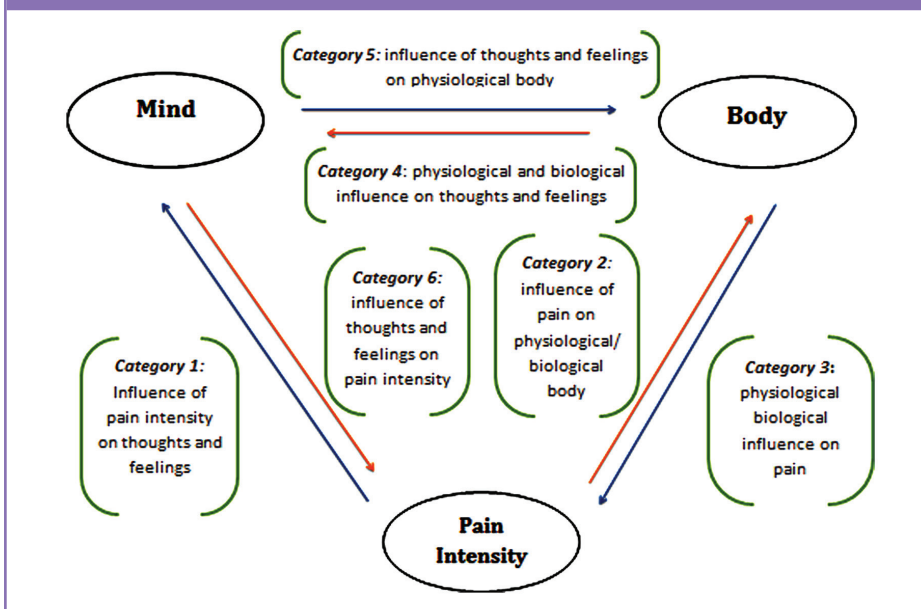
note scribe to record key questions and responses, one whiteboard scribe to actively illustrate discussed themes and ideas and one group facilitator. Following the focus group session, detailed notes were taken using an audio recording of the session. Qualitative thematic analyses were conducted by cross-referencing the post-session notes with those taken in-session to facilitate the natural emergence of key themes and sub-topics.

During analysis, key factors influential to the pain experience of VAD patients were identified along with emergent variables discussed to mediate the relationship between said factors. A model was constructed to visually demonstrate the conceptual relationship between identified key factors and variables within the pain experience. Identified variables were then described to enhance contextual value.

Results

Throughout the discussion, a key theme emerged regarding the interaction between body, mind and pain intensity. Thus, the factors *Mind*, *Body* and *Pain Intensity* were identified as key factors in conceptualising the pain experiences of VAD patients. The model constructed to illustrate these relationships was triadic in nature with influence acting bi-directionally between factors, as displayed in Figure 1.

Emergent variables identified as being influential to the pain experience were identified and placed categorically within

Figure 1. Influential pain factors with bidirectional interaction**Figure 2.** Category placement within triad model

the model to describe their role, as displayed in Figure 2. Exemplary of this categorical placement, several focus group participants noted that patients whose VAD implantation surgery involved a lateral thoracotomy seemed to experience more pain than those who underwent a central/median sternotomy. The variable *incision type* was thus identified and placed within Category 3 to indicate a bodily or physiological influence on patient pain experiences.

Many of the variables were discussed as having synergistic effects as they were

inextricably linked. Illustrating this occurrence, the topic of anxiety among VAD patients as impactful on pain experience gave rise to multiple variables. *Anxiety* was identified to encompass the contribution of a patient's pre-existing or VAD-related anxiety to their overall experience of pain. Patients with moderate levels of physical pain may experience heightened feelings of vulnerability, thus inflating their pre-existing anxiety levels. The *Perceived vulnerability* variable was identified to

describe this later process. Conversely, if a patient with moderate levels of anxiety receives *Patient-controlled analgesia* (PCA) to relieve moderate pain, their sense of *Control over pain* may increase, deflating their *Perceived vulnerability* to that pain.

Discussion/conclusion

With the number of patients requiring a VAD on the rise, an approach to VAD patient care which emphasises quality pain management should be utilised.¹ The multidisciplinary discussion of several issues inherent to the pain experience of VAD patients presents potential implications for VAD patient care moving forward. As the link between the physical and psychological experience of pain was mentioned throughout the session, referral to clinical psychology was deemed an appropriate course of action which should occur with more frequency to improve the well-being of VAD patients. Massage and relaxation therapies were also suggested as treatment options which should be used to address the physical/psychological interaction of VAD pain. Healthcare professionals should be aware of demographic characteristics which may impact VAD patient experiences. Additional pain management encouragement towards middle-aged males could address the issue of stoicism among this population and improve patient well-being.

The social aspect of physiotherapy was briefly mentioned as something which seems to improve patient well-being. The opportunities for social interaction should be a discussion point for future conversations regarding the care of VAD patients. Finally, it was agreed upon by participants that an approach which emphasises multidisciplinary cooperation among healthcare professions should be made in the future to improve patient

Pain and ventricular assist devices (VADs) from a healthcare professional perspective

well-being. The model generated as a product of this focus group session offers a tool which can be employed by healthcare professionals and patients alike to help verbalise and consequentially improve individual experiences with ventricular assist.

Variable descriptions by category

Category 1 (Pain Intensity → Mind)

- (a) *Perceived vulnerability*: increased pain intensity may result in heightened levels of perceived pain susceptibility
- (b) *Catastrophising*: tendency to describe pain experience in more exaggerated terms and focus on such pain more than usual

Category 2 (Pain Intensity → Body)

- (a) *Ability to do physiotherapy*: heightened pain intensity may limit a patient's physical ability to move around, resulting in adverse recovery experiences (i.e. post-op neuropathy)

Category 3 (Body → Pain Intensity):

- (a) *Incision type*: central sternotomy anecdotally identified as resulting in less post-op pain than lateral thoracotomy
- (b) *Pre-op treatments*: previous experiences such as extracorporeal membrane oxygenation (ECMO) treatment or stroke noted to result in higher incidences of neuropathic pain
- (c) *Drain placement*: post-surgical apical drains anecdotally identified as resulting in more patient post-op pain than basal drains
- (d) *Patient weight*: some reports of lower-weight patients being bothered by sensation produced

by VAD, especially when lying on left side

- (e) *Debridement*: recurring infections and complex wounds often result in painful treatments such as silver nitrate burning for over-granulation and more frequent dressing changes (up to three times daily versus once per week)
- (f) *Drain removal*: pain associated with drain removal impacted by factors such as patient age, drain placement and the use of medication: younger patients tend to report more pain with drain removal; apical drain placement observed to be more painful than basal placement; pre-emptive analgesia administration observed to help with pain; PCA also reported to improve patient experience
- (g) *'Overdoing it'*: over-participation in activity following discharge may lead to higher pain intensity and recovery setbacks; observed to occur most frequently among middle-aged male patients
- (h) *PRN*: over-the-counter medications such as paracetamol reported to aid in pain management upon discharge
- (i) *Movement/physiotherapy*: participating in physiotherapy and reasonable levels of physical activity increases patient physical strength and reduces risk for ITU neuropathy
- (j) *Anti-neuropathic medication*: used to relieve pain associated with neuropathy; reported to improve somewhat-common left nipple pain

Category 4 (Body → Mind)

- (a) *Massage*: physical massage suggested as future strategy to aid in mental relaxation/anxiety reduction
- (b) *Dressing changes*: usually once per week but can be two or three times per day with anti-coagulate administration; complaints of pain as dressing is pulled off (some relief offered via analgesic spray administration)
- (c) *Physiotherapy*: mood improvement observed with physiotherapy participation; said improvement speculated as a result of the social interaction offered by these sessions with other patients
- (d) *PCA*: PCA administration discussed as offering patient a higher perceived level of control over pain
- (e) *Infection/bleeding*: increased feelings of vulnerability observed with experiences of painful/difficult-to-manage complications
- (f) *Previous pain*: more past experience with physical pain may facilitate development of psychological coping mechanisms for pain management; conversely, pain suggested to compound with increased experience

Category 5 (Mind → Body)

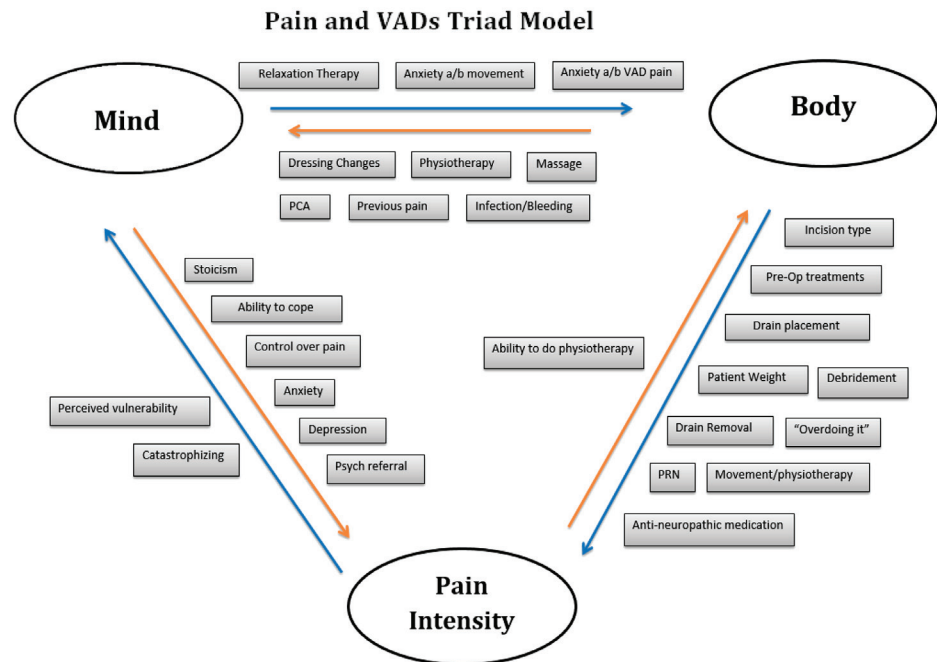
- (a) *Relaxation therapy*: psychotherapeutic relaxation techniques as a potential intervention to calm the body
- (b) *Anxiety a/b movement*: anxiety surrounding the impact of activity on VAD driveline may result in decreased physiotherapy participation and, consequentially, longer recovery periods

Pain and ventricular assist devices (VADs) from a healthcare professional perspective

- (c) *Anxiety a/b VAD pain*: anxiety surrounding the potential pain caused by VAD may result in decreased willingness to participate in recovery-aiding movement (typically occurs more often with younger patients; pain medication reported to increase willingness to participate in such movement)

Category 6 (Mind → Pain Intensity)

- (a) *Stoicism*: middle-aged males speculated as having increased feelings of necessary stoicism, potentially decreasing willingness to take pain medication to aid in pain management
- (b) *Ability to cope*: psychological capacity to cope with pain affects pain intensity perception
- (c) *Control over pain*: increased self-control over pain as potential mechanism to aid in reduction of patient anxiety regarding pain with potential to decrease pain intensity via measures such as PCA
- (d) *Anxiety*: pre-existing anxiety or VAD-associated anxiety as factors contributing to psychological pain experience
- (e) *Depression*: pre-existing depression or VAD-associated depression as factors contributing to psychological pain experience
- (f) *Psych referral*: assistance from clinical psychological noted as a treatment or preventative measure to decrease psychological experience



Pain and VADs Triad Model

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Analgesic management of rib fractures in elderly patients admitted in the non-trauma centre setting

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David Clarke



Samina Ishaq

Background

In the United Kingdom, in 2016, the Pan-London Trauma Network released a comprehensive guidance document focusing on the inpatient management of elderly trauma patients. The guidance describes best practice management of various traumatic injuries with specialist recommendations developed in the three London Major Trauma Centres and was disseminated among the smaller Trauma Units in the network.¹ In our District General Hospital, we have recently begun implementation of these recommendations and found the case for improving the management of rib fractures in the elderly particularly compelling from a Pain Medicine perspective. Here, we have attempted to summarise the recommendations, to highlight the vulnerability of this patient cohort and raise awareness of pain management techniques in elderly chest trauma for those practicing outside of a

Major Trauma Centre. The final section also includes our latest algorithms, which we have adapted from work produced by our colleagues at a London Major Trauma Centre to suit the needs of our local population and match our skill set.

Introduction

Across the United Kingdom, Emergency Departments are seeing a significant increase in trauma admissions from the frail and elderly.² Greater than 15% of all trauma admissions have documented rib fractures, and this number is higher in the frail/elderly population.³ Mortality from blunt chest wall trauma is high, ranging from 4% to 60% in the literature,⁴ and the complications of these injuries are myriad. To further complicate matters, up to 50% of rib fractures may be missed on plain radiography.⁵ Poor outcomes related to pneumothorax, haemothorax, pulmonary contusion and laceration of the abdominal organs are common acutely,⁵ but more insidious complications related to pain such as hypoventilation, atelectasis and pneumonia are also a significant issue.^{6,7}

In our centre, we define elderly patients as those who are greater than

65 years, or patients with significant frailty. When this cohort of patients is admitted with traumatic rib injury, they have been shown to be significantly more vulnerable to the previously described complications of chest trauma.⁸ Elderly patients show increased mortality and morbidity in the 24 hours post admission,⁹ but also increased risk of delayed complications such as pneumonia.¹⁰ A relatively recent study showed the rate of pneumonia to be as high as 31% in patients >65 years, with a 41% rate of pleural effusion. The rate of complication was shown to rise with number of rib fractures.¹¹ Patients >65 years have been shown to suffer higher mean ventilated days, longer ITU stays and higher risk of respiratory complications such as pneumonia or effusion.⁸ Evidence suggests that early diagnosis through computed tomography and early analgesia can significantly improve outcomes in this group of patients.¹⁰ A scoring system designed by Easter¹² relating the number of radiologically diagnosed rib fractures and age has been suggested to predict patients at high risk of morbidity. However, a subsequent study found the scoring system to have poor predictive value in elderly patients.¹³

The current best practice for analgesia in multiple rib fractures involves a step-wise multimodal approach culminating

Analgesic management of rib fractures in elderly patients admitted in the non-trauma centre setting

with regional anaesthesia in the form of either Thoracic Epidural Analgesia (TEA), which is often used in the setting of Major Trauma Centre, Paravertebral Block (PVB) or Serratus Anterior Plane block (SAB). There is some evidence that the use of these regional techniques improves both mortality and morbidity outcomes in chest trauma.^{14,15} At the Whittington Hospital, we generally advocate the use of the paravertebral block with catheter, performed by an experienced anaesthetist, due to its unilateral block and reduced systemic side-effects. However, if skill set dictates Thoracic Epidural or SAB are equitable alternatives provided there are no contraindications. In terms of risk stratifying patients, and given the questionable validity of the Easter scoring system in our cohort of patients, we felt it an unnecessary complication and instead recommend a high index of suspicion for severe morbidity and early referral and intervention in all elderly patients in whom there are clinical signs of deterioration or who are not responding to simple analgesia. Prompt referral to the Acute Pain Team and Anaesthesia should occur as soon as possible after admission.

In patients with flail chest and new oxygen requirement, early referral to a centre with a Cardiothoracic service should be considered,¹ as a small subset of these patients may benefit from surgical fixation of the fractures.¹⁶

Patients within this cohort are at high risk of delirium and may already have preexisting cognitive impairment and hence capacity should be assessed early and often. A simple and validated method of assessing this is to ask, 'Is {insert patient name} more confused than recently?'¹⁷ Capacity assessments should be documented regularly alongside any documentation of best interest treatment in all patients. Pain is a known exacerbating factor in delirium and hence ensuring patients receive prompt and effective management of

their pain may reduce their risk of developing delirium.¹⁸

Ongoing management of the patient should take a multidisciplinary approach with the patient admitted under the medical team with daily review by surgical team. Chest physiotherapy, early mobilisation and incentive spirometry should take place as soon as possible. Regular input from Acute Pain Service is also indicated. Patients with a new oxygen requirement should also be referred early to a critical care outreach team (CCOT) if this is available.

Definitions

Rib fracture

A radiologically diagnosed break in one or more of the bones of the thoracic cage.

Thoracic epidural

A needle is introduced into the epidural space through which a catheter is inserted to provide continuous analgesia bilaterally. Common practice when multiple rib fractures are present is to place the catheter at the level of the middle fractured rib.¹⁹ Choice of local anaesthetic varies between different operators but in our unit, we start with Bupivacaine 0.1% plus Fentanyl 2 µg/mL. A thoracic epidural is considered the standard of care in young trauma patients experiencing multiple rib fractures due to the quality of analgesia provided, but there are several contraindications that make the decision more complex in the elderly trauma population.¹⁹

Absolute contraindications

- Thrombocytopenia (platelet count $< 50 \times 10^9 \text{ L}^{-1}$)
- Coagulopathy (INR > 1.5)
- Thoracic vertebral body fracture
- Lack of consent from patient

Relative contraindications

- Patient admitted on warfarin/direct oral anti-coagulants (DOAC)
- Hypotension
- Hypovolaemia

- Moderate thrombocytopenia (platelet count $50 - 100 \times 10^9 \text{ L}^{-1}$)
- Unstable spinal fracture

Paravertebral block

Regional anaesthetic technique performed by placing a catheter into paravertebral space, a triangular space running either sides of the spinal column at the vertebral level the operator wishes to block. The catheter should be placed at the level of the middle rib fracture in multiple rib fractures and with adequate volume (we recommend Ropivacaine 0.2% running at 5–10 mLs/hour).

Using this approach, up to six sensory dermatomes may be covered. Analgesia is provided by local anaesthetic blockade of the spinal nerve at the side of the procedure. There is some evidence that since there is unilateral sympathetic blockade, rather than the bilateral block seen in thoracic epidural, there is a reduced incidence of haemodynamic compromise.²⁰ However, a study has shown contralateral spread of local anaesthetic following PVB, so haemodynamic stability should not be assumed.²¹ PVB is generally considered to have a lower risk profile, so may be more appropriate in the elderly population. The major risks of pneumothorax, intrapleural injection or vascular puncture may be ameliorated with the use of ultrasound guidance. The procedure is arguably safer in patients with coagulopathy or who are admitted on anti-coagulant therapy as while bleeding into the paravertebral space can be profound, it does not have the implications of epidural haematoma and neurological compromise that may occur with thoracic epidural. There are fewer absolute contraindications, and hence in our frail population, PVB is our preferred technique.¹⁹

Absolute contraindications

- Lack of consent
- Local anaesthetic allergy
- Local infection or sepsis

Analgesic management of rib fractures in elderly patients admitted in the non-trauma centre setting

Relative contraindications

- Patients on anti-coagulant therapy
- Marked thrombocytopenia (platelet count $< 50 \times 10^9 \text{ L}^{-1}$)

Serratus Anterior Plane block

This relatively novel technique is an alternative regional block to provide analgesia to the hemithorax. The technique involves first positioning the patient supine, with their arm above their head. Local anaesthetic is injected into the potential space superficial to the serratus anterior muscle, through which the intercostal nerves lie, under ultrasound guidance with a high-frequency linear probe. Effective analgesia can be provided to T2–T9, and with the placement of a catheter and pump, continuous blockade can be provided for up to 7 days.²² The technique can be used safely in anti-coagulated patients, and as it is performed, supine is an excellent choice for patients who are unable to be positioned laterally or sitting for PVB or TEA, and patients are able to mobilise with the catheter in situ. As with PVB, there is a risk of pneumothorax or vascular puncture, and as with any regional technique, there is a risk of local anaesthetic toxicity.

Conclusion

Pain in elderly chest trauma is an area in which prompt and effective management can reduce morbidity and mortality, and improve patient satisfaction. The mainstays of management should always be early diagnosis and recognition of the potential for deterioration with prompt initiation of analgesia. At our unit, we take a multidisciplinary approach with regular physiotherapy, early review by critical care teams and prescriptive guidelines which empower inpatient teams to refer early to our pain team. The pain team will consider early initiation of patient-controlled analgesia and regional techniques as required. All three of the regional techniques described have been

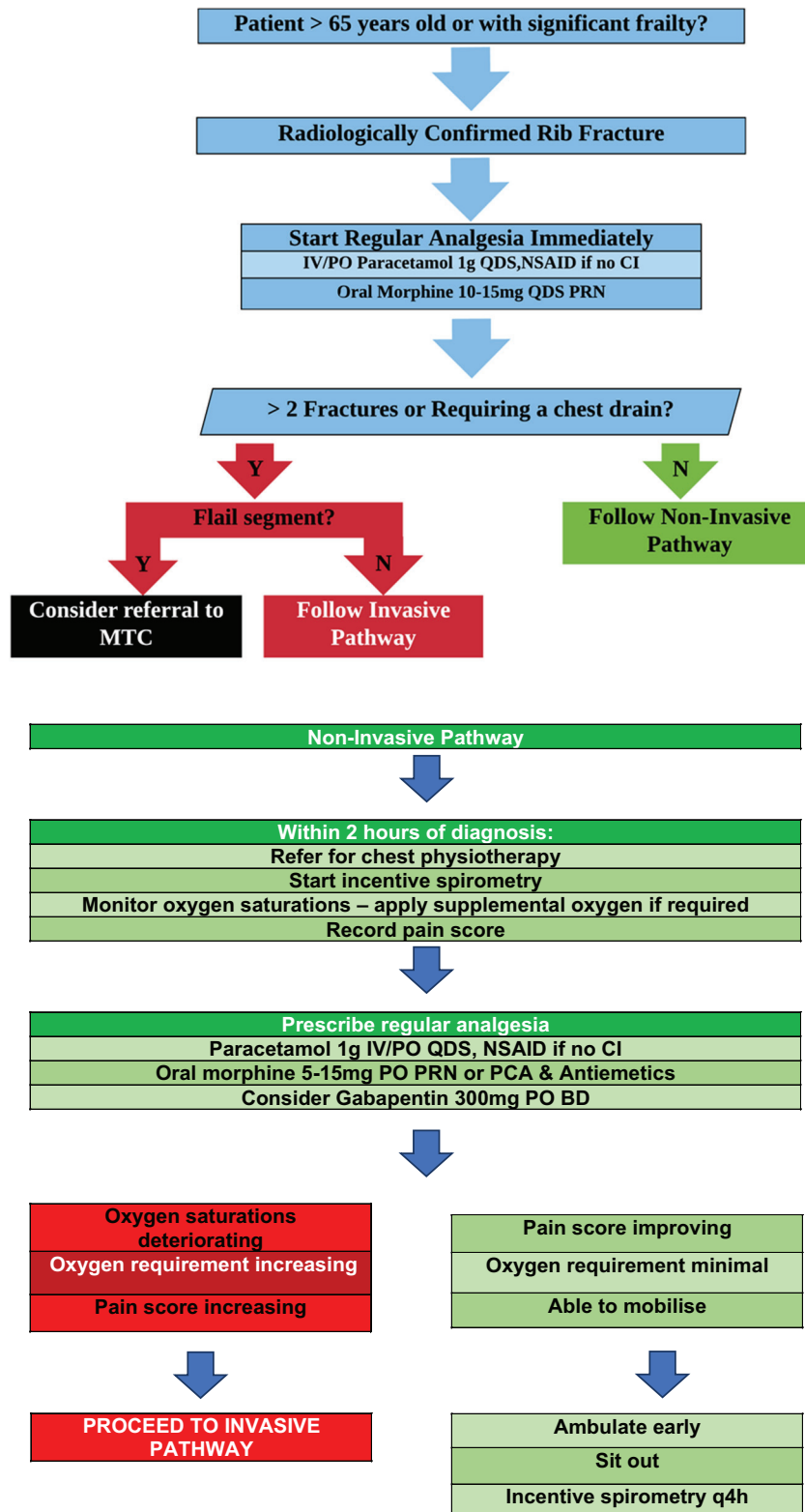
shown to be effective in the hands of a skilled operator, and clinical reasoning should be applied when deciding which technique is most appropriate for the patient. We are currently implementing the recommendations discussed here and will be auditing the impact on pain scores, length of stay, morbidity and mortality. We will report back here soon with the data from this work.

Key points

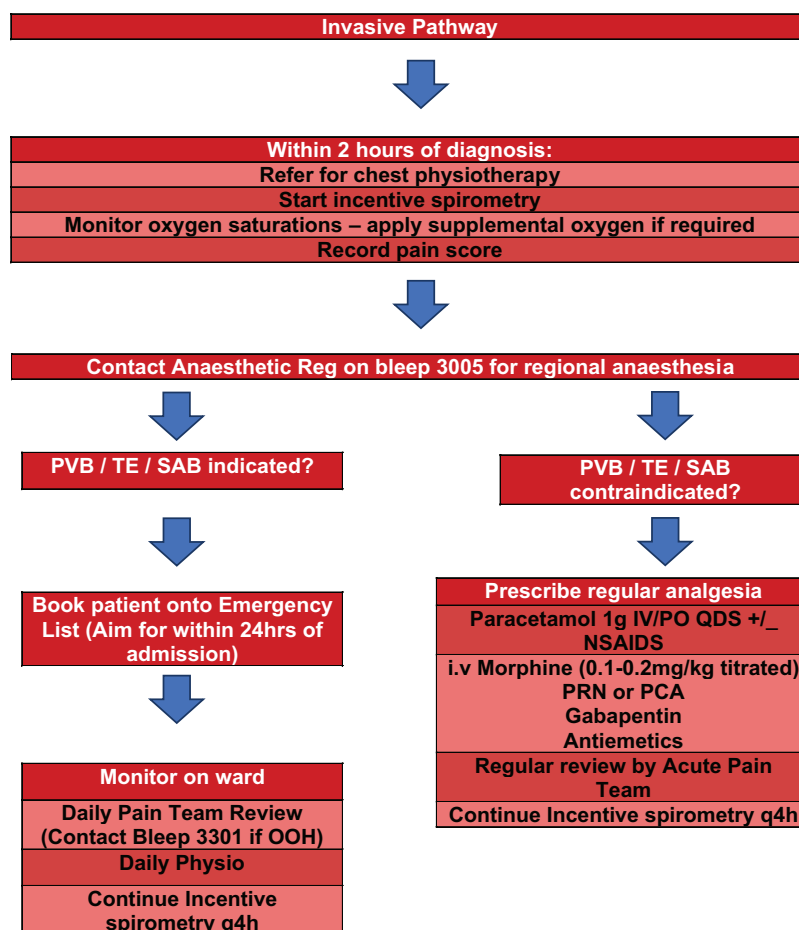
- Traumatic rib fractures are relatively commonly in the elderly and probably under diagnosed and treated.
- Early computed tomography (CT) imaging in the elderly can aid prompt diagnosis.
- If simple analgesic and patient-controlled analgesia methods are ineffective, early escalation for regional techniques can reduce morbidity.
- Thoracic epidural and paravertebral blocks are highly effective and safe when placed by experienced clinicians.
- Serratus anterior plane block is an effective alternative to TEA/PVB when these techniques are contraindicated.

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Appendix: Algorithm for Management of Analgesia in Elderly Chest Trauma:Adapted from St Mary's Hospital, London rib fracture management guidelines¹

Analgesic management of rib fractures in elderly patients admitted in the non-trauma centre setting

**PRACTICALITIES:**

We use continuous local anaesthetic infusion for the PVB Ropivacaine 0.2% running at 5-10 mls /hour

For TE use our standard low dose mixture of Bupivacaine 0.1% plus Fentanyl 2micrograms per ml.

Use our standard epidural pump (CADD SOLIS) clearly marked for PVB if using it this.

Hourly observations – BP/heart rate /Saturation/Respiratory rate /pain score and sedation scores

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Living well right to the end

Peter Wemyss-Gorman *Officer of the BPS Philosophy & Ethics SIG*

The Philosophy and Ethics SIG annual meeting

Rydal Hall June 2017

Despite our somewhat portentous title we in the Philosophy and Ethics SIG are clinicians, not philosophers. Our main preoccupation as pain therapists is the relief of physical pain and suffering, so far as it lies within our powers. But we are often troubled by the question: is this our only priority?

The theme of our meeting this year was suggested by the wonderful book *Being Mortal* by Atul Gawande, in which he addresses the potential conflict between the successes of modern biomedicine in prolonging life both in old age and terminal disease with the avoidance of unnecessary suffering. He avers:

“Modern scientific capability has profoundly altered the course of human life. People live longer and better than at any time in history. But scientific advances have turned the process of aging and dying into medical experiences, matters to be managed by health care professionals. And we in the medical world have proved alarmingly unprepared for it.

The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver's chance of benefit. They are spent in institutions where regimented routines cut us off from all the things that matter to us. Lacking a coherent view of how people might live successfully all the way to their very end we have allowed our fates to be controlled by the imperatives of medicine, technology and strangers”.

Atul Gawande, Being Mortal : Medicine and What Matters in the End. New York: Metropolitan Books, Henry Holt and Company, 2014.

Gawande describes the change in the trajectory of life from a more or less straight line followed by a precipitous fall to death in the days before the advent of modern medicine to the present, when the descent is much more gradual and ‘bumpy’ as episodes of illness are followed by periods of recovery which are never complete, with progressive limitation of ability and activity. He continues:

We in the medical professions tend only to be interested in the downhill stretches of these trajectories and fixing discrete problems. We think our job is to ensure health and survival. But

is it is much more than that? Is it also to enable well-being? - the reasons one wishes to be alive, which matter not just at the end of life or when debility comes, but all along the way.

This led us into the general area of wellbeing and its promotion in chronic illness and suffering throughout life, not only at its end.

The talks presented in this issue and the ensuing discussions occupied the first day of our meeting. More of these articles will appear in the next two or three issues, on aspects of wellbeing ranging from spiritual to economical. A complete transcript of our proceedings including the lively discussions will be published as a booklet in the New Year.

For more information about the Philosophy and Ethics SIG, including downloads of transcripts of previous meetings, please look at our page in the BPS website <https://www.britishpainsociety.org/philosophy-ethics-special-interest-group/>

Next year's meeting: The venue is Launde Abbey on 2nd-5th July, 2018, and the twin themes are ‘Stress and Burnout’ and ‘Language and the effects of our words on patients’.

Taking Care of the Person in Chronic Illness

Sara Booth

The Philosophy and Ethics SIG annual meeting

Rydal Hall June 2017

Breathlessness

The best definition of breathlessness was penned by Comroe in 1966:

Dyspnoea is "... is an *unpleasant* type of breathing, though it is not painful in the usual sense of the word. It is *subjective* and, like pain, it involves *both* the perception of the sensation by the patient and his reaction to the sensation"

Breathlessness is subjective; if you are running and out of breath it's not unpleasant - it can even be exhilarating.

The perception of the sensation involves our lungs, our heart and our thoracic walls and many other receptors, but in chronic incurable breathlessness when the disease is maximally treated, the central way in which we can intervene in chronic breathlessness is by paying attention to the patient's reaction to the sensation, and also helping with the way the people around them react to their breathlessness.

The severity of dyspnoea is a much better predictor of 5-year survival than measures of airway obstruction (? Lung function) in patients with COPD. However damaged your lungs are it doesn't give as accurate a forecast of prognosis as the severity of your breathlessness. That is surely because breathlessness is a measure of many other things about the person: their motivation, their activity, their psychological status and their family

circumstances etc. whereas the purity of the lung function tests doesn't give any other indications except how effectively the lung is working – this is clearly important but not as important as how the person reacts to their disease. Many people with very poor lung function may be quite active, mobile, social and self-caring while others are mainly sedentary and isolated.

Breathlessness is a terrifying symptom. Torture survivors report that the feeling of suffocation is far worse than any pain.

"It's like being strangled while you have a big weight on your chest" (patient from BIS study)

"Will I get much shorter of breath? Can I manage it? Is something terrible going to happen? (patient from BIS study)

"It's terrible to see it ... and you feel so helpless, so useless – I don't know how you can help" (relative from BIS study)

It can be invisible; if someone is sitting down but has 'severe breathlessness on exertion' it may not be noticed by clinicians. They have to ask about breathlessness and many do not.

An international coalition of respiratory physicians (GOLD) classify COPD into four categories according to severity. A is 'low risk, less symptom; B is low risk more symptoms, C high risk, less symptoms and D is high risk more symptoms.



Credit: Funky-data

The Breathlessness Intervention Service (BIS)

In the Breathlessness Intervention Service, BIS, we use a complex intervention consisting of a number of non-pharmacological treatments, addressing the sensation of breathlessness, talking over the way people think about their breathing. Breathlessness may be about the way an individual is breathing, the way it affects their functioning, or the way they think about their breathlessness. The different aspects of breathlessness can be managed by different interventions, which target one aspect of breathlessness. Of course breathlessness is usually affected by and affects all three of these concepts.

This is a long list of an eclectic range of interventions and we need to prioritise. Breathless patients are usually extremely fatigued and asking them to learn a huge range of different interventions at the first visit would be far too much. We start by determining the predominant problem for that individual. Has he got into a dysfunctional, inefficient breathing pattern

Breathing	Thinking	Functioning
Breathing techniques	Relaxation techniques	Pulmonary rehabilitation
Handheld fan	CBT techniques	Exercise/activity
Airway clearance techniques	Mindfulness	Walking aids
Singing therapy	Self-hypnosis	Pacing
Inspiratory muscle training	Acupuncture	

involving increased work of breathing and therefore more tiring than it needs to be. This is often accompanied by an increased respiratory rate or overuse of accessory muscles, or dynamic hyperinflation as occurs with COPD when air is trapped in the lung. Does the breathless person have unhelpful, mistaken thoughts about their breathlessness, perhaps paying too much attention to the sensation of breathlessness when they exercise and becoming more breathless as a result, or feelings of anxiety, panic, frustration or anger are making their breathlessness worse. Some may have had one very frightening experience in the past which colours their whole attitude to their breathlessness. Perhaps someone they loved who died very breathless (this was common in the past) or perhaps an occasion when they felt very short of breath and this was accompanied by feelings of panic or distress. Forever after the feelings of breathlessness and panic are linked. Many people find it helpful to learn that they are not going to harm themselves by being more active – and that if they feel breathless on exercise it is a good sign, although it feels uncomfortable, because they are doing more. Being breathless helps people to become desensitised to the sensation so in the end they notice it less and less and it does not inhibit them so much. Deconditioning due to inactivity can become a vicious spiral aggravated where someone feels breathless at lower and lower levels of activity as he becomes unfit by trying to avoid breathlessness and

therefore becomes breathless at lower and lower levels of activity.

The '*breathing thinking functioning*' (BTF) model helps people to understand why the symptom may seem out of keeping with the disease severity. Sometimes people are told "You shouldn't be so breathless - you're not that ill" and that just makes them feel demeaned. The BTF helps people to find motivation as somehow it makes sense and gives a way of mastering the sensation.

It has been shown that if a individual with a chronic illness, feels that they have an ability to influence the course of their illness by their own actions or thought – referred to as an internal locus of control – their medical outcomes will be better. For instance, if you give a fan to someone with severe breathlessness and explain how they use it, i.e. cool their face when they feel breathless, going fully into the scientific rationale and demonstrating it, they have something now that they can initiate safely at any time of their choosing to reduce the sensation of breathlessness. This action enhances their control of their symptom and sets up a virtuous circle of increased self efficacy.

Singing therapy is being more and more recognised as helpful to many people with lung disease. It also is pleasurable and usually carried out with other people, additional virtues, particularly as so many people with breathlessness become isolated – feeling stigmatised if they are breathless in public. Cognitive behavioural therapy

(CBT) can be used, for example, to help people understand that although breathlessness is very unpleasant it is not of itself actively harmful. This is analogous to the education that is so important in managing chronic pain. Non-pharmacological therapies are often underfunded, there is less of a advertising budget behind them although they have a large effect size. Only 4% of people who are eligible for pulmonary rehabilitation actually get it and yet the evidence that it works is overwhelming. Exercise and activity, perhaps facilitated by walking aids, increases fitness and although the maximal level of breathlessness that an individual feels is the same, he will be able to do much more before reaching it – increasing quality of life and self efficacy.

Pacing, carrying out daily activities at a less frantic pace and approaching activities strategically enables people to accomplish more things with less exhaustion. It requires a careful evaluation of what someone does and how they do it but can be very helpful in helping people avoid exhaustion and increase their quality of life.

The importance of symptoms in managing general medical conditions has only recently been recognised. The GOLD (Global Initiative for Chronic Obstructive Lung Disease) guidelines (2107) which are used by most respiratory physicians for the diagnosis, management and prevention of COPD have only mentioned symptom control as a priority for patients in the last two sets of guidelines.

The GOLD guidelines give the most prominence to palliative drug therapy although it is not the first choice for patients with breathlessness who are mobile. Pharmacological therapy may help to reduced breathlessness but is most suitable for people with very severe disease – breathless on minimal exertion or at rest. Oral morphine, in low doses, has the best evidence base, probably attenuating the central perception of

Taking Care of the Person in Chronic Illness

breathlessness. It is good to see that the GOLD guidelines highlight the importance of rehabilitation and physical activity, and of assessing co-morbidities including depression and anxiety. Improving these can affect mortality and frequency of hospitalisation. Many people with COPD go into hospital at least three or four times every winter and come out with nothing changed in their medical condition and their psychosocial distress, often associated with the frightening sensation of breathlessness, not addressed.

Chronic illness as a war of attrition

Unlike acute disease in chronic illness there are endless new insults coming every day which have to be contended with. Illness infiltrates every aspect of someone's life. Uncertainty, not knowing where or when the next difficulty is coming from, is fantastically difficult to live with. Cancer and its treatment, like chronic illness, can be attended by a wide range of physical and psychological effects that do not recede with time. We may not be aware of these problems as patients don't bring them up spontaneously and we aren't very good at asking about them.

'Cancer survivors experienced altered lives and had needs related to *fear of recurrence* and facing the spiritual aspects of having *survived* a life-threatening illness'

Oncology Nurses Forum: 1995,
22(6):915-922

Many diseases are becoming chronic that were once life-limiting. There are new personalised treatments appearing all the time, not only in cancer. Survival times are increasing, and many people have morbidities and symptoms that persevere over many years.

I'm sorry to say a lot of young people do not get the help they need because they don't fit in to one of the big chronic illness groups e.g. they cannot meet the COPD nurse as they have another

illness. I met a very inspiring group of young women with LAM (Lymphangioleiomyomatosis: at their annual meeting. It is a rare cause of lung disease in young women with only about 100 sufferers in the UK. Fortunately there are now more effective treatments available but before the establishment of the national LAM centre, many of these young people were highly symptomatic with breathlessness but did not receive any symptom control, simply an annual visit to the pulmonary function laboratory to receive bad news. Knowing they were getting worse but receiving no support.

I was motivated to try and find out more about supporting young people by my involvement with a 32 year old man who had had Crohn's disease since he was 11. I had a great sense of helplessness. He was simply visiting Addenbrookes for a procedure and I was asked to see him about pain. He had experienced interrupted schooling, had been unable to sustain any sort of work and was totally dependent on his now elderly parents. He was admitted to the gastro-enterology ward for nutritional support, and when I met him I experienced a very strong sense of his isolation and despair. I could see that if things like nutrition, psychological support, exercise and symptom control had been more actively pursued in his childhood and young adulthood he might not have been in the state he was now in his early thirties. He had no hope; he didn't fit into the hospice pattern as it was then, and was concerned anywhere so where could he go?

Chronic illness is like compound interest in reverse: if you don't intervene with things like poor nutrition and exercise early the results are cumulative. You lose your general health year by year and gradually become more isolated. Symptoms like breathlessness are very isolating both because people become more physically inactive and they feel embarrassed at being breathless and coughing in public. Their nearest relatives,

usually a spouse, take on all the physical work and find their own lives limited socially. Sometimes a breathless person will dread seeing the grandchildren as they are so exhausting, naturally the other one wants to see them and so conflict, guilt and resentment enter the atmosphere at home.

Psychoneuroimmunology and Inflammation

Recent studies have confirmed links between psychological stress and immune downregulation. For instance of natural killer (NK) cells, this is mooted to explain a possible increase in the incidence of cancer. In addition, distress or depression is associated with two important processes that promote carcinogenesis: poorer repair of damaged DNA, and alterations in apoptosis. The possibility that positive psychological interventions may enhance immune function and survival among cancer patients surely suggests that we should take this further, as does the evidence suggesting that social support may be a key psychological mediator in improving mental and physical health. It has been suggested that because chronic inflammatory states have such a close relationship with cancer prognosis, we need to take an personalised anti-inflammatory approach from the time of diagnosis using agents like omega-3 fatty acids, Vitamin D and cytokines inhibitors, allied to impeccable symptom control and access to nutrition-rehabilitation programmes geared to strengthen and maintain function and control fatigue.

Francheschi's concept of *inflammaging* suggests that accelerated ageing, diseases of old age and associated multi-morbidity are associated with chronic low grade inflammation. It may be that an individual's inability to inhibit inflammation contributes to a higher level of multimorbidity in chronic disease. Many chronic illnesses like COPD and diabetes are associated with accelerated aging. It may be that osteoporosis,

coronary artery disease and sarcopenia are all part of that same process i.e. multi morbidities not co-morbidities. There is mounting evidence of the role of inflammation in the pathogenesis of diseases like schizophrenia and depression.

I think that one of the most important papers to emerge in recent years is that by Tawakol et al (2017) on the association between amygdalar activity (as assessed by PET scan), levels of stress measured by the perceived stress scale and cardiovascular disease events. This relationship seems to be mediated by increased bone-marrow activity leading to arterial inflammation promoted by cytokines and inflammatory mediators.

The amygdala is part of the brain which is acts rather like a sentry, keeping watch for threats and initiating a response when it detects one. If the amygdala is sensitised, the individual is hypervigilant, and when stressed may perceive a threat when it is not there. This response can be very powerful in generating the sensation of breathlessness which like: pain, thirst, and panic is mediated in our central nervous system.

Learning how to respond rather than react to events can help, in time, to tone down this hypervigilance and reduced perceived stress.

Hypnotherapy

When I was a senior registrar at the John Radcliffe in Oxford, and later as a palliative care consultant at Addenbrookes, I found a huge unmet need in the people I saw with people living with chronic illness for a long time, particularly those with respiratory disease. Their needs seemed more pressing and less understood than those of dying people. I realised that particularly for people with neuropathic pain and cancer and for people with breathlessness in both malignant and non-malignant disease, there were clear

limits to what we could achieve with drugs or other medical interventions. I became interested in hypnosis as a way of helping people develop more control over their symptoms and studied for a diploma in the department of psychology at UCL.

Learning self-hypnosis gives patients a way of managing their symptoms. Leslie Walker, a psychologist who has extensive work in this field, writes that:

These studies have provided evidence that relaxation therapy, guided imagery and hypnotherapy can be very beneficial in helping patients cope with the diagnosis and treatment ("of cancer"). Intriguingly, there is some evidence that they may prolong life.....

Walker, *Contemporary Hypnosis*, 21:35-45

There have been a number of clinical trials of hypnosis in people living with cancer these show positive effects on pain, distress, nausea, fatigue and hot flushes.

A typical patient was Mrs A.B who had a slow-growing spinal tumour of which she was unaware until she had a sudden onset of tingling and weakness in her legs and She had probably had the tumour for years, but it had been asymptomatic until it nearly transected her cord.

When I saw her, she had her operation, which successfully removed the tumour. She was very symptomatic with neuropathic pain in her lower limbs. She as was frightened of taking exercise because she had a vision of it damaging her back, and she was utterly exhausted.

The first objective of the hypnosis was to reduce her anxiety and distress, and to herself in her mind leading to a greater sense of physical freedom. She chose imagery such as metal gates within the pain pathway preventing the pain, represented by a snake, reaching the

spinal cord. We also employed the psycho-social effects of hypnotic intervention to improve her general health.

The beauty of hypnosis in cancer and palliative care is that it is dynamic and creative. It can be energising and enable people to relive lost activities, such as walking before paralysis or amputation, This revisiting surprised me as I thought it would be painful. People also like focusing on what is working in their lives rather than endlessly dwelling on what they had lost.

Hypnosis is a staged procedure: you and the patient decide what the main problem is (e.g pain, distress or breathlessness). This main problem is addressed first, if this improves it may enable the individual to have the energy to tackle other issues such as anger and tense family relationships later. Hypnosis can be combined with other medical interventions and as well as symptoms can be very helpful for individuals to find a way of managing corrosive anger, which is very common in people who have had a delay in diagnosis.

We need also to look at the 'priors' that may act as triggers. Priors are previous sensitisers to anxiety. For example, someone with severe breathlessness may get even worse when they retain sputum and may panic feeling as though they were going to die. A patient who has been told they have very serious COPD but actually don't may sharply deteriorate from that moment. Changing these overperceptions – priors – can make a huge difference to a patient's general health, and improvements are correlated with observations of regional brain activity. Hypnosis can modify these sensations of 'prior anxiety' through control of conscious and unconscious, biologic and somatic processes.

There is an overlap between hypnosis and meditation. Meditation, mindfulness and mind/body practice can become part of a strategy to build psychological

Taking Care of the Person in Chronic Illness

resilience and be of use in treating specific problems. As well as treating disease in a reactive way we need to spend time building up resilience in a proactive way when we make the diagnosis of serious illness. The psychology of resilience and wellbeing focuses on thriving rather than morbidity. Personal resilience can be learned firstly by focussing on maintaining engagement with the world breaking the all too common cycle of growing isolation in people with COPD who can end up essentially home bound. Another important aspect of care is helping people in their search for meaning in their illness, perhaps just be listening to them, or helping them to feel as well as possible and therefore as psychologically robust, without the draining impact of serious symptoms.

Mindfulness-based stress reduction (MBSR) can facilitate a less distressful interpreted experience of physical disorders. This might help someone to begin not to interpret every pain as a signal that their cancer is coming back. The efficacy of mindfulness-based stress reduction on the mental health of breast cancer patients was demonstrated in a meta-analysis (Zaindal et al 2012), with a moderate to large effect size. Many antidepressants cannot claim such a powerful impact. It must be said that most of the studies were carried out in well educated Caucasian women and the generalisability of MBSR needs further examination. I conducted, with colleagues, a feasibility study of a self-administered wellbeing intervention. It was an six -week course that the individual carried out at home with the support of a guide book and diary. It included physical relaxation exercises (a 'body scan'), space for the patient to record three good things that had happened each day and a reminder for them carry out a pleasurable activity

each week. The intervention was highly acceptable and showed a trend towards reduced anxiety and depression (Ramachandra et al, 2008).

I believe we need a multifaceted approach to illness from the time of diagnosis, directing as much effort towards symptom control as to finding a diagnosis. Every tem needs to take a psychologically informed approach and help patients find the team that can help them achieve the psychological framework to live as well as possible with their illness. Exercise and activity are important components of such a strategy and are key to increasing wellbeing and resilience. The role of nutrition is controversial but surely has a part to play, as does adequate sleep and excellent social support. Ensuring that carers and family have their own personal network to support them is essential.

The 'Five Ways of Wellbeing' are part of Foresight's Mental Capital and Wellbeing Project (2008). The ideas offer a framework rather than a fixed formula, enabling it to be fully personalised.

The Five Ways are

Be active ... Walk, run, cycle, garden dance ..., find a physical activity that suits your level of mobility and makes you feel good.

Take notice ... Be curious. Notice beautiful and curious things. Savour the moment, whatever you are doing, rather than dwelling on the past or worrying about the future. Be aware of the world around you and your feelings about it.

Connect ... with the people around you – family, friends, colleagues and neighbours. Building these connections will support and enrich you in every way.

Give ... Do something nice for a friend or a stranger. Volunteer your time or join a community group. See yourself and your happiness linked to others.

Keep learning ... Try something new or rediscover an old interest. Learn a new skill: riding a bike, playing an instrument or knitting. Set yourself a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun. Even if you have a serious or life-threatening illness you can keep your brain alive.

They are simple, memorable and perfectly adaptable to any state of health.

A study of personalised respiratory medicine concluded that:

'Systems biomedicine has the potential to transform biomedical research and clinical practice from a reactive to a proactive practice of medicine'.

Clinicians need to be as active in thinking of the ways they promote health at the same time as they are treating disease. These strategies for health need to be as precise and personalised as drug and biological treatments are becoming.

This is well summed up by Coats, a cardiologist, writing an editorial on a paper describing how yoga could help arterial oxygen saturation in heart failure. He wrote:

'.... There are more ways to improve symptoms than stimulation of the failing organ, and the progress of disease in human beings is complex and multifactorial and offers multiple approaches to amelioration.'

Creative approaches to working with 'total pain' in palliative care

Kate Binnie *Music & Mindful Yoga Therapist, MSc in Palliative Care*



Credit: NikkiZalewski

The Philosophy and Ethics SIG annual meeting

Rydal Hall June 2017

The concept of 'total pain' suggests that addressing the emotional, relational and spiritual aspects of pain can reduce the intensity of the experience of physical pain and begs the question: how does working creatively with the whole person (body, breath, mind and emotions) affect symptom control and outcomes of interest to clinicians? I also want to talk a bit about embodiment, and about the split that often occurs between the reality of the lived body and the perceived reality of the mind – the latter influencing so much of our experience of pain and suffering beyond the parameters of the 'envelope of the body'. (RD Laing)

In therapy, I work with the body, breath, mind and emotions (noticing my own as well as the patient's) and music is also present as a mode of expression,

relational connection and as container for the session. I'm a singer – so the relationship between breath, sound and voice is my instrument, and my work involves developing ways in which this can be used therapeutically to promote relationship and healing (in the broadest sense).

In 12 years of music therapist practice, I have worked in palliative care, with children and young adults with learning, physical and mental health difficulties, as well as people with severe brain injuries and dementia. I've found that there is something about the voice that enhances relationship, and this may not be to do with *words* at all. The relationship is built on the sounds, feeling tones, timbres and shapes of shared vocal sounds (maybe becoming song) that are so conducive to making an authentic connection and relationship. This is what Daniel Stern calls 'vitality affects' – the feeling tones of relationship building that are cross-modal (voice, touch, body, breath and

sound). So, it's not so much about *what* you say or do, as *how* you say it, and *how* you move, breathe, wait, listen and respond. It's about intention, and embodiment.

One day at the hospice, I was asked to see a very agitated and delirious patient on the ward while the nurses got some sedative medication for her. I sat down by her bed, grounded my feet on the floor and my body in the chair (aware that I felt a bit nervous). I held her hand and started to regulate my own breathing, and then invited her to breathe with me. *Breathing in ... letting go and breathing out ... receiving the inhale ... and letting go softly and completely ... Allow your body to relax ... and ... let go ...* Then I started to hum so my breath became a sound. I didn't really have a plan – it all happened quite naturally. It was some sort of improvised lullaby in time with the rhythm of my breath, becoming her rhythm, a slow rocking, lulling tune at a low pitch. The patient's agitated movements stopped, she turned her face towards me, her breathing rate slowed, and her body visibly relaxed into the bed. We had *co-regulated*. The nurses came back with the drugs but the patient had gone back to sleep and later the doctor asked me what I had 'done to the patient'. I explained that I had grounded myself in my body and breath, and then helped the patient to self-regulate her body and breath. I had used all the tools at my disposal (nothing 'medical') just my breath, my body and my voice. I subsequently found out that this 'vocal holding' in palliative settings has been described by Australian music therapist Clare

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O'Callaghan as 'lullament' – the exquisite blending of lullaby (three-time, soothing and holding) and lament (minor key, supporting and expressing grief).

This experience led me to undertake further training and eventually to the Cicely Saunders Institute at King's College London where I was lucky enough to get a scholarship from the Samuel Sebba Foundation to do an MSc in palliative care. I completed with a research project involving a narrative synthesis of mind–body interventions for pain across nine conditions with palliative care needs. The outcome of this piece of work was that the measures used for pain scoring (in quantitative studies) suggested small or non-significant reductions in pain. However, the aggregated qualitative data consistently showed that patients perceived pain as a far more subtle and holistic concept ('total pain') than the parameters of a Likert scale for 'pain intensity' would allow. Even if pain *intensity* was not reduced through body–mind interventions, pain coping, a sense of embodiment, a relationship with the body in pain and a sense of confidence in the body were consistent themes. Furthermore, an enhanced sense of relationship, improved mood, reduced anxiety and a sense of spiritual connection and acceptance were all repeated themes, revealing *processes* of cognitive, psychological and spiritual or existential change towards well-being that could not possibly be explained or revealed by a pain tool, applied pre–post after a short time period of exposure.

'Total pain' defies objective measurement. It is a holistic concept that demands a phenomenological approach, and which medical philosopher Havi Carel describes as 'giving precedence to the *lived experience* and the embodied nature of human existence'.

Walt Whitman said, *Everything we do, have done or will do, we will do in our*



Credit: FatCamera

bodies. We experience the world and each other through this fleshly prism. Yet, so many of us live a very long way from the body – far away, in the insecure and ever-changing landscape of the mind. So, how to integrate the mind and body? How to be embodied? The Buddhists, yogis and mindfulness practitioners have some answers for us here. Breath is the foundation of our experience. The first thing we ever do is to take a breath and the last thing we ever do is exhale. Breath is the constant thread of our lives, and (unlike other autonomic functions) it can be consciously manipulated with extraordinary results for regulating not only breathing but also emotions, physical sensations and our ability to connect with others

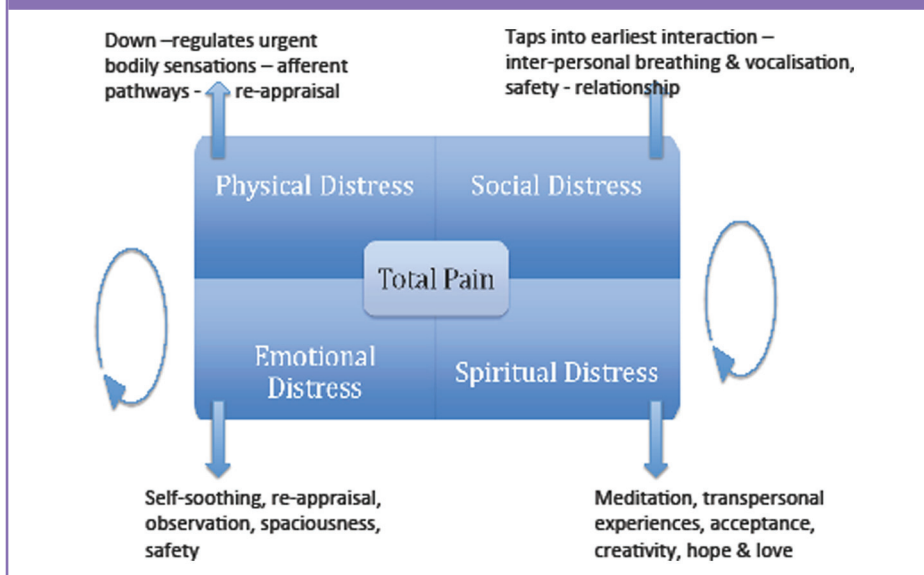
Breath is the bridge which connects life to consciousness, which unites your body to your thoughts. Whenever your mind becomes scattered, use your breath as the means to take hold of your mind again. (Thich Nhat Hanh; Miracle of Mindfulness)

Mindful yoga

With this in mind, I have been running a mindful yoga group in a day hospice in Oxford for 6.5 years. All are welcome: patients attending day hospice, patients on the ward, carers, volunteers and staff. 'If you can breathe, you can do mindful yoga' is my strapline – the group includes those with late-stage motor neurone disease (MND) who are unable to speak or move, those on oxygen or with syringe drivers and those with cognitive difficulties due to brain malignancy. The only really tricky thing to deal with is profound hearing loss. It defeats the point to BELLOW 'relax your feet into the floor'!

This year, I evaluated the group which involved collating replies to a simple questionnaire based on feedback (outcomes of interest) to previous groups. Similar to the results from my narrative synthesis, patients reported that mindful yoga helped with a broad spectrum of suffering that could be described as 'total pain' relief. Furthermore, they described this not in the language of *deficit* or *symptom*

Figure 1. 'Cycles of positive affect and effect' for total pain using mindful yoga



reduction but in positive terms connected with holistic well-being: acceptance, relatedness, spiritual awareness, self-compassion towards the body in pain and a sense of confidence in the breath. A strong theme (again, corroborated by published qualitative evidence) was that patients perceived breath to be the most useful and accessible take-home tool. For example, *'I can use my breathing when I go into a scanner or when I'm lying awake at four in the morning and can't catch my breath'*. The mindful yoga techniques seemed to provide a practical skill to manage living with uncertainty both psychologically, and also to manage frightening body sensations in the moment, and it gave them back a sense of control.

Processes at work

Models of change processes point to the down-regulation of bodily sensations through an interaction of afferent and efferent pathways. This is not simply a 'top down' cognitive behavioural approach; we work with the body-in-fear first. By working with immediate, urgent,

frightening body sensations and emotions in the moment, there is an immediate regulatory effect on the limbic system. With practice, the intervention promotes the development of meta-cognitive awareness, an ability to 'witness' the system in fear/pain and so on, without getting too caught up in anxious thoughts and misperceptions. I call this a 'cycle of positive affect and effect'.

From an attachment theory perspective (especially thinking of the most vulnerable towards the end of life), this way of working is tapping into our earliest interactions – the baby in the womb experiencing the whooshing of its mother's blood and the sound of her breathing and voice. When we breathe with somebody, touch them soothingly, use a calm voice and in an attitude of 'being with', we are holding them in a very deep and simple way.

In music therapy, we talk about 'motherese' (C. Trevarthen), which is the earliest communication between mothers and babies – the cooing, facial expressions and mirroring that 'affirms' the relationship and which promotes the release of oxytocin involved in making a secure attachment. My belief is that in

working with people in this way, the therapist facilitates the re-visiting and teaching of a self-regulatory skill that is built first through relationship and then becomes something people can find for themselves, especially if predisposed towards anxiety, chronic pain or other dysregulation that may have been set up very early in life. (see Allan Schore's work on repairing infant trauma.)

This way of relating to distress may seem absolutely obvious and innate, yet sadly in medical settings, families may be unsure of how to approach an agitated or distressed loved one, they may feel de-skilled or unsure of their own abilities to soothe. In some settings (especially where staff are under-supported), nurses are so hurried and task-focused that these 'softer' skills are neglected and under-valued.

As a music therapist (rather than a clinician with a more 'task focused' job), I have the luxury of time with patients in the hospice. I can take time (using the skills from my yoga and mindfulness training and practice) to tune into clues presented by breath, body posture and facial expression before *doing* anything. Here is a basis on which to begin to make a relationship *from where someone is now*. I have found that working with body and breath initially forms a direct bond based on a feeling of safety, from which grounding we can start the psychodynamic work (where appropriate, some patients I only see once, right at the end of life) perhaps talking about the past, what they are hoping for or fear, or perhaps writing a song together or playing with instrumental music. As animals, or organisms, only when we feel safe, can we be creative and 'play'. When we are frightened or in bodily distress, the fight/flight/freeze response takes over. So, making a safe relationship with patients on a body/breath-based level allows the space and freedom for humans' innate creativity and drive towards what Maslow called 'self actualisation' to flourish in what can be a

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wonderful, creative, spiritual flowering, even towards the very end of life. It has been a constant surprise and delight to be part of.

Nigel Hartley, a distinguished music therapist working in palliative care, said that 'creativity moves us on'. So, we might not know what we think about something as a coherent cognitive thought until we paint a picture or write a poem or a song about the feeling of that thing (whether it be a relationship, the idea of dying or a past experience). Active and supported creative expression offers a way of processing, playing with and exploring the things that happen to us that perhaps we cannot articulate in words. As Havi Carel says, a diagnosis of terminal illness presents a *violent invitation to philosophise*. This process can take us from confusion, overwhelm and fear to a place of articulation, getting a handle on something, understanding what it means to us, and this can be hugely therapeutic and relieving psychologically, spiritually, relationally and somatically.

Conclusion

Dying happens to each of us only once (as far as we know!), and we will all experience

losing those we love at some stage. In the same way that person-centred pre and post natal care has become accepted and promoted as important for not just maternal but child and societal mental and physical health outcomes, surely dying well should be of equal importance not just for those dying but also for those family members caring and being bereaved, and for the professionals supporting them.

What does this all mean in terms of service provision in cash-strapped times and in an era dominated by evidence-based medicine and the demand for outcome measurement? Some hospices may be able to employ body-mind and music therapists with charitable funding, but we are still thin on the ground as part of core NHS services. And what about all the other settings in which people live with illness and then die?

Access to interventions that support the whole person (despite the exhortation to deliver patient-centred care) is patchy and inequitable. My feeling is that alongside a need for high-quality research to evidence these types of interventions supporting the effectiveness of holistic care on symptom management (and a preventative effect further upstream) plus qualitative research to

understand more about the experiences of patients, carers and staff, there is a need to up-skill healthcare professionals on the front-line. Teaching nurses, doctors and allied healthcare professionals to utilise simple body-mind techniques and building confidence to rely on themselves as a vital clinical tool could support compassionate communication and resilience-building within every interaction.

For Kate's courses on these topics, see Sobell Education Centre (upcoming day: 6 October; <https://sobelleducation.org.uk>) and University of Worcester Centre for Palliative Care (<http://www.worcester.ac.uk/discover/about-the-centre-for-palliative-care-cpc.html>; upcoming day: 3 November) or contact Kate directly if you are interested in yoga therapy training and research (katebinnie@yoga-voice.co.uk)

The longer I live, the more I am satisfied of two things. First that the truest lives are those that are cut rose diamond fashion with many facets. Second, that society is always trying in some way or other to grind us down to a single flat surface. (Oliver Wendell Holmes; *The Professor at the breakfast Table*)

Living with the uncertainty of cancer

Karol Sikora *Consultant Oncologist and Dean, University of Buckingham Medical School*



Credit: BrianAJackson

The Philosophy and Ethics SIG annual meeting

Rydal Hall June 2017

The healthcare trajectory is changing dramatically. The fundamental feature of the change is that now people have all the information and it isn't hidden. I remember going on ward rounds as a student where we bypassed the patient with metastatic cancer. We talked about mitotic activity, NG for new growth, neoplastic disease – all words to ensure that the patient didn't know what was going on. Now we're very good at telling people they have cancer but not so good at telling them what it really means; unless they actually ask, and surprisingly few people do ask ...

Giving someone a cancer diagnosis is easy. What is much more difficult is to tell someone that if you've got metastatic

breast cancer your average survival is less than 24 months, and prostate cancer maybe a bit longer. But, these are of course *averages* and reflect a huge uncertainty. I've had breast cancer patients who have died within a month of having a breast lump with infiltration of bone marrow failure and widespread metastatic disease totally unresponsive to therapy. At the other end of the spectrum, I have a delightful lady of 87 years who we have treated for metastatic cancer she has had for more than 30 years. So the problem we have is that there is so much variation in outcomes and the patient has to live with that uncertainty. The title of this talk is 'living with the uncertainty of cancer' in an age when there is information everywhere. You can't read a Sunday paper without finding something about cancer in it.

This leads to another important question. If I tell you you've got cancer

and 6 months to live how much would you pay me to give you another 6 months? How much is *your* life worth? If I were to say if you give me a pound you could live a year longer – would you give me the pound? Of course you would. If I say give me 10 million pounds for that year most people would say that's ridiculous – that's not possible.

When you try to make rational judgements the extremes are easy. The trouble is that the reality is in the middle. And that's where we have a crisis now. One of my pet hates at the moment is crowdfunding sites for patients who are essentially dying with metastatic cancer to get drugs not available on the National Health Service (NHS) or even to travel to America. It is increasingly difficult for patients faced with the situation that they may only have 6 months to know what to do. Should they believe the onslaught from the media and the Internet about

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what is available? Or do they say 'enough's enough, this is not worth it, I'm going on a cruise, going up a mountain, visiting relatives I haven't seen for years to be at peace with myself' and then let go.

And that's where palliative care is so good in Britain – it sort of balances the aggressive therapies in the United States which are based on immortality which is completely unachievable at any cost. It may delay things a little bit but creates total uncertainty in a patient's mind. I vividly remember a patient, a wealthy industrialist, with pancreatic cancer (which has a 5-year survival of less than 3%). He came to me for a second opinion. He said, 'They tell me there is nothing more they can do at the Marsden and I've come to you as there must be *something*?' His liver was full of metastases, he had had all the chemotherapy possible and I told him that there was nothing I could offer. He said, 'I want to go to the States; which centre should I go to?' I told him that it was a complete waste of time but suggested the Memorial Sloane Kettering Institute in New York. He went there and a month later came back to see me and admitted that I'd been right – there really was nothing to be done. That was his way of coming to acceptance.

It is increasingly difficult with all the information available to let people accept the fact that death is not something really to be frightened of, but more something that we've got to get through. That is creating huge amounts of tension. And of course it is fuelled by all sorts of drivers such as the pharmaceutical industry (the most expensive cancer drug now costs £400,000 for a single treatment). The other things are the media and cancer charities. If you look at the Cancer Research UK or the Macmillan websites, you'd think cancer had been cured several times over. So people wonder why they can't get things that seem to be going to other people like the ones in

the little anecdotes that are used in advertising for charitable donations.

Future directions: the four boxes

In cancer, there are four boxes for the future. The first is the *technology box*, which is really easy as all you have to do is draw a line from the last 30 years forward for the next 30 years. But what you can't predict in technology are step changes – someone coming up with an idea that you couldn't have anticipated even 5 years previously. An example is the computed tomography (CT) scan which has changed the whole way we assess and stage cancer and determine its likely outcome and how best to treat that patient. Another step change is the polymerase chain reaction (PCR), a technique to amplify tiny amounts of DNA to allow the whole molecular analysis of body tissues; so the pathology report today bears no resemblance to those of even a decade ago and provides all sorts of ways to determine the likely outcome of the cancer and the optimal treatment for that patient.

Surgery is much less damaging with far fewer days in hospital. It's great because you spare normal tissue and it's much less destructive; there's less need for rehabilitation and you're back home and back at work in a few days. But it has a profound psychological issue because if you're going to have breast surgery in a day there's not much time to chat to anybody about the fact that you've got cancer. This is very different from the days when you were in for a week for a mastectomy.

Radiotherapy is now much more precise, thanks to computerised imaging and planning, with much more selective delivery of radiation dose at to the cancer but not to normal tissues. We can use the PCR to determine the optimal chemotherapy drugs for individual patients, and indeed, we are beginning

to enter the era of personalised medicine and the results are gradually improving all the time.

When I became a consultant, the survival rate for cancer was about 35%. Now it's about 52%, and it's going up slowly every year. And that sort of information and positivity is in everyone's head when they or someone they care for get cancer. So the technology box is exciting, it's dramatic, it's where the money is, it's what the newspapers write about and TV programmes talk about.

The second box, the *society box*, is much more challenging. We are all living longer – there is much more loneliness in the world than there was 50 years ago as family structures are imperilled by high divorce rates, trans-generational mixing, second marriages and so on. Church attendances are at an all-time low but it's not so much this that matters; it's more the depth of faith. If you have a crisis on your life – if you're told you have metastatic cancer – in the past you could turn to whatever was your faith; it didn't have to be Christian. But for many people now there is nothing. We have created a whole structure of counselling and complementary therapies: all sorts of things to help fill the gap where there isn't the strength of faith that there was in the past.

The place and function of women in society has changed: many women have families and then go back to work, whereas two or three generations ago the woman's place would have been in the home so if Granny had cancer there would be instant support for her. That's all gone. Society has created the expectation that everything is the same. But it's not; it's changing and is going to change even more and more. The Smartphone has changed the way people communicate. More people are Internet aware, even when they reach the age when cancer is more likely to strike, and are going to use it as a way to access information about all sorts of

things: how can they get the best care possible, about which they may be misled.

The third box for the future is how we *deliver cancer care*, including psychological support. When I started in oncology there was almost no psychological support. Sometimes you got the diagnosis and sometimes you didn't, but there was no support whatsoever. As a young registrar, I was obsessed with the blood counts and the X-ray findings and the response to treatment and I didn't want to talk about how the patient felt. Now we – indeed all professions within healthcare – are much better at talking to people and trying to assess the amount of information they want.

But we still deliver cancer care in the 'cathedrals of medicine' – the big city centre teaching hospitals. These may be difficult to get to, especially for the elderly. A woman with breast cancer may need up to 80 visits in the first year for diagnosis, chemotherapy, radiotherapy, removal of the lump and follow-up with more X-rays and blood counts. So it's a struggle, but it's not necessary. There are ways of getting round this, and I predict that what we are going to see in future is a much more user-friendly system. The NHS doesn't value people's time and there is no incentive to make it adaptable to the modern online world. So I can see chemotherapy and radiotherapy being distributed to smaller and smaller centres so that you avoid having to go to the metropolis for your cancer care. This will allow you to get to know people and they see the same receptionist every time. This has a huge impact on people. A cup of tea kindly given with empathy can have more benefit than the most expensive drugs. So we need to redistribute the way in which we give care. We can ensure that the quality of that care is excellent with a computer; everything you do can be quality assured and monitored centrally. That will

transform the convenience of treatment and won't cost much extra.

The fourth box is the most difficult one: *how are we going to pay for care?* How are we going to decide how much to spend on you if you have metastatic cancer? Should it be different if you are 80 or 30? Does it matter if you have children? Does it matter what type of cancer it is? If you have lung cancer and you are a heavy smoker, do we really want to give you £250,000 worth of drugs? If you look at any equitable solution you've got to take everybody into account. Do you allow people to say: OK, you give me the drugs you can give me and I'll buy my own on top? I'll go crowdfunding for the expensive ones and you can give me those as well. Is that fair?

In the last decade, we have had a very complex and politically sensitive scheme, called the Cancer Drugs Fund. It became clear in 2010 that the NHS couldn't afford all the drugs that were coming forward for cancer. Even before this when David Cameron was elected Prime Minister, the Conservative manifesto stated that every cancer patient could get any drug that was recommended by their consultant. That had to be implemented and £300 million was put into a fund that every year, top-sliced from the NHS, to give people high-cost drugs. The average duration of benefit from these drugs was less than 3 months, and in many patients, there was no benefit at all. So there was huge cost with very little benefit, but politically it was very difficult to stop. We then had to fill in five-page forms on the NHS computer which were sent off to a central body where it would be ratified and a decision would be made. We were allowed to put social value things in, but how do you give these values? Do you give someone with lots of kids a higher social value than a prisoner? Now we are going back to the National Institute for Clinical excellence (NICE) making the

adjudication on whether people will or won't get a drug.

But, all this noise creates untold uncertainty for patients. Drug companies love stories in the press which suggest that a celebrity has been denied a very expensive drug as they think they can sell more although the data show that the actual prolongation of survival is pretty minimal. There are a few studies of patients and how they actually feel at the end of life. Some suggest that if you offer something they will always take it. In one study from about 20 years ago, 91% patients with metastatic cancer would try something with less than 1% chance of any benefit at all.

The challenge

So the difficulty we as health professionals face in helping cancer patients to come to terms with their situation is that although living with uncertainty is terribly difficult, predicting what is going to happen to any individual is impossible. With metastatic cancers you know roughly the averages, but with an individual you really have no idea.

The technology box is going to go on generating more excitement, but the societal box will continue to provide challenges which the health professions are going to have to step in and do something about. General practitioners (GPs) don't know their patients anymore and they can't get appointments with the same doctor. The challenge of trying to make the end of life better is that we've got to work out how and when we can allow and help people to let go, at a time of their own choosing. We must separate the money and the dreadful crowdfunding business from it all and accept that everyone has to die; and give people the time and help they need to come to terms with this. That is difficult. Telling people they have cancer is very easy because they don't necessarily see it as a death sentence. But when you say

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the cancer has spread and they ask 'can you cure it' we say,

we can't cure it but we can control it, but the time for which we can control it is going to be hugely variable. It's going to depend on how the drugs work on the cancer, what side-effects cause you and are these going to limit the dose we can give.

So what in the past would have been a 10-minute discussion before starting chemotherapy now takes at least 30 minutes and maybe even an hour. And it depends on good rapport between the doctor or the cancer specialist nurse and the patient. It may involve dealing with a lot of anger, often from families rather than patients, if they perceive that a drug has been withheld

to save money when you know it do no good. Telling someone that it would be best to withdraw from more active treatment is like taking the breast out of the baby's mouth. They often regard the treatment as their only hope of avoiding death. If you are going to be brutally frank with somebody you may be removing the last vestiges of hope; hope is absolutely vital but has to be realistic.



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

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

Thank you for supporting the BPS!

When estimating other's pain intensity, to what extent do clinicians rely on non-verbal behaviours?

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Introduction

Pain management remains a major health concern and a challenging task. Despite an increasing understanding of the biological and psychological aspects of pain, numerous studies highlight that pain is often unrecognised and underestimated.¹⁰

Personal experiences of pain are encoded in an array of verbal and non-verbal pain behaviours. Such pain behaviours enable observers, including caregivers and pairs, to perceive, estimate and accordingly manage other's pain.¹¹ Verbal self-report has commonly been described as the gold standard of pain assessment. However, language competence is not fully available to all individuals especially infants and young children, people with cognitive and expressive impairments.⁷ Moreover, expressing the complexities of pain experiences in a direct and representative manner can prove to be challenging. Fortunately, relevant information can also be derived from non-verbal expression. Pain non-verbal expression comprises communicative behaviours that include facial expressions and paralinguistic vocalisations (i.e. crying, moaning or deep breathing), as well as protective behaviours that correspond to any action that is intended to reduce the probability of further injury, minimise the experience of pain or

promote recovery from injury (e.g. guarding or holding the affected area of the body). Protective pain behaviours could also serve communicative fashion since they are used by others to estimate pain intensity and disability. Hence, numerous behavioural observation systems have been developed in clinical settings in order to improve patient's pain assessment through the use of non-verbal behaviours.¹⁴ These systems allow the codification and assessment of behavioural information. Although particularly useful, the use of such systems brings at least two questions that will be addressed in this article: How clinicians value and then combine information from each pain behaviour when estimating other's pain intensity?

The few studies that have addressed these questions^{12–13,16} have based their conceptual and methodological framework on the Information Integration Theory (IIT).^{1–3} The basic aim of IIT is to identify the algebraic rules whereby different sources of information are combined for the purpose of everyday judgment and decision-making. This theory describes three processes that operate between the detection of one or several information and the time of judgment or decision, that is, the valuation, the integration and the action. Valuation refers to the process of transforming each observable information

(Φ) into a psychological representation (Ψ). It comprises the attribution of both psychological scale values and weights (importance) to the presented stimulus. The integration operator then combines these psychological representations into a unified implicit response. Integration may be accomplished by different types of algebraic rules: adding, multiplying or averaging (with equal or differential weights attributed to each source of information). Finally, the action operator converts the implicit response into an observable one, such as a rating of other people's perceived pain on a Visual Analogue Scale (VAS).

Through these theoretical and methodological frameworks, we conducted a study focusing on the means by which clinicians (novice versus experienced), in comparison with non-specialist individuals, value and combine information from non-verbal behaviours when estimating pain intensity in patients with chronic low back pain (cLBP). In 2015, the Global Burden of Disease Study reported cLBP as being the single most disabling musculoskeletal condition, and the leading cause of years lived with disability in most countries.¹⁸ Therefore, it appears worthy to deepen the knowledge about the way clinicians rely on patients' typical behaviours when making judgements about them. Two pain behaviours

When estimating other's pain intensity, to what extent do clinicians rely on non-verbal behaviours?

already recognised as reliable cues to assess cLBP outcomes were of interest. Facial expressions of pain are commonly used by clinicians to assess pain intensity in patients with health problem in general and with LBP specifically.^{4-5,15} Lumbopelvic kinematics (LK) also constitute relevant back pain-related information. LK refers to a simultaneous movement performed in a rhythmic ratio of lumbar movement (L) to pelvic rotation (P), during a complete cycle of trunk flexion and extension. Individuals with cLBP tend to increase lumbar flexion (i.e. having larger L/P ratios compared to healthy individuals) during the early stages of forward bending and decrease lumbar flexion (i.e. having lower L/P ratios) during midrange of forward bending.⁸ Such adaptations are put forward by patients experiencing pain to reduce the threat to spinal tissue and possibly prevent further pain and injuries to the spine.

Methods

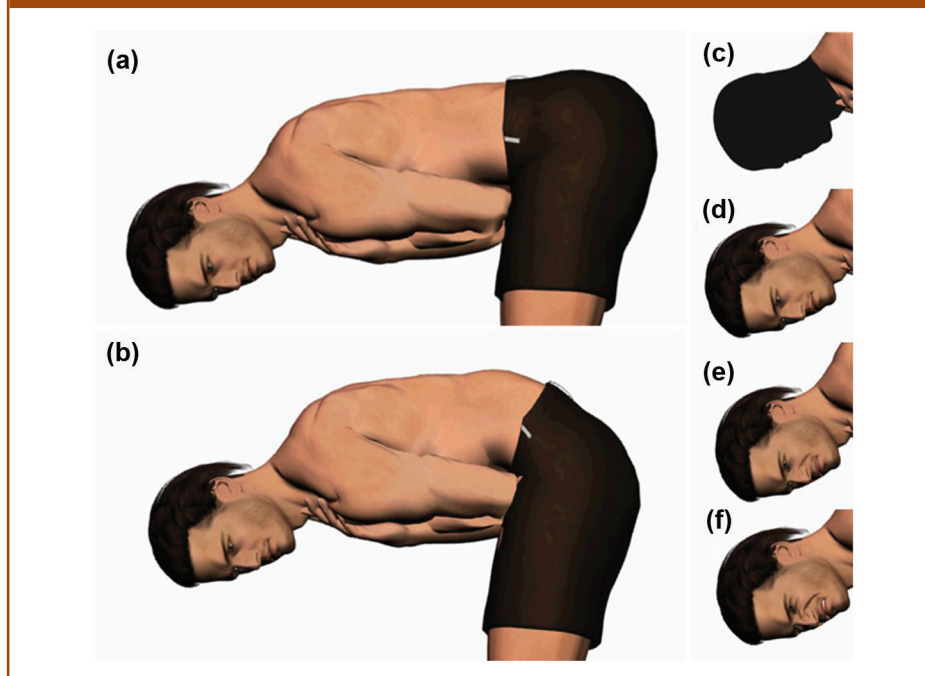
Participants

A total of 58 participants were recruited and assigned to three groups according to their clinical experience: 21 experienced clinicians (all chiropractors, that is, spine specialists: 9 females, 12 males; mean age = 42.24 years, standard deviation (SD) = 12.38; years of practice = 16.4, SD = 10.9), 21 novice clinicians (all chiropractic interns: 13 females, 8 males; mean age = 23.48 years, SD = 1.47) and 16 non-specialist individuals recruited in the control group (9 females, 7 males; mean age = 38.44 years, SD = 13.03). If participants had experienced an episode of cLBP in the past, they were not included in the experiment.

Stimuli

Stimuli consisted of a set of three-dimensional (3D) realistic characters performing a trunk flexion-extension task,

Figure 1. Illustration of the different kinds of stimuli. On the left, examples of trunk flexion frames taken from a video: (a) prototypical low back pain lumbopelvic kinematics 'LBP LK' and (b) prototypical healthy lumbopelvic kinematics 'healthy LK'. On the right, examples of facial expression intensity (FEI): (c) mask FEI 'masked FEI', (d) neutral FEI 'FEI0%', (e) mild FEI 'FEI50%' and (f) maximum FEI 'FEI100%'.



with an avatar imported from the Poser8[®] software library. For each stimulus, LK and facial expression intensity (FEI) were manipulated. To begin with, two realistic movements replicating the character's trunk flexion and extension were created. The LBP LK was developed to simulate a typical guarding behaviour observed in patients with cLBP (i.e. increased hip flexion and decreased lumbar flexion during midrange of forward bending), whereas prototypical healthy LK was developed using kinematics data derived from healthy adults. In the second step, different facial expressions were associated with each avatar's back pain condition. According to previous studies, three facial actions were targeted for modelling pain expression: brow lowering (AU4), orbit tightening (AU6&7), comprising 'cheek raise' (AU6) and 'lid

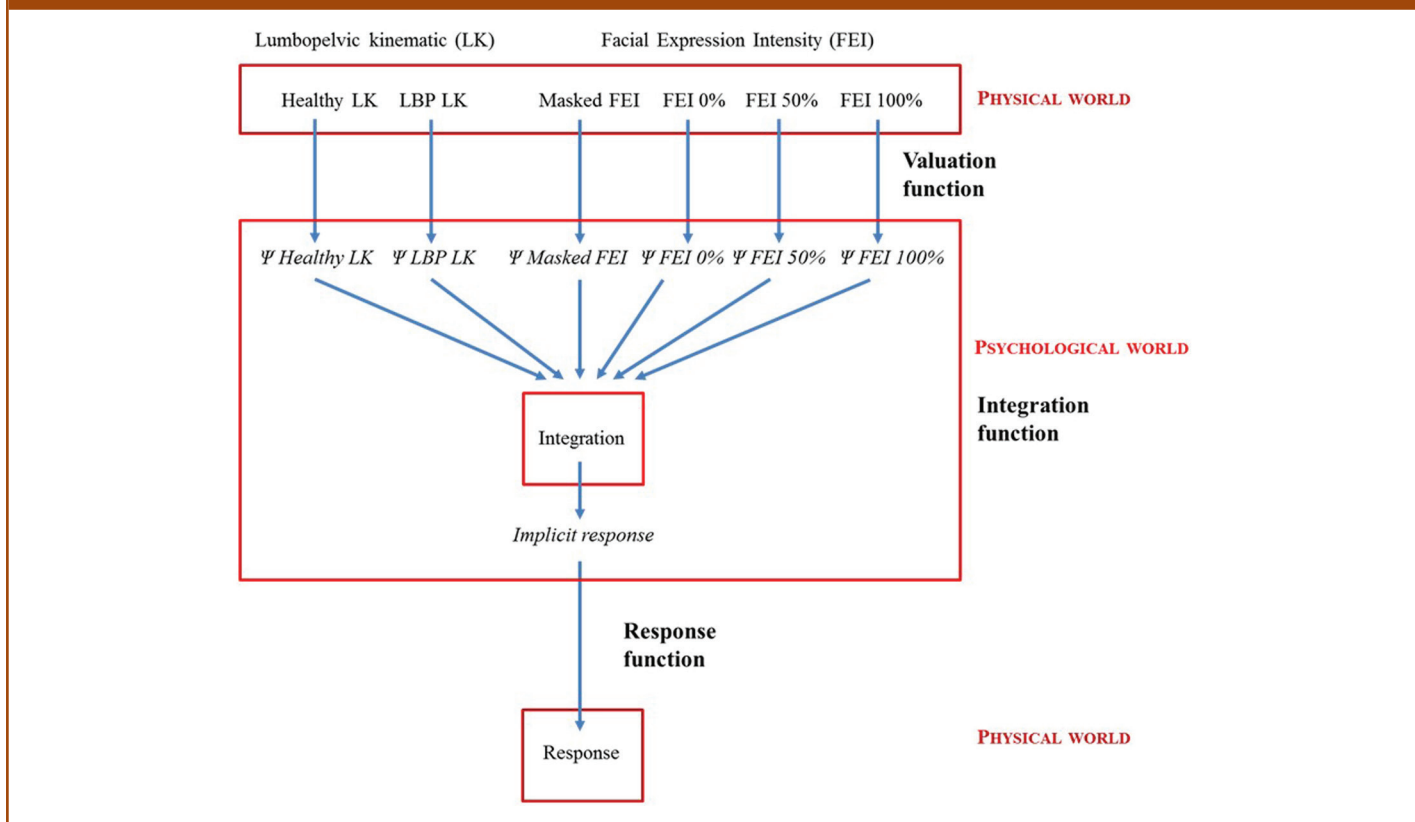
tightening' (AU7), and levator contraction (AU9&10) including the effects of 'nose wrinkling' (AU9) and 'upper raise' (AU10). The degree of mobilisation related to the facial actions' contraction was modulated according to different intensities (i.e. 0%, 50% and 100%). The unfolding of each facial expression was linear (i.e. constant increases in intensity) and was generated using morphing. In order to obtain a reference relative to the observer's judgments about kinematics only, and to test for the potential use of all algebraic rules, an avatar presenting masked FEI was also created. Figure 1 illustrates the variables used in this study according to the theoretical framework of IIT.

Procedure

Participants were asked to estimate back pain intensity from a virtual character

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Figure 2. Illustration of Anderson's Information Integration Theory applied to this experiment.



performing a trunk flexion–extension task. The experiment began with one block of practice trials during which all stimuli were displayed. Following these practice trials, participants watched two blocks of 16 random video trials, each video being presented four times. After each video, a 10-cm VAS, only anchored from no pain to maximal pain, was displayed at the bottom of the screen. Participants had to score, using a mouse click, the pain intensity they perceived, which automatically triggered the following trial.

Data analysis

The way participants valued the different behaviours they faced was first examined. The related analyses enable the assessment of observers' subjective internal scale for LK and facial expressions

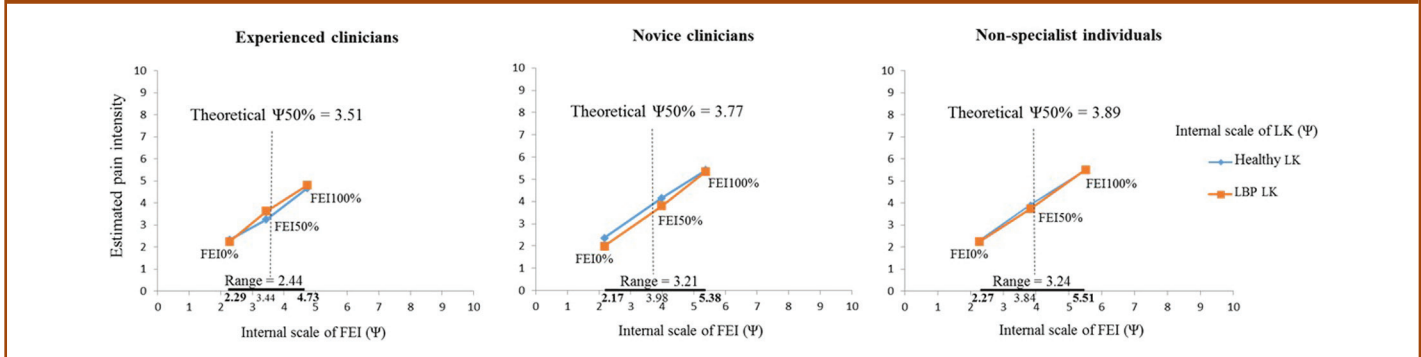
when estimating cLBP intensity. The valuation process corresponds to the transformation of each physical stimulus value into a subjective internal value mapped on the VAS. Internal values (Ψ) are approximated by the marginal means of responses given by participants for each physical Φ LK or Φ FEI condition. For example, experienced clinicians estimated pain intensity for Φ FEI100% through two sets of stimuli: Φ healthyLK_FEI 100% (mean = 4.66) and Φ LBPLK_FEI 100% (mean = 4.80). Therefore, the corresponding subjective internal value Ψ FEI100% (Ψ FEI100% = 4.73) represents the marginal mean of Φ healthyLK_FEI100% and Φ LBPLK_FEI100% pain estimates (see Figure 2).

Second, the integration process was studied to highlight the algebraic rules observers used to combine the different

subjective values into an internal response. Cohen's criterion was used to determine if participants integrated LK and FEI. According to Cohen's d formula ($d = \text{Mean effect}/\text{SD effect}$), an effect is negligible if its d value is lower than 0.2 (i.e. if the mean effect is less than 1/5 of its associated SD). The respective effects of LK and FEI were considered relevant if the individual mean effect was greater than 1/5 of its SD. Each participant's integration process was studied through the number of variable(s) integrated and from visual inspection of the factorial graphs. Participants who integrated the two pain behaviours were classified into an 'integration pattern' category which could comprise additive (parallelism pattern), multiplying (fan pattern) and averaging (comprising equal weight averaging with a parallelism of LK \times FEI

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Figure 3. Estimated pain intensity as a function of the internal scale of facial expression intensity (FEI) and lumbopelvic kinematics (LK) for each group.



$$\text{Theoretical } \Psi_{50\%} = (\Psi_{\text{FEI}100\%} - \Psi_{\text{FEI}0\%})/2 + \Psi_{\text{FEI}0\%}$$

Table 1. Distribution of integration patterns across participants.

	Additive rule	Multiplicative rule	Averaging rule	No integration
Experienced clinicians	4	1	8	8
Novice clinicians	4	0	8	9
Non-specialist individuals	2	0	2	12

conditions together with a crossover line for the masked FEI condition, and differential weight averaging with a non-parallelism of LK \times FEI conditions together with a crossover line for the masked FEI condition) algebraic rule.

Clinicians' data have previously been published with different statistical analyses and without a control group.⁴

Results

Regarding the valuation process, Figure 3 represents each group's subjective internal scale expressed as a function of their subjective scaling $\Psi_{\text{FEI}0\%}$, $\Psi_{\text{FEI}50\%}$ and $\Psi_{\text{FEI}100\%}$. First, data suggest that, for each group, the subjective representation Ψ of $\Phi_{\text{FEI}50\%}$ lies in the middle of their internal scale (i.e. between $\Psi_{\text{FEI}0\%}$ and $\Psi_{\text{FEI}100\%}$). These results highlight that the magnitude of change in Φ_{FEI} (from FEI0% to FEI50% and from FEI50% to

FEI100%) is proportional with clinicians and non-specialist individuals' psychological scaling (Ψ). In other words, the psychological increment from FEI0% to FEI50% is similar to the psychological increment from FEI50% to FEI100%.

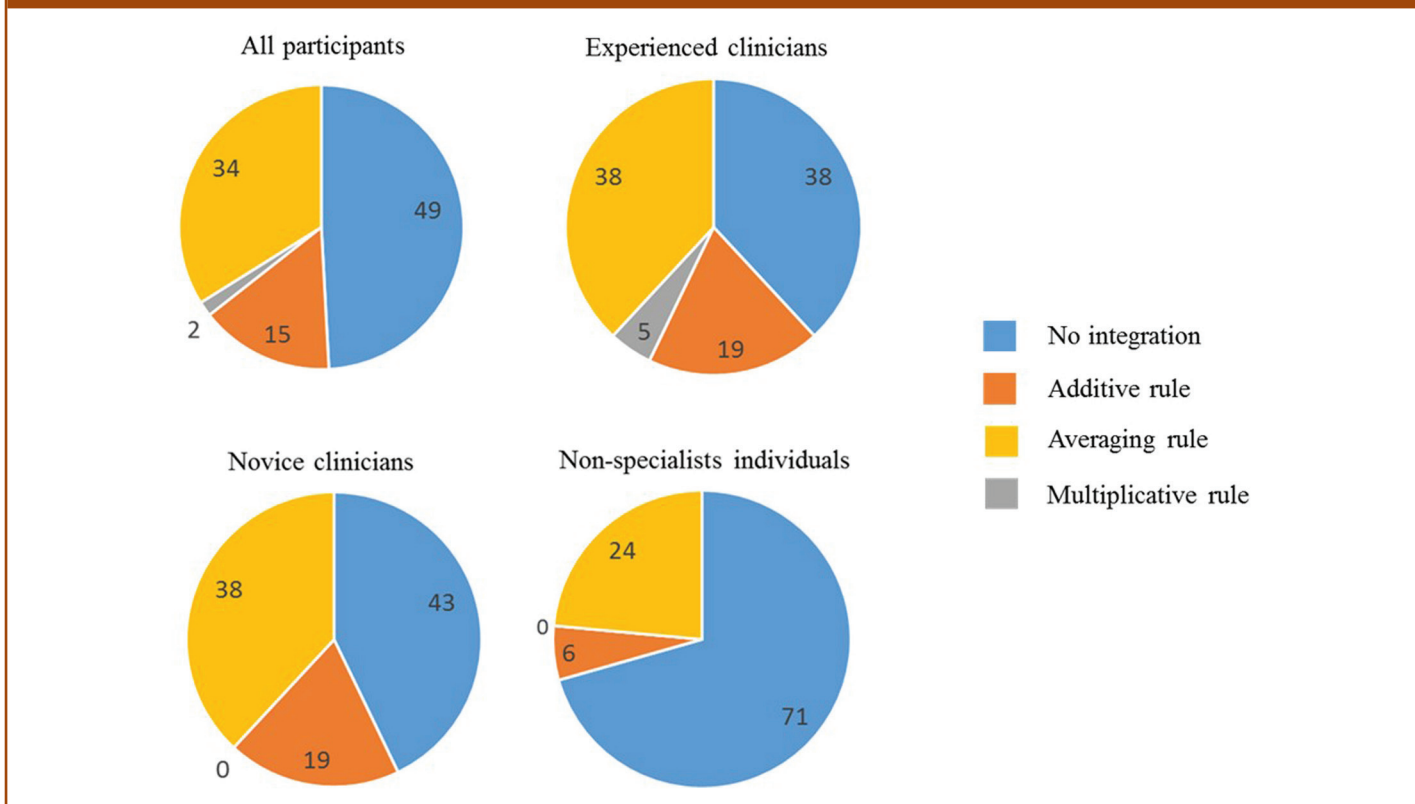
Thus, there is no under- or overestimation of one increment from another in participants' psychological representation. Second, descriptive analyses tend to show that experienced clinicians present a smaller internal scale range of FEI than novice clinicians and non-specialist individuals. Although descriptive, this result might illustrate the contribution of clinical experience in clinical judgements.

Regarding the integration process, results revealed that almost half of experienced and novice clinicians did not rely on both sources of information when estimating the patient's pain experience (cf. Table 1). This surprising

result suggests that although FEI and LK are typical pain behaviours, they are not systematically taken into account by clinicians when assessing pain intensity. Compared to clinicians overall, a larger majority of non-specialist individuals did not integrate, and thus did not combine, both sources of information (cf. Table 1). This result emphasises the contribution of clinical experience, showing that individuals facing a person experiencing cLBP are less able to rely on typical behaviours when they are unfamiliar with such musculoskeletal disorder. Among all participants who integrated both sources of information, the averaging rule prevailed on the additive one, since it was used by 34% against 15% for the additive. Precisely, averaging seems to be particularly used by clinicians, and to a lesser degree used by non-specialist individuals. For an explanation of the different patterns (see Figure 4).

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Figure 4. Proportion of algebraic rules of integration used among participants of each group.



Discussion/perspectives

This study was designed to examine how clinicians (in comparison with non-specialist individuals) value and combine information from typical pain behaviours when estimating patients' LBP-related intensity.

Results revealed that the psychological representations of FEI0%, FEI50% and FEI100% were in accordance with the magnitude of change of the physical stimuli in each group. These results contrast with a previous study emphasising that clinicians (in this case, physiotherapists) underestimated effort pain FEI in paraplegic patients.⁷ Along those lines, further studies might be conducted in order to specify and extent such diverse findings. Of particular interest, results showed that even though numerous cLBP-related behaviours may be displayed by patients, all are not

systematically used by clinicians when estimating pain intensity. In addition, analyses conducted on participants who integrated both sources of information reveal that averaging rules as a whole predominate compared to the additive and multiplying rules. These results contrast with real-time behavioural systems, which suppose that an accumulation of pain behaviour reflects greater pain, suggesting the use of an additive rule.¹⁶ In other words, information given by one particular pain behaviour does not necessarily result in an increase in perceived pain by clinicians, since it is averaged rather than summed when information arises from other behaviours. These results provide some perspective on potential implications for professional issues, including clinical training and supervision. It would be interesting to investigate why

clinicians do not systematically rely on all available pain behaviours.

Beyond these results, this study presents several limitations that should be considered. First, pain can be estimated through different behaviours that were not manipulated in this study. Besides, only selected information was given about the patient's pain history. Yet, these pieces of information are known to participate in the clinicians' judgment elaboration. Second, the avatar characteristics such as age, sex and attractiveness were not manipulated in this experiment. Yet, patients' characteristics are recognised to influence healthcare perceptions of individuals with pain.⁹ However, given that the aim of this article was to focus on how observers value and combine information from pain behaviours, it was a deliberate choice to focus on two

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typical pain behaviours instead of patients' characteristics. Finally, it can be argued that using virtual patients instead of real patients may have biased the processes involved in others' pain assessment.

Nevertheless, although different from real patients, virtual characters are recognised as reliable tools, recently used in studies investigating others' pain assessment.^{16,4} These limitations notwithstanding, this study highlights the potential usefulness of using the information integration framework when investigating how clinicians (novice and experienced), in comparison with non-specialist individuals, elaborate pain-related judgements from non-verbal pain behaviours.

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Anaesthetists' views of managing children's pain post-surgery

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Background

Pain management within acute care settings is managed by professionals who have a high workload and competing demands, and it must include monitoring the child's pain and evaluating the effectiveness of an intervention.¹

While the gold standard for pain assessment in children is always likely to be self-report,² this does not overcome issues related to the subjectivity of the assessment of pain by health professionals. Although recommended pain assessment tools (see Tables 1 and 2) have a core role to play in pain assessment, they were not developed to be used in isolation from careful clinical history taking, and Lundeborg³ rightly emphasises the need for both clinical assessment and engagement with the child and/or their parents.

Optimal management requires good knowledge of pain assessment and management and a willingness to use knowledge and implement best practice. However, Lundeborg³ notes that the knowing-doing gap is common within paediatric pain management. Anaesthetists have a particularly pivotal role to play in pain management through liaison with patients and their families/carers, nurses and other members of the peri-operative care team to ensure that pain is assessed and suitable ongoing

analgesia is administered.^{2,4} Yet, despite the key role played by anaesthetists in pain management, little is known of their knowledge, views or use of pain assessment tools. Most research work on pain assessment has focused on nurses as they are the professional group who undertake most assessments, although similar inconsistencies are identified across other professional groups.⁵ No studies were identified that explicitly examined paediatric anaesthetists' knowledge of and use of pain assessment tools. This article sets out to address this gap in the literature.

Method

The e-survey, consisting of 25 questions, was developed to examine anaesthetists' views, confidence, knowledge, training and use of pain assessment tools with children following surgery. Three typical scenarios were outlined and respondents were asked how they would respond to each (see Table 3). Email-based, snowball sampling via the research teams' contacts and through established pain networks meant that the final version of the e-survey was sent to anaesthetists working in UK children's hospitals and to all members of the European Society of Pediatric Anaesthetists (ESPA).

Ethics and consent

Due to the nature of the survey, formal ethics approval was not required. Permission was received from ESPA. All those who were sent the survey were notified of the intended use of the data for a workshop at a paediatric anaesthesiology conference and of potential future publication and that returning their completed questionnaires would be deemed that they were giving consent for their anonymised data to be used.

Results

A total of 185 respondents participated mostly working at a senior level. In total, 86% (n = 159) were consultant paediatric anaesthetists, 11 (6%) were paediatric anaesthetists working in a non-consultant career grade and 15 (8%) were working as trainee paediatric anaesthetists. In total, 80% (n = 148) had more than 5 years of experience, 28 (15%) had 1–5 years of experience and 9 (5%) had less than 1 year of experience in paediatric settings.

Formal training and support

When asked about their experience of formal training and support, all participants responded and more than half (60.5%, n = 112) stated that they had received formal training on the

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Table 1. Recommended pain assessment tools for acute procedural and post-operative pain assessment based on the child's chronological age (assuming that the child has normal cognitive development)².

Child's age	Measure
Newborn–3 years	COMFORT or Face Legs Arms Cry Consolability Scale (FLACC)
4 years old	Faces Pain Scale–Revised (FPS-R), COMFORT or FLACC
5–7 years old	FPS-R
7 years old	Visual analogue scale, Numerical Rating Scale or FPS-R

Table 2. Recommended pain assessment tools for children with cognitive impairment².

Child's age	Measure
For acute procedural/disease-related pain assessment	
1–18 years	The Paediatric Pain Profile (PPP)
3–18 years	Non-Communicating Children's Pain Checklist (NCCPC-R)
For post-operative pain	
1–18 years	PPP
3–19 years	NCCPC-PV (Non-Communicating Children's Pain Checklist – Postoperative Version)
4–19 years	Revised FLACC

assessment of children's pain. However, of those who had received training, fewer than half (n=48) had received training in the last 3 years. In all, 63 respondents identified ways in which their pain assessment skills could be enhanced and responses ranged from education (primarily formal training) through to experience (primarily, pain rounds and regular exposure to complex paediatric pain issues).

When asked who they would ask for advice if they were unsure about whether a child was in pain, 108 anaesthetists responded. Respondents could tick more than one response. The most frequent response was (n=88, 81%) 'ask a parent', followed by 81 (75%) responses stating 'ask a nurse', 63 (58%) responses selected 'ask the pain team' with only 32 (30%) responses selecting 'ask a more experienced/senior anaesthetist'.

Use of formal pain assessment tools

In total, 26 respondents (14%) reported never using pain assessment tools. However, the majority of respondents (n=155, 86%) reported using formal pain assessment tools in the management of children's pain; of these, 54% (n=83) stated they used such tools 'infrequently' while the remaining 46% (n=72) stated that they used them with 'most patients'. A total of 20 different tools were reported as being used; some respondents reported using more than one tool. The most frequently reported tools were faces scales (59%), the visual analogue scale (VAS) (40%) and the Face Legs Arms Cry Consolability Scale (FLACC) (10%).

Child pain scenarios

The responses to the scenarios reflect the differences in the respondents' use of

tools showing a general trend for tools to be most frequently used in the simpler assessment scenarios and less confidence in pain assessment in the more complex scenarios.

In Scenario 1 (see Table 3), 99 (76%) of 131 respondents reported that they had used pain assessment tools with children like Ralph. When asked specifically about their proposed assessment of Ralph's pain, 121 responses were received and of these 34 (28%) respondents stated that they would talk to Ralph and 19 (16%) stated they would talk to his mother with only six (5%) stated they would talk to his nurse. A total of 71 (59%) respondents stated they would undertake an assessment using a self-report tool (e.g. VAS, Numerical Rating Scale (NRS), a Faces scale). However, some did not think that tools were of value, for example, 'I would tend to assess cases

Table 3. The three scenarios used in survey.

Scenario 1: Ralph	Ralph, aged 10 years, presented with a perforated appendix and is now 6 hours post-operative. Despite having morphine via PCA (Patient Controlled Analgesia) he is unsettled and whimpering. He says he has pressed his pain medicine button but it is not helping. His mother is worried.
Scenario 2: Ahmet	You have been called to see Ahmet, aged 9 months, who is now 24 hours post closure of ileostomy. Ahmet is crying and is tachycardic. Despite having morphine via NCA (Nurse Controlled Analgesia), the most recent boluses do not seem to have settled him. How would you assess Ahmet to determine if he was in pain, and if so, how severe his pain is?
Scenario 3: Ruby	Ruby is aged 8 years and has complex health care needs. She is profoundly cognitively impaired and unable to communicate verbally. She is now 48 hours post orthopaedic surgery. Despite having been given your standard epidural analgesia (+/- additives), she appears distressed and she did not sleep last night. Her mother has had to go home and the ward staff think that Ruby is in pain and have asked for your opinion.

like this clinically without use of pain scores/scales'. Half of the respondents (n=61) described how they would take a pain history and/or undertake a clinical assessment taking into account the child's behavioural and physiological indicators.

A total of 85 respondents (71%, n=120 responses) reported that they had used pain assessment tools with children like Ahmet (Scenario 2). Of these, 109 responded to the question asking them how they would assess Ahmet's pain: 24% (n=26) reported that they would use clinical assessment/examination and 32% reported they would use either FLACC (25% n=27) or KUSS (7% n=8). In total, 11% (n=12) proposed to focus on crying and tachycardia and 11% (n=12) reported excluding other causes of distress in their assessment of Ahmet's pain. Some respondents reported they would gain input from parents (n=15, 14 %,) and/or nurses (n=14, 13%).

Only 61% (n=68) of 111 respondents reported that they had used pain assessment tools to assess pain in children like Ruby (Scenario 3); of these, 102 responded to the question asking them how they would assess Ruby's pain. The most frequent response was clinical assessment/examination/pain history with a focus on behavioural and

physiological indicators (22%, n=22). In all, 23 respondents (23%) reported they would use the FLACC or r-FLACC; other tools mentioned included the Non-Communicating Children's Pain Checklist (NCCPC) (n=3), the COMFORT scale (n=3) and a VAS (by proxy) (n=4). In total, 25 respondents (25%) reported that they would discuss Ruby's pain with her mother, with several stating they would telephone her mother; and 13 (13%) stated they would discuss it with a nurse.

Discussion

Anaesthetists appear to value the judgement of both parents and nurses in assessing a child's pain, as they reported that in cases of uncertainty about a child's pain, respondents most frequently stated they would 'ask the parent' (n=88) or 'ask a nurse' (n=81). Fewer responses suggested they would 'ask the pain team', possibly reflecting the fact that not every setting will have a pain team to provide advice. There were only 32 responses stating 'ask a more experienced/senior anaesthetist' possibly due to the fact that most of the respondents were senior and experienced consultants. It is worth noting that in each scenario it is likely that a nurse has called an anaesthetist to review the pharmacological pain

management of a child who has been judged to be in pain. Thus, when an anaesthetist is unsure about a child's pain, the most knowledgeable available colleague will be the nurse who has asked him to assess the child. Anaesthetists have a pivotal role in the management of a child's post-operative pain and recognising a nurse's role in assessing a child's pain exemplifies good practice as suggested by Howard et al.² and Australian and New Zealand College of Anaesthetists (ANZCA).⁴

Although the respondents had a good knowledge of pain tools and most reported using the tools, fewer than half used a pain assessment tool with 'most patients' and some respondents were dismissive of the value of pain tools preferring to rely on 'common sense' or 'clinical judgement'. This finding is similar to findings from other health professionals, including nurses, where pain knowledge, attitudes towards tools and other factors limit their consistent use in practice.⁵⁻⁸ The use and utility of pain assessment tools differed across the scenarios with a higher likelihood of respondents using an *appropriate* pain assessment tool with the verbal 10 year old (Scenario 1, 69%) than with the preverbal and nonverbal situations (Scenario 2, 32% and Scenario 3, 25%). This again would mirror findings from

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other studies which show that pain assessment tools are more likely to be utilised in older verbal children than infants⁹ and that tools are used less frequently with cognitively impaired children.¹⁰ The respondents in this study were mostly highly experienced anaesthetists working at consultant level whose 'common sense' or 'clinical judgement' would be drawing on considerable clinical expertise. All of the scenarios presented a multi-faceted situation in which it would be expected that a range of clinical skills would be drawn on; the reliance on the use of pain assessment tools (that tends to focus in a reductionist way on pain intensity) would be inappropriate.¹¹ There is a growing body of evidence that supports the use of clinical judgement in pain assessment^{12–15} as this facilitates, for example, the comparison of the child's self-report to a biologic measure such as heart rate.¹⁵ It has been suggested that the very nature of pain intensity due to its many variant influences means there is no logical way to arrive at one true pain score¹⁶ and that pain assessment is a 'clinical art'.¹⁷

Most respondents had received formal training on the assessment of children's pain and they were open to enhancing their current knowledge and skills, and there was a clear sense of wanting to 'know and do',³ particularly in relation to more complex issues. In relation to anaesthetists' education on pain management, Overton and Smith¹⁸ report on consensus work that has examined priorities for the curriculum, including preferred methods of learning, engagement and assessment that could inform knowledge development for anaesthetists. It could be suggested that multidisciplinary education would enhance both practitioners' knowledge

and their propensity to work together to manage children's pain.

Limitations

The respondents tended to be both experienced and senior and therefore not necessarily representative of more junior colleagues. The study, to a large degree, also focused on responses to scenarios rather than actual patients, and this creates a challenge for respondents to imagine how they would respond. The findings also present what the anaesthetists reported they did, or would do, rather than what they actually do in practice, so the picture painted may be somewhat ideal.

Conclusion

Most anaesthetists had received some formal training in pain assessment. However, it was apparent that this training was often opportunistic, fragmented and much training had occurred experientially. However, perhaps because much of the training had occurred experientially (in practice), the respondents expressed confidence about assessing children's pain and reported using the range of validated pain assessment tools used within their own clinical settings. Despite this confidence, when uncertain about assessing a child's pain, the majority of anaesthetists stated they would refer to nurses for their judgement, demonstrating good practice in pain management.

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Experiences and challenges of young people with a chronic pain–related condition: a summary of a British Psychological Society–funded seminar

Line Caes *Lecturer in Psychology, University of Stirling*

Abbie Jordan *Senior Lecturer in Psychology, University of Bath*



Credit: Jon Sparks ©

Pain is a common experience in young people with a chronic illness, which can pose a burden for many of these young people. Young people experience ongoing pain report poor outcomes in

terms of psychological, physical, social and peer-related functioning. While the impact of pain on normative adolescent development is assumed, little is known about the exact social challenges that these young people experience. Moreover, the limited work in this area has typically focused on use of more traditional methods of interviews and questionnaires to explore this area. To further our understanding of social challenges faced by young people experiencing chronic pain, it is crucial that the chosen research designs match both the communication mediums and styles of young people. To this end, we

organised a seminar series, kindly funded by the British Psychological Society, to discuss more creative and/or online research methods to better engage with young people in a research context.

The symposium comprised three seminar days spread across two locations:

- 3 March 2017 (University of Stirling);
- 19–20 April 2017 (University of Bath).

Below we summarise the events that took place during the first seminar day at the University of Stirling, which focused on the experiences and challenges of young people with a chronic condition.

Working with young people with diabetes: psychological interventions for better outcomes

Vivien Swanson *Reader in Health Psychology, University of Stirling*

Reviewed by: Ms Harriet Whitby-Tillott, *MSc in Health Psychology student, University of Stirling* and Dr Line Caes, *Lecturer in Psychology, University of Stirling*

For the first talk of the day, Dr Swanson introduced us to the prevalence of diabetes in Scotland thereby highlighting that management, in terms of glycemic control, can be particularly problematic in 15–25-year olds. The treatment of diabetes

involves 90% self-management, which can be quite overwhelming for young people and their families, although it is important to note that many adolescents do effectively self-manage their diabetes and maintain a high quality of life. Placing

this in the context of adolescence, Dr Swanson illustrated that self-management behaviours (e.g. self-monitoring blood glucose, injecting insulin, adhering to a strict diet) do not fit with the typical activities of an adolescent who is trying to

Experiences and challenges of young people with a chronic pain-related condition

establish an autonomous identity. Dr Swanson explained that puberty is characterised by risk-taking and freedom, with acceptance by peers viewed as the main driver of behaviour. These typical pubertal characteristics contrast starkly with the self-management behaviours that adolescents with diabetes are required to adhere to. For example, an increased attention on body image in this period has led to young women using their insulin to control their weight. Dr Swanson highlighted the 'burden' of diabetes by alluding to the fact that diabetes needs continuous attention, there is no 'holiday' from diabetes and unfortunately a good self-care regime does not always pay off.

Interestingly, Dr Swanson illustrated some innovative ways to better match the required self-management behaviours with adolescent lifestyles, which, believe it or not, included feeding pet fish. Combining blood sugar testing with the time you need to feed your pet fish, seemed to slightly increase adherence in younger adolescents (Maranda et al., 2015). Dr Swanson also emphasised the key role of 'good' communication with families, peers and health professionals for better glycaemic control, with a focus on collaborative partnership building. Examples of this are The NHS 'House of Care' model being trialed in Scotland, Motivation, Action, Prompts (MAP) Training for health professionals working in Diabetes Care and

Video interactive guidance (VIG) training which allows health care professionals to record and re-watch clinical consultations together with young people, to highlight examples of positive interactions. A small pilot study revealed that this technique resulted in adolescents feeling more able to openly talk to health care professions about diabetes (Webster, Greene & Greene, 2015).

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Clinical challenges of assessing and treating young people with ongoing pain-related conditions: a multidisciplinary approach

Ewan Wallace *Consultant in Pain, Royal Hospital for Children Glasgow*

Janie Donnan *Consultant Clinical Psychologist, Royal Hospital for Children, Glasgow*

Reviewed by: Dr Line Caes, *Lecturer in Psychology, University of Stirling*

In this clinically focused session, Dr Wallace and Dr Donnan provided an overview of the Pain Service at the Royal Hospital for Children in Glasgow, the largest pain service in Scotland. Dr Wallace began the session by providing some background information about the number of new and return patients seen each year and the expanding multidisciplinary background of the pain team staff. Dr Wallace discussed the changing perceptions of the pain service, noting the importance of emphasising that the pain service does not have a magic wand to alleviate pain. In the latter part of this talk, Dr Wallace used a case study of a typical 14-year

old female to explore how a multidisciplinary approach to treating pain can understand and work to address the needs and functioning of a young person with pain and their family.

Following on from Dr Wallace's talk, Dr Donnan introduced the aims of psychological intervention, assessment and formulation. Throughout her talk, Dr Donnan explored some of the key treatment approaches to treating paediatric chronic pain: psychoeducation, pacing, cognitive behavioural therapy and acceptance and commitment therapy. In particular, Dr Donnan took time to explore the 'Boom and Bust' idea, noting that this was often

observed in their adolescent patients, with young people needing to learn a pacing strategy to enable them to undertake a graded return to previous functioning. Dr Donnan explained that a key challenge when working with young people with pain is that they sometimes cannot see the point in doing something if they can't do it perfectly, thereby preventing graded return to activity. To complete the session, Dr Donnan raised some important questions about the use of the term 'medically unexplained symptoms' and the importance of focusing on functioning rather than questioning the source of the pain or its origins.

Interventions for young people with pain-related health conditions

Christina Liossi *Professor of Paediatric Psychology, University of Southampton*

Reviewed by: Ms Harriet Whitby-Tillott, MSc in Health Psychology student, University of Stirling

Beginning this session, Professor Liossi explored how we understand pain. Discussion focused on a recent definition that recognises pain as more than just a biological phenomenon, but instead as a complex interaction of biological, psychological and social factors (Williams and Craig, 2016). The main focus of Professor Liossi's talk concerned exploring the quality of evidence concerning psychological interventions for children with acute or chronic pain.

To provide some context for the session, Professor Liossi explained the importance of taking a biopsychosocial approach to understanding and treating pain in children. Starting with acute

pain, Professor Liossi focused on exploring evidence of the effectiveness of current pain management techniques for children. These included evidence for common forms of distraction that can be employed by parents in the presence of painful procedures such as counting, singing and playing games. Extending this focus on distraction, Professor Liossi discussed the role of imagery and hypnosis with regard to enabling the child to use their imagination to change the focus of their attention away from the painful procedure. To illustrate this, the audience were shown a clip of Professor Leora Kuttner using the Magic Glove as a hypnotic technique

for children undergoing a range of painful procedures.

Moving the discussion forward, Professor Liossi began to consider the evidence in support of psychological interventions for paediatric chronic pain. As explained in the talk, psychological interventions such as cognitive behavioural therapy (CBT) and relaxation can be effective in reducing pain, disability and depressive symptoms for children with chronic pain. To conclude, Professor Liossi reminded the audience of two things, that as pain is not solely a physical or psychological phenomenon, a unimodal approach to treating pain will not succeed and of the importance of meeting the treatment needs of the individual.

Creative, mobile techniques to collect data

Ross Tuffee *Co-Founder and CEO of DOGF.ISH*

Reviewed by: Dr Line Caes, Lecturer in Psychology, University of Stirling

Just before lunch we took a rather different direction, by having Ross Tuffee, co-founder and chief executive officer (CEO) of DOGF.ISH, illustrate their approach to integrating mobile techniques with data collection. Using examples in his talk, Ross highlighted the need for researchers and companies to work closely together as a team from the start to create a mobile application (i.e. app) that is both scientifically valid as well as user-friendly. DOGF.ISH can already aid in the fundraising or grant application

process by rapid design and production a prototype of an app. Their currently most successful example is the Change4Life Sugar Smart app which allows you to scan a large variety of products to see how much sugar and fat they contain. The collected data are saved in an accessible database, which can be used for research projects and further fine-tuning of the app. For example, early on substantially more engagement with the app compared to the associated website was noted.

Ross also shared insight regarding what facilitates users' engagement. For instance, the simple swipe up integrated in Facebook's newsfeed in combination with a variable reward (e.g. mostly reading boring stories but every now and then seeing a funny picture) is what keeps you engaged in the newsfeed. The presentation illustrated the rapidly expanding involvement of technology, with the possibility of now even capturing people's real-life reactions to specific aspects of the app through the

integrated camera on smartphones. Ross concluded the talk with an example of how they consult with users early on in the design process to ensure

the app fits the needs of the intended users. For example, adolescents revealed that an app could facilitate communication during consultations by

allowing them to log notes of events that took place in-between appointments which could be reviewed during the appointment.

Creativity or chaos? Researching with children, young people and their families using stories and art-based methods

Bernie Carter *Professor of Children's Nursing, Edge Hill University*

Reviewed by: Dr Abbie Jordan, *Senior Lecturer in Psychology, University of Bath*

The final session ended with a creative highlight, a participatory session hosted by Professor Carter, focusing on the use of arts-based methods in paediatric research. The session began with a discussion of the importance of using arts-based approaches throughout the research process, from initial patient and public involvement to dissemination. Subsequently, the benefits of using arts-based approaches with children were outlined (e.g. reduced dependence on language and literacy). Next, Professor Carter introduced the 'camp-fire effect' (Rollin, 2005); the idea of art empowering children to narrate their stories by transferring the focus from the child towards the art. This has

implications for conducting healthcare research with children that focuses on difficult issues.

Within the main body of the session, Professor Carter discussed examples of particular arts-based methods such as drawings, stories, photo-elicitation and poems. Providing clear examples of use of these methods from her own body of research, Professor Carter really helped to bring the material alive for delegates.

Finally, Professor Carter asked the audience to unveil their creativity through two participatory activities. First, delegates were asked to use a postcard to draw and describe their worst headache. Despite initial hesitancy about artistic ability, delegates engaged well

with this task. Building on enthusiasm, Professor Carter next asked delegates to 'create' their worst pain ever using large body maps and a variety of materials including felt, wool and pipe cleaners. The art produced was impressive, highlighting the accessibility and appeal of using arts-based methods. To conclude, Professor Carter outlined some of the limitations of using arts-based approaches with children, cautioning us to move beyond eliciting art from children that is 'pretty but useless'. In summary, this was a hugely enjoyable and thought-provoking session for delegates that will no doubt sparked ideas for using arts-based methods with children in future research.

Looking ahead to the upcoming seminars at the University of Bath

In summary, this first seminar set the stage for the next two seminars by providing an in-depth exploration of social challenges faced by young people with a chronic condition as well as getting people to think more creatively

about conducting health-related research with young people.

While not all talks were pain focused, they all informed more creative techniques for future investigations of the social context of young people who

experience pain. If you are intrigued by these summaries and to read even more about the seminar in Stirling, visit Storify in the following link:

<https://storify.com/LineCaes/bps-stirling-seminar.html>

Twitter Chats as an educational tool for pain

Amelia Swift *Senior Lecturer, School of Nursing, University of Birmingham*

Kate Thompson *Senior Physiotherapy Lecturer, Leeds Beckett University*

Alison Twycross *Deputy Dean and Lead Nurse/Professor of Children's Nursing, London South Bank University*

On behalf of the British Pain Society's Pain Education SIG



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Twitter Chats bring together groups of invested and influential people and organisations to debate important topics, raise awareness and network. Twitter® began in 2006, the brainchild of Jack Dorsey who developed it as a way that groups could keep up to date with what participants were doing. It grew relatively rapidly as a means for tech conference participants to share their thoughts. Tweets were shared to users and non-users alike via the now familiar streams published on screens around conference venues.

Developments to the system were driven by users, that is, the ability to acknowledge another user in your tweet using their Twitter name (e.g. @nurseswift) and the ability to index tweets using hashtags (e.g. #ebnjc). By 2008, healthcare professionals (HCPs) were publishing papers about the potential of Twitter to be used as an educational tool: the first paper indexed on Medline was Skiba.¹ Since then, Twitter has grown in popularity with educators and HCPs with all major health organisations now using twitter as an outlet to share, promote and disseminate information. This makes it a current and effective educational tool.

Twitter's effectiveness is in bringing more people to the platform and facilitating people to connect with, debate and follow others who are influential with substantial numbers of followers. Similarly, people follow organisations such as the British Pain

Society (@BritishPainSoc) and the International Association for the Study of Pain (@IASPPAIN and @PainResForum), journals (e.g. @PAINthejournal) and charities (e.g. @PainConcern) to keep informed of updates and as a means of communication.

Twitter is often used to build networks.^{2–4} It can enhance confidence and self-efficacy when used in this way by students, early career researchers and clinicians.⁵ It offers a way to become part of a network that you might otherwise feel is inaccessible to you. Going up to an eminent researcher at a conference is too scary to do cold, but Twitter offers a way to introduce yourself and your ideas that you can later follow up on in person (we often have people come up to us at conferences who we have met on Twitter).

Developing a network, finding people and organisations with similar interests, allows real-time dissemination and debate. The limitation is your reach – it pays, therefore, to have people of influence in your circle, that is, those with large numbers of followers. A retweet by an influential person with a large number of followers will gain your initial tweet more attention.

Most commonly, educators use Twitter to publish content or links to resources.⁶ This can be popular⁷ and is proving a very effective way of increasing the reach and impact of research.^{8,9} While educators are reportedly using Twitter as

an effective tool in this way, it is not thought to be a particularly popular platform for health students in Europe.^{10,11} In most cases where Twitter is introduced as part of an educational offering, it has been necessary to encourage and support the students to use it.¹² Given the potential benefits of students using Twitter (e.g. communicating with the wider health community, keeping up to date with health research and policy and engaging with experts), it would be advantageous to make their first experience straightforward and useful so they are encouraged to use this as an educational tool.

Most of us are familiar with conference tweeting, but there are limitations and tweeters can misquote or fail to capture the key message the presenter or organisation wants communicated: one way around this is to encourage the presenters to tweet themselves.¹³ This introduces quality control over the product and introduces an expert into the heart of any discussion. The Twitter Chat has a similar principle – while encouraging participation and open discussion between all interested parties, it can also be moderated by one or more of the participants who act as hosts. The hosts also pose questions, bring in new tweeters to participate, market the chat and often collate the resultant discussion into a format that can be easily digested by the participants and a wider audience

Box 1. A case study.

Professor Alison Twycross (@alitwy) is the editor of Evidence Based Nursing. She has been using Twitter Chats for several years and was one of the first journal editors to do so. These chats have many repeat participants: the marketing strategy enables a broad reach. The pain-related chats have led to ongoing work and collaboration as well as growth in the personal networks of the participants. The first Pain Education SIG chat took place in the evening following the Annual Scientific Meeting (ASM) in Birmingham, which enabled it to be advertised to delegates during the day at the conference.

Brand24 analytics show that the Evidence Based Nursing Journal Twitter Chats have a potential reach of 64,596 accounts, generated 473 interactions (interactions are when a user clicks on, expands, reposts, likes, follows from it, link it and so on), were shared 189 times and attracted 284 likes. We can also see the most influential participants, which is based on several metrics. This is very healthy for a relatively young chat, and further analysis will enable us to build the following.

An example of two Twitter Chats the Pain Education SIG has hosted in conjunction with Evidence Based Nursing can be seen at:

Do we need to rethink how we educate healthcare professionals about pain management? (May 2017).

<https://storify.com/alitwy/do-we-need-to-rethinkhow-we-educate-healthcare-pro#publicize>

Why is it so difficult to transfer knowledge taught in the University to the clinical practice setting? (September 2017).

<https://storify.com/MeliSwift/why-is-it-so-difficult-to-transfer-knowledge-taugh>

(e.g. using Storify®). Advertising to the target audience and seeding your chat with people that others will want to engage with, who will bring other tweeters with them, is vital for success.

The success of a Twitter Chat can be measured in many ways

- The number of participants (but there will be many more who are observing).
- The Twitter influence of participants.
- The number of retweets and subsequent reach.
- Increase in the number of followers.
- Qualitative analysis of the collated tweets (use Storify®).

These analytics can be gathered via Twitter, or using a more specialised and sophisticated analytic tool such as Brand24®. These metrics provide relatively superficial information and do not tell us anything about change in behaviour or practice that result from the chat. That is the next challenge, because improving practice is one of the key objectives of the exercise.

Tips for successful Twitter Chats

- Pick a theme that will attract people and lead to purposeful debate.
- Choose a unique, short and memorable hashtag (e.g. the Evidence Based Nursing Journal chat is #ebnjc). The hashtag will be included in every tweet and you only have 140 to start with. Avoid double letters and underscore symbols – they take a long time to type and can be easily mistyped.
- Provide some background for the chat by publishing a blog beforehand, linking to a contemporary issue or linking it to a recently published paper.
- Prepare some questions – as the moderator, it is your job to stimulate discussion. Chats can sometimes flag, and it is good to have a prepared question to get the conversation going again.
- Get out of the way of the smart people – this comes from Mack Collier's top tips – he reminds us that the moderator is the facilitator, not the loudest voice. People will not come back to your chat if you dominate and do not listen.
- Provide easily accessible instructions to help the novice join in. We often recommend TweetChat which allows you to follow the hashtag and contribute without all the other noise of Twitter to distract you. You could also look at BeatStrap, Chat Salad, Twubs, Nurph or TwChat.
- Choose a good time of day. Trying to include shift working health professionals and crossing time zones makes this tricky.
- Get feedback from the participants – learn how you can improve your chats and act on that advice. Try to build a loyal following.
- Welcome new people as they arrive – it can be intimidating to join a group who look like they all know each other because the conversation is flowing.
- Thank the participants by direct message and try to co-opt them to co-host roles.
- Collate and disseminate the key messages. We often use Storify® for this, which allows you to search for a

Box 2. An introduction to Twitter and Twitter Chats.

Twitter – it's a sort of Marmite thing, but love it or loathe it, it's going to be around for some time yet. A tweet is a 140-character written communication that is launched by the account holder into the ether. Account holders who follow the author receive the tweets, read them (sometimes), reply or retweet. The authors are individuals or organisations who use Twitter to converse or influence creating large networks. Tweets can be sent and received using a smart phone, tablet or PC.

The ability to reply to tweets and to see a conversation develop is one of the strengths of this social media behemoth. Conversations occur spontaneously, but can also be timetabled – these formal conversations are called Twitter Chats. A Twitter Chat is advertised ahead of time and marketed to people and organisations that will be interested in the topic area. Tweeting and retweeting encourages a wide reach to maximise the number of diversity of participants. Usually, a Twitter Chat is preceded by a Blog post or publication of some kind that introduced the topic area and questions that might be raised. At the prescribed time, the moderator introduces the chat, welcomes the tweeters and poses a question to stimulate discussion. Everyone uses a predefined hashtag (#hashtag), which indexes the relevant tweets and allows participants to collate the whole conversation using twitter or a specialist programme like TweetChat.

hashtag and drag and drop tweets into a smart looking Wiki page. You can also add other content (e.g. your text, YouTube videos, items from Facebook, gifs, images and more).

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New Members



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Name	Current Post	Hospital
Mr James Anderson	Pain Psychologist	Aberdeen Royal
Ms Pamela Andrews	PhD Student	Glasgow Caledonian University
Dr Sarah Aturia	Consultant	Milton Keynes University Hospital
Mr Nathan Augeard	Physiotherapy Student	Glasgow Caledonian University
Dr Rav Bhandal	Clinical Psychologist	Royal Hampshire County Hospital
Dr Sarah Blackshaw	Specialist Clinical Psychologist in Pain Management	Manchester and Salford Pain Centre
Dr Katy Bourne	Clinical Psychologist	Withington Community Hospital
Dr Lindsay Brassington	Clinical Psychologist	Astley Ainslie Hospital
Dr Shona Brown	Clinical Psychologist	Astley Ainslie Hospital
Mrs Catherine Buckley	Clinical Lead Physiotherapist	Royal National Orthopaedic Hospital
Mrs Catherine Burns	Specialist Physiotherapist	South Manchester Pain Centre
Dr Katherine Carraretto	Locum Clinical Psychologist	Frimley Park Hospital
Ms Máire-Bríd Casey	PhD Student	University College Dublin
Miss Laura Cassar	Psychology Student	Swansea University
Dr Elaine Cockerham	Consultant Clinical Psychologist	Isle of Wight NHS Trust
Mr Andrew Colwill	Clinical Specialist Physiotherapist	Bronllys Hospital
Mrs Dawn Day	Senior Physiotherapist	GP Federation
Dr Anna Graham	Clinical Psychologist	Glasgow Pain Management Programme
Dr Michelle Hall	Lecturer	University of Nottingham
Dr Katie Hatton	Clinical Psychologist	Blackpool Teaching Hospitals Pain Management Service
Mrs Kay Hildersley	Clinical Lead Physiotherapist	Astley Ainslie Hospital
Dr Rachel Irwin	ST5 Anaesthesia Pain Fellow	Belfast City Hospital
Mrs Isabella Jobson	Member of the Centre for Health Service Studies	University of Kent
Miss Shruti Kaushal	Psychological Wellbeing Practitioner	Walsall Talking Therapies
Dr Oonagh Koppel	Clinical Psychologist	Southmead Hospital
Mrs Ruth Lewis	Specialist Physiotherapist	Astley Ainslie Hospital

Name	Current Post	Hospital
Mrs Paulene Madoc-Jones	Specialist Nurse	NHS Tayside
Miss Lucy Manico	Physiotherapist, MSK and Pain Management	Astley Ainslie Hospital
Miss Pooja Modhawadia	Psychology Placement Student	Gloucestershire Royal Hospital
Mrs Jeanette Moxham-Mead	Clinical Specialist Physiotherapist	North Bristol NHS Trust
Mrs Pippa Neal	Advanced Occupational Therapist	Sheffield Children's hospital
Ms Sarah O'Carroll	Occupational Therapist Pain Management	Tallaght Hospital
Mr Olakunle Odunayo	MSK Physiotherapist	Spencer Private Hospitals
Dr John O'Sullivan	Specialist Clinical Psychologist	Sutton Hospital
Dr Sarah Parsons	Salaried GP	Norwich Road Surgery
Mrs Jody Phillips	Specialist Physiotherapist	Astley Ainslie Hospital
Mrs Tracy Robertson	Pain Management Physiotherapist	New Victoria Hospital
Dr Tauheedur Shaikh	Consultant Anaesthetics / Pain	Bucks NHS Trust
Mrs Lynne Sheridan	Advanced Physiotherapy Practitioner	Ninewells Hospital
Mr Sami Stagnell	Specialist Oral Surgeon	Royal South Hants Hospital
Dr Jonathan Todman	Clinical Psychologist	NHS Tayside
Dr William Vogt	Clinical Psychologist in Pain Management	Kings Mill Hospital
Dr Lauren White	Clinical Psychologist	South Camden Centre for Health (part of Royal Free Hospital NHS Foundation Trust).
Mrs Sarah White	Advanced Practitioner - Physiotherapist	Nottingham University Hospital NHS Trust
Mrs Janet White	Senior Occupational Therapist	York Hospital
Mrs Susan Willison	Specialist Physiotherapist in Pain Management	Epsom & St Helier NHS Trust
Dr Katherine Wright	Principal Clinical Psychologist	St Luke's Hospital
Dr Sarah Young	Clinical Psychologist	Astley Ainslie Hospital

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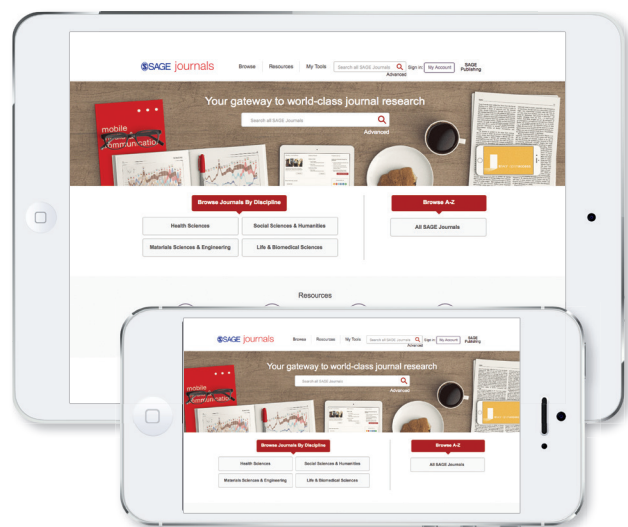
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