



THE BRITISH PAIN SOCIETY

Special Interest Group for Philosophy and Ethics

Changing the culture of pain medicine

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Editor's note

Preparation of this transcript has involved some paraphrase and rearrangement of material to enhance readability. The editor apologises for any misrepresentation this may have occasioned. In representing discussion, the words of the speaker are in normal type and contributions 'from the floor' in italics.

Cover photo: Launde Abbey Courtesy of Ian Clarke

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Introduction

Peter Wemyss-Gorman

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

Margaret Mead

“It is better to light a candle than curse the darkness”

Ancient Chinese proverb

At the 2012 meeting on Care Ethics, we acknowledged the reality that identification of the shortcomings of contemporary pain medicine was of little use if they continue to be regarded as inevitable. So we decided that the task of this year’s meeting would be not only to define a new culture of pain medicine but also to determine the best means of ‘evangelising’ the message of the need for change, not only to our colleagues in the speciality but to the medical and health professions as a whole.

The realisation that we had set ourselves a formidable if not insurmountable task was if anything reinforced by our keynote speaker, John Loeser. His name was among those my generation of pain clinicians would have pronounced with hushed awe and he still stands among the giants of the pioneers of our profession. As one of the founders of the IASP and its president from 1993 to 1996, he is uniquely placed to command an overview of pain management throughout the world, and to have observed the trends and changes that have emerged during his long professional lifetime. The picture he painted of pain management in the USA now totally dominated by the business model and the power of insurance companies to dictate treatment, resulting in the virtual disappearance of multidisciplinary pain management, was dismaying. We can only hope that the increasing dominance of a profit-driven business model over the NHS will not drive us down the same road.

But the success of the IASP under the leadership of Michael Bond in promoting pain education, and the establishment of new IASP chapters championed by John Loeser, around the developing world, was much more encouraging. And we were inspired by Clare Roques’ account of the relatively small but nevertheless vital contribution of the BPS Developing Countries SIG.

Education is indeed a vital part of the process of changing the culture and Professor of Medical Education Ed Peile presented a reassuring account of progress in undergraduate teaching guided by values. But pressures to abandon these after graduation, and to attend to other priorities than the management of pain, are still difficult to resist.

We must use all the means at our disposal to ‘spread the word’ and included among these is the social media, hitherto somewhat neglected, at least by my generation. Trish Groves of the BMJ was an enthusiastic advocate of Twitter.

We hope we at least ‘lit a candle in the darkness’ at this meeting. Although it continues to flicker somewhat feebly we should be comforted (in the original sense) by the words of Margaret Mead quoted above in our determination both collectively and individually to bring about the changes we know are so necessary.

Can we change the culture of pain management?

John Loeser

“The control of medical practice by market economics does not serve the healthcare needs of patients optimally and is not compatible with an ethically based profession of medicine.”

My remarks are based predominantly on what I know, which is the United States, and the USA and the UK have very different health care systems. So many of the issues that I will address may be more prominent and problematic in my country than in yours. But my travels have told me that the same issues come up in every country I have been in; it's just the relative proportion of which issue is the big one that changes.

Culture

The standard definition in the Oxford English Dictionary is 'The distinctive ideas, customs, social behaviour, products, or way of life of a particular nation, society, people, or period,' and I will address what I see as the culture of pain management that surrounds me.

The first problem we have to address is the question: is there a culture? Or are there several cultures? Or – more likely – is it just chaos with no culture behind it where everybody has their own viewpoint about how things should be done. An example of that is the list of the pain societies in the USA [numbering at least ten]. Every one of these organisations promulgates guidelines, has meetings in which their various products are presented; often threatens litigation against people who say or do things that aren't in their particular best interests. Many of these organisations have state- or region-based chapters so you end up with multiple sub-groups. If you simply ask a pain specialist what organisation he belongs to you can tell exactly what they do for a living. For example, there is the International Spinal Injection Society which has a national chapter and you know very well what they do, without knowing what their training or background might be. I'm sure in the UK you have something similar. I am aware of the revolution you had in the Pain Society because of the President's agreement to standards of care that did not meet the desires of many of its members, when Michael Bond was drafted in to solve the problem. If you look at a set of guidelines – and we are saddled with guidelines in our country – you can immediately tell who wrote them, because they reflect what people do for a living. Far too many patients get what the provider does irrespective of what the patient needs. There are pain clinics in the USA where 100 per cent of the patients get an injection without a history taken or a physical examination. There are people getting surgical procedures who have never had an appropriate evaluation. Part of the chaos and lack of a common culture in our country is that there is no standard of what should be done before surgery or treatment is implemented. And we have guideline wars with different organisations promulgating directly opposite guidelines and each provider (mainly private insurers) deciding what they are going to pay for – one may pay for three injections and another for one or none.

Why the chaos?

The first problem is that many people have wrong conceptual models. There are many physicians who are fixated on a biomedical model of disease and just cannot

conceive of the issue that something outside of a patient's back may be responsible for their pain behaviour. In our society where the vast majority of physicians are funded through their practice or an institution in which they practice which needs revenue. I work in a big university hospital. The management wants to keep the beds full and the operating rooms running 20 hours a day, and the MRI scanner busy 24 hours a day, so there is all sorts of emphasis that comes down to the providers that utilise our services and the physicians who are pushed into doing the work.

We lack outcomes data. You are lucky if you can find data for one month and what does one month mean for a chronic pain patient? You are really lucky to find three month's data, and a year's follow-up, which I would argue is reasonable for a chronic pain patient, is ridiculously rare. Without outcome data you don't have feedback on what your intervention did for this patient so you keep doing the wrong thing over and over again.

There is unequal remuneration by providers. We have a ridiculous system in our country in which I as a surgeon can generate more revenue in one hour in the operating room than I can in eight hours in the pain clinic seeing patients with chronic pain. It's much easier doing an operation, partly because I can completely control the environment in the OR, but you can't do this with pain patients. We therefore have a surplus of people who do procedures and a dramatic shortage of primary care physicians who should be the first step in any pain patient's evaluation and treatment.

Then there are patient expectations. We were talking at breakfast about people going to Germany for laser treatment. I can't tell you how many patients who have said to me "I came here because I hear you do laser treatments"; I say "for what?" and they reply, "I don't care what it's for – I just want the laser treatment"!

In our country, physicians are pushed into seeing more patients per day and more per hour so they don't have time to listen, so they fail to pick up on the patient narrative and the meaning of life for the patient and things like that which are critical to outcomes.

We have failed to deal adequately with questions even as basic as how should pain best be diagnosed and treated and who should manage pain patients?

A major issue is the proper role of opioids in pain management. We have a new epidemic in the US of inappropriate opioid use and diversion. The latest data show that there are more deaths from prescription opioids than from heroin, and more than are killed on our highways every year. About a third to a half of the deaths are in the person for whom the prescription was written, and a similar proportion in a person for whom it was *not* written. Commonly a teenager will find his mother's pills in the medicine cabinet and take them to a party where he and his friends mix a bunch of pills together, and some of them die. The role of opioids in chronic pain has become a big issue because most of these incidents occur where the drugs have been prescribed for chronic pain.

Is pain always a medical problem?

That depends on how you use the word pain. People use it to mean many different things including suffering. Suffering is certainly not always a medical problem, and for many of our patients pain is not really a medical problem and doesn't require some sort of medical intervention, although it may demand some kind of social intervention.

You should all remember that pain was thought of only as a by-product of disease until John Bonica. If you look at medical textbooks prior to 1950 you will never find one that has a chapter or a section on pain. Bonica was in medical school during World War Two and was drafted into the Army and based near Seattle. In 1947 he went into private anesthesiology practice in Tacoma for about 15 years. In 1953 he wrote a book entitled *The Management of Pain*, of some 1500 pages, of which he was the sole author apart from a few chapters written by some friends. This was the first literature in the English or any other language on pain that I can find. From his position as Professor and Chairman of at the University of Washington, to which he was appointed in 1960, and as Secretary-General of the International Anesthesiology Association, he really pushed the development of chronic pain as a medical problem. As we know there are a variety of political, religious and economic issues that influence pain and its management. But just as the Melzack Wall hypothesis revolutionised thinking about the basis for pain and strategies for its management, Bonica's push to establish pain as a subject matter was revolutionary.

The need for pain

Why do people have pain? Why have we evolved as a species with the ability to perceive pain? There have been teleological explanations: it's good, it protects us from things. There have been social and moral explanations, some of which I find very interesting. If you look at the history of thinking about pain, the word comes from the Latin *poena* meaning punishment: if you did something wrong and offended the gods you would be punished by it. In the Dark Ages the prevalent thought was that sin led to pain and suffering. In general the philosophical viewpoint of human beings was that people were born evil and somehow needed pain and suffering to make them worthy. So there was a value placed upon undergoing pain. There were many tales of people who deliberately endured pain and suffering to somehow make themselves better as human beings. The Renaissance changed things and people were generally thought of as born good and not in need of pain and suffering to become healthy adults. There was an attempt to abolish pain and suffering in the nineteenth century through the development of social organisations and welfare programmes. But in the modern era of the twentieth and twenty-first centuries we have the issue of biomedicine promising the abolition of pain – a drug that will guarantee you pain relief. We have extensive welfare programmes – at least until Margaret Thatcher came along. Medicine – perhaps more in the US than the UK – has essentially ignored human suffering. We have seen progressive limitation of the social resources to deal with human distress and suffering. So at the present time we have some tension in our societies about the uses and needs of pain and suffering between those who believe that they are needed to control behaviour versus those who believe that they should be eliminated for all, and the huge care costs associated with that, although we know that that doesn't do a good job in this respect.

Modern society is not monolithic. There are many people who still utilise ancient, medieval, or renaissance concepts and values. Unfortunately, providers and payers of healthcare are not immune to these archaic ways of thinking so there are problems with what you can get funded for providing care for pain patients.

Why does pain exist?

The first is the obvious teleological consideration that it allows the organism to avoid tissue damage, and a damage avoidance system consisting of unmyelinated axons and damage sensitive receptors exists in every animal from the sponges up.

Everybody knows the highly mechanistic Descartes model of the body and the fire whereby energy travels up the veins, arteries and nerves to the pineal in the brain – the seat of the soul – where humours were put into the ventricles which flowed back down to the muscles and the body removed his foot. That was a pretty good model for its time. Then there was the Melzack and Wall gate hypothesis in 1965 which totally revolutionised the way physicians thought about pain, and was the seminal act in leading to the development of a pain world.

Pain can be said to permit learning about dangerous things and how to avoid dangers. It may exist to trigger protective and adaptive reflexes but a fascinating story about this is that of angina. Angina, which is probably a sign of ischaemia in the myocardium was totally relieved by bilateral thoracic sympathectomies, which was the most common neurosurgical operation done in the first half of the twentieth century. If you look at the literature of the time you see the medical types arguing: if you do that and the person doesn't feel the angina they won't know that they had better stop exercising and they'll kill themselves. But the physicians said that there was oodles of evidence already that the fact that you no longer perceived ischaemia in your heart did not change your outcome one iota. In the modern era, spinal cord stimulation in the thoracic region for a patient with angina is an excellent method of controlling it and guess what: you have the exactly the same stuff in the literature as 75 years ago, that without the perception of ischaemia you are going to die. Not a shred of evidence to support that – people with and without stimulators die at exactly the same rate.

Does suffering have social uses? Perhaps by manifesting it you enlist the help of others. It is also suggested that unless you feel pain yourself you will not have the ability to empathise with someone else in pain, and empathy is part of the glue of society – that's an interesting viewpoint. There are some who believe that somehow it is good for people to suffer and this makes us better human beings. It has been called God's megaphone. Philosophies of bringing up children have been based on the idea that a little bit of suffering goes a long way in getting them to behave themselves. Can suffering be used to allow social controls and teach moral behaviour?

C.S. Lewis, best known as the author of the chronicles of Narnia, in his fascinating book, *The Problem of Pain* wrote in the preface that "all arguments in justification of suffering provoke bitter resentment against the author". He got into a lot of debate because he actually said that the reason why human beings have pain and suffering is that without it they would forget their God.

Although suffering has many causes other than pain including, fear, anxiety, isolation, depression, hunger, fatigue and loss of loved objects, we continue to use the language of pain for all kinds of suffering. Language is important: when people use the language of pain when they speak of suffering it tells you how they perceive the world around them.

Suffering is not presented uniquely to healthcare providers. Taxi drivers will tell you they hear a lot of suffering from their passengers, as do attorneys, bureaucrats, social workers, and of course spouses.

Physicians tend to ignore suffering, perhaps because of the biomedical model, and perhaps because they don't want to ask. They may deny the importance of narratives because they don't have time to listen. Can I remind you that there are loose linkages between tissue damage, pain, suffering, pain behaviour and the patient's narrative – what he says and does? And these loose linkages need to be investigated.

Capitalism and Care

We have to face the reality of capitalism: that money motivates behaviour. How and what physicians are paid strongly influences what services they provide. Money always trumps ethics. In our country the insurance industry will not pay for multidisciplinary pain management, even though EBM (evidence-based medicine) studies clearly show it to be the most cost-effective treatment available. We know that the quality of care declines the more business pervades medicine. It is not just the spectacularly bad actors who make the headlines whom I am concerned about; it is the every day practice of medicine that has been subverted by the business model. The control of medical practice by market economics does not serve the healthcare needs of patients optimally and is not compatible with an ethically-based profession of medicine.

George Bernard Shaw saw this clearly:

“That any sane nation, having observed that you could provide for the supply of bread by giving bakers a pecuniary interest in baking for you should go on to give a surgeon a pecuniary interest in cutting off your leg, is enough to make one despair for political humanity.”

Preface, *The Doctor's Dilemma: A tragedy*.

This was written 120 years ago.

My belief is that the focus of the provider must be on the care of the patient. Conflicts of interest are worldwide and exist in every healthcare system today. ‘Patients’ have become ‘consumers.’ ‘Doctors’ have become ‘providers.’ ‘Clinical judgment’ has been replaced by ‘evidence-based practice.’ The traditional focus on humanism and caring has been threatened by the business aspects. Voltaire knew that:

“Doctors pour drugs, of which they know little, for diseases of which they know less, into patients—of which they know nothing.”

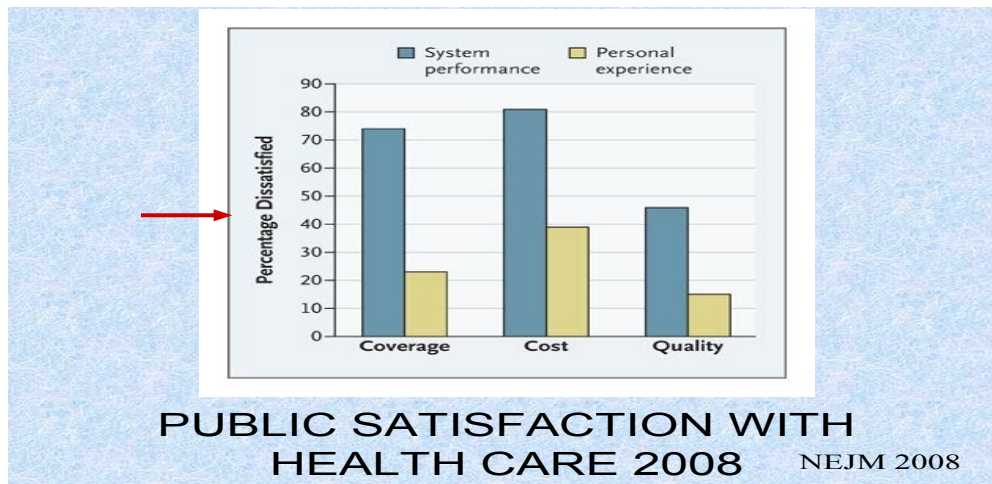
In his book *Ingenious Pain*, Andrew Miller wrote:

“All pain is real enough to those who have it; all stand equally in need of compassion”

This is a novel set in eighteenth century Russia and England, the protagonist of which is a child who clearly has the now well-recognised congenital defect of indifference to pain. It is a fabulous read, and brings tremendous insight into pain and empathy.

The treatment of pain is based on the highest ethical principle in medicine; it should not be impaired by transient regulations or fears of retaliation or economic factors. Many people have realised that healthcare in the US is in trouble but efforts to reform it have been undermined by the public's ambivalence toward government and by the dichotomy between the perceived overall system performance and personal care experiences.

I have one bit of data for you: this survey was published in the New England Journal a few years ago of the public viewpoint of personal experience versus performance of the health system



You can see that people's perception was that although coverage and quality of the system were seen to be poor and cost too high, there was much less dissatisfaction with personal experience; they thought it was worse for other people – how they thought they knew this I don't know. In other words 'my healthcare is OK but in general it's not so good.' It's a very interesting paradox that has led to the chaos we have in the US. I don't think anyone argues that the US has a good healthcare system, but how to change it is hotly debated. To some degree, we have placed the burden of good health on the doctor and not the patient. We have people smoking who don't feel they have adequate care for their chronic lung disease. Healthcare has been driven much more by incomes than by outcomes. We have what is called 'reimbursement driven medicine'; in other words what gets done by the doctor is what gets paid for. As to outcomes data there isn't much available considering the number of procedures that are performed. What are meaningful outcomes? Assessment of these must involve a duration of follow-up of at least six months to a year or even longer, and include self-reported pain, functional improvement, healthcare utilisation especially as regards medication, work status and quality of life assessment.

When the first Europeans arrived in Easter Island they found no human beings left at all – only the wonderful statues, and you might ask what leads to the complete disappearance of a culture and all of its people.

Some Loeserisms:

"The absence of proof is not the proof of absence."

"The plural of anecdote is not data."

"We should not think of pain as a thing; instead it is a process: a way of interpreting data from within and outside the body, filtered by past experience and anticipated consequences. It needs a verb rather than a noun: we should talk about people 'pain^{ing}' rather than 'in pain' and 'to pain', rather than 'to have pain'. Pain isn't a sort of tank into which you can put a dipstick and measure something called pain."

Conclusion

So how are we to change the culture of pain management? First of all we will need to select different healthcare providers. You don't want surgeons or anesthesiologists to be the front line. Secondly, if you live in a capitalist society you need to use capitalist principles to reward behaviour that is desired. One third of the American healthcare

budget is spent on administrative costs, and no patient ever got any better because of administrative activity. We have to eliminate the intermediaries who wish to change healthcare into a business. Thirdly we must evaluate functional status, not just self-report of pain, and only then will we learn what treatments work.

Part of the problem in our country at least is that we pick the wrong people to be doctors. We select physicians based on their ability to take tests. We ought to assess peoples' narrative sensibilities. A huge problem for us is the overwhelming amount of debt medical students accrue by the time they graduate which forces them to choose the more remunerative specialties to pay off their debts.

We have to improve remuneration for primary care physicians to get more people to do that. We should mandate that most pain management is done at the primary care level. Pain specialists should be generalists, not proceduralists, and referral from a pain generalist should be required to see a procedural specialist. Nobody should walk into a pain clinic and get a block a half hour later. Chronic pain management should not be under the aegis of anesthesiology; it is a primary care function and procedural specialists should not be the entry point for care.

But perhaps above all we need to change pain education. Pain must be introduced into the basic professional curriculum for all health sciences. I am happy to say that at least from my perspective there is currently a revolution in American medical schools to make pain part of the curriculum.

Discussion

I think most of us would agree with everything you have been saying. What alarms us at the moment is that the NHS is turning into a mirror of what is happening in the US. We have increasing business practices in the NHS to try to conserve costs and we are living in a very dangerous time at the moment. We have to take to heart a lot of what you have said and take a very careful look at what we do.

I feel quite disempowered. I feel it's very difficult for me to change things.

You're absolutely right. In the US physicians have allowed themselves to be pushed out of the decision-making process. It's something we are not wholly responsible for – it's been done to us – but some of it has been our turning our backs on things. For example when Medicare – a centrally run programme for people over 65 – came into the US in 1965, American medicine boycotted it and fought it tooth and nail, so they got completely left out of the planning and management of it. So now if we are unhappy with it we are impotent and people say, "you got what you deserved!"

Coming back to the cost aspect: I work for a day a week (sometimes more) on an honorary basis in the pain clinic in Bath. A couple of weeks ago I was approached to be told that they have a bit of money to spare and they could pay me for a whole four hours of my time. But they said I would have to sit down and justify it on a financial basis. It would cover costs if I were to spend 15 minutes with each patient. Currently on an honorary contract I can spend an hour or more with them, because I think it's really important to hear a patient narrative. But they measure success by throughput of patients and not whether you are successful in their treatment. The same patients come back time after time and are measured as new admissions.

We have exactly the same problem. I always like to refer people to the automobile business. If General Motors or Ford or anybody made cars which people drove around

for a week before they dropped dead there would be some feedback! We don't have that in healthcare. You have described a system that has no outcomes feedback. That is what needs to be fought for. We have to fight for a system based on outcomes rather than numbers seen.

I've been working with the King's Fund for a year introducing [?] methodology... multidisciplinary multiagency projects and looking at outcomes. The thing that is challenging us is that people...see benefits they are really enjoying it and they are really working together, so it's effective teamwork to change the culture along with the projects we are looking at...strategically aligned objectives...outcomes...was really disheartening...chief executive and finance directors buy into that no matter how much the consultants worked to get the outcomes and can deliver changes in culture through effective team working. They want to know what return on investment and how many pounds they can make...doing it effectively...

Evidence-based medicine tells us that multidisciplinary pain management is the best treatment we have available, but you try telling that to a funding agency – they say who cares?

It was Denny who said that to reduce costs you had to improve quality; if you try to reduce costs you end up by reducing quality.

In the US we have a huge problem because we have divorced healthcare expenditure from wage replacement (*income entitlement after injury*). We let the private insurance companies fund healthcare without paying any attention to whether it leads to some return to work or not. That creates complete chaos because they failed to recognise that the ability to go out and earn a daily wage is a critical outcome.

You mentioned medical associations, and the other day I looked at the IASP annual report for 2011. The membership is very interesting. Out of 7106 members, 2260 are anesthesiologists, not all of whom talk to their patients, and 1141 are neuroscientists who only talk to rats and guinea pigs. So half the membership represents these people and there is a huge imbalance between what the patient needs and what is provided. People who have chronic pain can't leave behind their broken relationships and their debts which are a huge issue for people who are out of work due to chronic pain. They really need people to listen to them about this sort of thing. If people are lucky they may get to talk to a psychologist but we don't provide social workers and debt advisers in our pain clinics. Until this is addressed I don't think we can move on. I notice that there are only 377 nurse members of IASP and there are 597 psychologists. IASP represents the body that sets out the world issues on pain and I think that we perhaps need to think about employing people who can address the patients' needs rather than the providers' needs.

You've raised a very interesting issue. First of all IASP consists of people who choose to be members – it doesn't go out and draft people...

...I'm suggesting they do...

...Well that's an interesting concept, but the IASP reflects the people who are interested in being in such an organisation. You also need to recognize that IASP has tried very hard to recruit members in developing and even undeveloped nations where there aren't psychologists, social workers etc. and almost all will be physicians. So in some degree its membership reflects the policy of trying to bring pain management in its basics to countries with inadequate healthcare in general. I have no role in the current IASP but in my time of being an active member and leader of that organisation

we tried desperately to get non-physicians into it. There were several issues: one was who has the money to belong to an international organisation, that in those days met every third year and now every second year, in some corner of the world that may not be near where you live? You will find if you talk to social workers or psychologists they will say 'I can't afford to join'. You are absolutely right that we need more non-MD providers to be active in the world of pain. But I am not so sure how we are going to achieve that and I suspect we are only going to be able to develop it on a local or national basis. The BPS needs to address this in the UK and not look to the IASP...

...And it has. The British chapter of IASP has tiered membership. I don't belong to IASP and have attended once when it was in Glasgow as a nurse. My Trust would just laugh if I said I wanted to go to San Diego. The BPS and local chapters can address that. But you're right – you have to be prepared to write a cheque...and by the time you have written other cheques such as the sub for your professional body...

Are we talking here about the vocation of care? The 'scientification' and impersonalisation of medicine actually started out in the Western world as a caring thing in monasteries. We seem to have lost that and with our scientific fix-it-quick attitude we seem to have lost that so everything that is wrong with our patients gets ignored.

How do we train our physicians? This is one of the big issues we are fighting about in the US. If you want people who are going to listen to peoples' narratives you have to train people who are going to listen. On the other hand if you want people who are going to apply high science then we do as we do now – we take the best and the brightest examination takers...

I didn't list the nursing organisations in the US having something to do with pain. It's similar to the one I had for pain medical professional organisations, and there are 20 of them in this category. In general they are way ahead of the physician-based organisations in terms of understanding what chronic pain patients need. There are too few social workers. They are not a group of people who travel to remote places for big meetings. We tried very hard to get some social workers to join IASP but very few had the resources or the interest.

Well, Rangan Roy has done a lot to try to improve that. He's written several books and a lot of papers and has encouraged a lot of social workers but still he's the only voice.

I agree with Beatrice's comment. I've been on the Council of the BPS for three years. I go to various meetings, not just on philosophy but intervention and information meetings etc. The first question people ask is "what has the BPS done for us?" But it is not like the BPS sitting there and doing everything. Council members are all volunteers. The Society is us – we have to be involved. Like Beatrice says, more than 800 people out of 1400 are still anaesthetists. I think there are about 300 nurses. We mustn't fight between factions. We have to promote more of our colleagues to join. The College of Anaesthetists and the Faculty of Pain Medicine are doing a great job in making sure that all anaesthetists who select the pain profession – the numbers are dwindling now – have skills in communication and team-working and to make sure that factions like non-anaesthetists have to get involved and have the necessary skills. So the Society is looking hard at the issue but there are only a few volunteers to do the job. It is up to us to encourage our colleagues and make sure that the pain work is done.

Apart from analysing the type of professionals we need, maybe the focus should be on the type of service we offer. There are a lot of physicians who are empathic and

compassionate but many surgeons who are very black and white – two extremes – and lots of anaesthetists who are very caring about their patients. So it's not so much about who treats the patient as how we treat them and how we incorporate these things; yes we need to keep these specialists involved but we need to focus on the type of care the patient needs.

Yes but it's not just compassion and empathy, it's addressing the real problems people have – no matter how compassionate you are you cannot solve the debt problems of people who have become unemployed...

...But if you are aware of that you...

... I am a volunteer in the citizen's advice bureau and we are inundated with people in debt, and a lot of people suffer chronic pain. There isn't the sharing of knowledge that there should be...

...But part of what I am saying is that we need to share knowledge across the board...

Part of this is also integration with primary care. If you don't have a functioning primary care system which isn't distracted into all the bureaucratic stuff – unless you have that... our secondary services are just playing around on the tip of the iceberg. We're not dealing with the core issues.

To paraphrase Beatrice, the major cause of chronic pain is poverty, if you look at it from an epidemiological point of view. It's very hard to stand in front of a group of healthcare providers and say the problem is poverty and you guys have to do something about it. But that's not the way we function as a group. There isn't any question in my mind that it's as true here as in the US – poverty is one of the major causes of *all* illnesses, let alone chronic pain...

...Relative poverty...

... Income disparity...

...You see very little chronic pain in the affluent.

... But is that the role of the chronic pain clinic?

... The role of the chronic pain clinic is hopefully to restore people to gainful employment. If they have no skills and there are no jobs...a classic example in our part of the world [northwest coast of USA], we have had two big industries, logging and fishing. In the last 50 years they have cut down all the trees they can so there are no more loggers. Logging is a high injury related job, and loggers are people who never finished high school; they have no social skills, little education, and you can't rehabilitate them. Same thing with fishing; we've overfished so there is no fishing industry left in the Northwest USA – there's still some in Alaska but none in Washington – and fishermen also have a limited bag of tricks of things they can do for a living, and you can not restore them to gainful employment. Is this a health-related problem or a social problem? It's surely a problem, and I don't know what the solution is but it's clear that healthcare alone isn't going to solve it.

Compassion in Healthcare: Exploring and sustaining compassionate practice in healthcare

Report of a meeting held at the Royal Society of Medicine on the
12th November 2013

Frances and Sarah Dixon

[Frances attended the meeting at the Royal Society not knowing she would be asked to provide a report and prepared this from her notes and her own subjective impressions of speakers' meaning. No accuracy as to their actual words is claimed. It was presented by Sarah (her mother), as Frances could not attend this meeting. Sarah's own additional thoughts are also included in the text without any attempt to distinguish them from those of the speakers]

“The scientific and human approaches are not incompatible. It is perfectly possible – indeed essential – for a doctor to be technically highly proficient as well as a compassionate human being.”

Aims and objectives

This meeting was run jointly by RSM Open Section & Institute of Medical Ethics, in association with The Human Values in Healthcare Forum. Attendees included doctors, ethicists, allied health professionals, chaplains, managers and students.

The word compassion comes up in so many conferences but what does it mean? Is it just a box for medics to tick? This conference was dedicated to showing that it is a thing and a process and not just a nebulous concept, and its aims were very straightforward: they were to share ideas, resources and experiences of effective strategies for developing, promoting, delivering and sustaining compassion in healthcare. The objectives were to address the barriers and facilitators to compassionate practice and to examine the ways in which education can affect compassion.

Medics tend to be compassionate, so what can stop them from behaving compassionately? How can an environment be created in which they can do what they naturally want to do? Students go into their education wanting to help people but become more and more cynical, and have to relearn their compassion.

There were six presentations in all:

The science of compassion in the healthcare context

Paul Gilbert, Professor of Clinical Psychology and Head of Mental Health Research Unit, University of Derby

Professor Gilbert started by stressing the importance of defining what we mean by compassion. When we talk about it we can mean different things and spend a lot of time talking at cross-purposes.

He felt that this definition by the Dalai Lama:

“Sensitivity to the suffering of self and others with a deep commitment to try and relieve and prevent it”

was really a very good one. Note *self* and others. In Western culture, and particularly in the caring professions, it is very easy to overlook the importance of self; compassion is all about other people and self gets ignored. Compassion starts with ourselves; that's not selfish or egotistic, it's essential. It's like love: unless you can love yourself any love you can give out is always going to be conditional. Compassion always has to be unconditional. We don't want anything back from our patients. All the speakers came back to this.

Professor Gilbert went on to say that compassion was not nebulous but something with an actual measurable outcome. It affects the brain in many regions, for example, those involved in behaviour and motivation. Threat and competition also affect these regions (in different ways) and therefore reduce compassion; it's difficult to be compassionate if you feel threatened.

Compassionate goals (for example, 'Be supportive of others') often work against self-image goals (e.g. 'Avoid the possibility of being wrong'). Ideally compassion should be accompanied by reduced self-image goals.

Compassion is not just caring. It involves caring and helping. If you look at any number of lineages – not just yours but Yoga and Buddhism – you always have the head knowledge and the direct experience. You can be as compassionate as you like but if you don't get out there and do it what's the point? In Yoga we are taught that you can meditate as much as you like but if that doesn't change how you relate to other human beings you've completely wasted your time.

Humans function best (for instance as regards the immune and cardiovascular systems) in a compassionate, non-threatening environment and the human brain is very sensitive to kindness and compassion, and that includes being compassionate to self. Compassion is promoted through relationships and is not just up to individuals. I think we are all in a stage of our lives when we understand that the most important things – perhaps the only important things that have ever happened to us – involve our relationships with other human beings.

Professor Gilbert continued by describing the three systems by which emotion is regulated. The first involves our response to threat and self-protection. Let's imagine, for example, wanting our children to do well in their exams. So this system is 'get an A or I'll kill your guinea-pig'! The second is the reward system: 'get an A and I'll buy you a guinea pig'. The third involves enhancement of contentment and promotion of feelings of safety: 'how are the guinea pigs doing? – How's the swotting going? – Let me get you a cup of tea'. We probably all find ourselves slipping into the first two because they are easy and have directly measurable results. The third one gives the best results but is so difficult to measure.

When threat level is high, we respond in a threatened way: threat-focus takes over and leads to threat-focused solutions. If threat is low we can form more collaborative relationships and creativity flourishes. We would all like to be in an adult to adult relationship with our patients but all too often find ourselves in a parent-child situation where the patient is acting as a child and wanting you to be the parent.

When the NHS was set up most of the doctors were used to working in a setting where only people with money could pay their bills, and you would see country GPs working all hours milking their rich patients so poor people could be treated for very

little. They were highly committed to providing healthcare for all. In the beginning, the NHS was a collaborative and cooperative venture informed by a compassionate and facilitative mentality, but it has moved towards a threat/reward mentality – the easy option – driven by competition, fear of error and litigation, and targets. Threat reduces compassion, as their psychologies are incompatible.

There is a pressing need to identify inhibitors and facilitators for the development of compassion. It's no good just telling people they have to be more compassionate. When I want my students to learn how to relax I have to tell them what to do inch by inch. It's the same with learning compassion.

Compassionate care from resilient professionals: Removing the barriers
Dr Alys Cole-King, Consultant Liaison Psychiatrist, Betsi Cadwaladr University Health Board

Dr Cole-King spoke primarily from her experience of people who had tried to commit suicide.

She wanted to examine the feasibility of compassion in the real world: to take it from something that would be nice to something *actual*. She felt that there was a need to remove barriers between doctor and patient. These are not only organisational barriers or those imposed by 'good working practice', but also included personal and professional barriers like lack of time, and the fear of missing something or making matters worse. Distress tolerance is very important.

She acknowledged that it is more difficult, if not impossible to be compassionate if you are having a bad time yourself, for instance if you are being threatened by your superiors or in competition with your peers.

Looking at the context of suicide prevention, Dr Cole-King pointed out that if you don't develop a compassionate relationship with your patient they are not going to open up and tell you their 'most shameful' secrets. They are likely to go out of the door and try again. (There is a death from suicide every 20-30 seconds worldwide, and twice as many deaths from suicide in UK than from traffic accidents)

Compassion can make the difference between suicide and carrying on. Identifying and addressing issues and *listening* can make a huge difference. Samaritans provide a great example of compassionate listening; it's very difficult to learn to listen without giving advice.

She provided a 'waterway' analogy: you can rescue someone from 40 foot waves in helicopter but it would be so much better just to put out a hand and pull them to safety just as they are getting out of their depth. People at every stage will benefit from compassionate care.

Compassion and the education of doctors
Professor Jenny Firth-Cozens, Clinical and Organisational Psychologist, Special Advisor on Postgraduate Medical Education London Deanery, Visiting Chair Imperial College

My (Sarah's) own recent experience of being a patient has been illuminating. I can tell you the exact difference between compassionate and non-compassionate healthcare. You want to get better for the nice doctor! You want to be a good patient. The relationship between patient and doctor is tremendously important. Patients tend to put you on a pedestal.

So what prevents compassion in doctors? Like everyone else, doctors have an innate fear of things like death, disease, distress and disfigurement happening to themselves, and physical and psychic pain can cause pain to those witnessing it. Some coping strategies such as avoidance of death and failure to engage with dying patients, and the inappropriate use of humour (which many patients find upsetting) are incompatible with compassion.

Doctors often work with high levels of stress, and are especially vulnerable to depression, burnout and anxiety. They score 25-30 per cent above threshold for such problems on GHQ12 (General Health Questionnaire). The levels are even higher in managers than doctors. Psychiatrists and GPs have particularly high stress and depression levels, perhaps associated with a tendency to high levels of self-criticism. Organisational factors such as targets also increase stress, and decrease compassion if they increase distancing from patients.

The biomedical model of training doctors – looking at the disease instead of the patient – is not in itself conducive to learning compassion. There is evidence that empathy decreases over training. Students enter medical school wanting to help people but find they want to do this less and less over time. To counter this tendency it has been suggested that there should be proper assessment of and reward for compassionate care, and compassionate care should be included as part of personal and professional development. But this is really difficult because it is so difficult to measure.

Role models for students are tremendously important but are not all good. They should model self-compassion, and look after juniors compassionately. All medical students know the doctors whose firms they would like to be on, and which they would not.

Learning to get close to patients may be facilitated by sessions in which students play the roles of patients, or by sharing the experience of doctors who are themselves, patients. 'Family liaison' sessions involving talking to the families of patients are also very valuable.

Sessions where juniors can express their feelings and difficulties in a non-judgemental setting are very important. All too often, if a medical student sees something that doesn't seem right – for instance the way a doctor spoke to a patient – they may have no-one to talk to about it.

Organisation of hospital care is frequently not conducive to compassionate care. Compassion takes time. There has been strong advocacy for the adjustment of A&E targets with this in mind. Managers must be compassionate too, and need to address staffing issues leading to high levels of stress. High bed occupancy (currently approaching 100 per cent in some hospitals) makes compassionate care particularly difficult.

Compassionate care is important not just because it is nice, and good in itself, but because it also has significant practical good consequences. It increases patient satisfaction and improves outcome. It reduces the risk of litigation. Even if mistakes are made. Re-attendance rates are lower if the patient is treated with compassion. It's better for staff and their satisfaction, and reduces rates of staff turnover.

Compassion and the education of nurses

Dr Ann Gallagher, Reader (Nursing Ethics) and Director for the International Centre of Nursing Ethics, University of Surrey

Dr Gallagher advocated the adoption of 'slow ethics' and the need to calm our frenetic lives and let virtues such as integrity, patience and respectfulness prevail. The 'slow movement' is the antidote to our obsession with fast – fast food, fast travel, fast parenting, and fast life. Its advocates recommend that life should be approached with care and attention and that we should attempt to live in a meaningful, thoughtful, sustainable and pleasurable way. It requires courage and integrity as well as patience.

This contrasts with the prevailing 'fast ethics' involving a 'quick fix' mentality, focussing on single values with little or no interrogation and over-simplification of complicated issues. It is typified by the tendency of doctors to hurry into dealing with patients' current symptoms and disease and unwillingness to listen to their back-story, and a disinclination to learn from past failures of treatment (or, as John Loeser lamented, to keep proper outcome measures)

She used the term 'bleeper ethics' which appears to refer to over-reliance on ethicists (especially in the USA where large hospitals apparently employ an ethicist who can be bleeped if an ethical problem arises) instead of working things out for ourselves. Value Ethics, the theme of our conference a couple of years ago, is of particular relevance in this context as it asks, in a particular situation, the question 'how should I be' rather than 'what should I do?' – a much better guarantor of right judgement than reliance on algorithms and speedy expert responses.

So how are we to implement 'slow ethics' in healthcare? Dr Gallacher suggested four key measures: firstly listening and dialogue – taking time with patients, families and practitioners; secondly learning from research, scholarship and engaging with other disciplines, thirdly leading by example in articulating, aspiring and valuing care both as professionals and citizens, and lastly living slowly and mindfully – appreciating and celebrating people, places and practices.

One might be forgiven for wondering how practical an approach this is in the context of the NHS, but as a guiding philosophy it has much to recommend it.

Strategies for enabling compassion

Professor Raanan Gillon, Emeritus Professor of Medical Ethics, Imperial College London. President of The Human Values in Healthcare Forum

This was a most inspiring presentation. Professor Gillon suggested that a cynical, anti-humanity attitude is contagious. If high-level managers or doctors don't believe in a compassionate, hands-on approach and express these views it will foster a culture with reduced compassion.

The scientific and human approaches are not incompatible. It is perfectly possible – indeed essential – for a doctor to be technically highly proficient as well as a compassionate human being. Self-reflection is very important.

The King's Fund Point of Care review

Dr Jocelyn Cornwell, Director of the Point of Care Programme, The King's Fund

This programme “*aims to help healthcare staff deliver the quality of care they would want for themselves and their own families.*”

Dr Cornwell quoted many testimonials of horrifyingly bad care (like women with breast cancer being left alone outside the operating theatre wearing only a hospital gown). Staff seemed astonishingly unaware of patients' distress, and to ignore their feelings, until they were told about these after the study. She conceded that it was extremely difficult to leave your personal prejudices at home & avoid being judgemental.

‘Patients feel that they are not always treated with kindness, compassion and understanding... There is concern about quality of information, communication and relationships with families. Although there are high levels of satisfaction with the NHS, and staff go to work wanting to provide good care, in today's vast ‘medical factories’ the pressure of work is intense and good care can get squeezed out.

The Point of Care Programme starts with a focus on hospital and staff experience. Every action – bed management, communication between caregivers, staffing levels and financial investment has an impact on patients and their families. It works at all levels of the system and includes policy analysis and advice, research, evaluation of practical initiatives including the Experience-based Co-design Tool and Schwartz Center Rounds.’

From the Kings Fund website

Schwartz Center Rounds are monthly hour-long meetings that give healthcare staff time to open and honestly share and explore their feelings in a non-judgemental setting. They enable staff to feel less alone, and even if only small proportion of staff attend it will have a large subconscious effect on other staff.

Workshops

At the end of the programme participants split up into several workshops. Although Frances could only record the conclusions of one of these, it seemed that the same central themes, involving building relationships, came out of all the groups.

These were, firstly, connecting with the person as an individual, not a diagnosis or label. When you stick a label on a person you don't see them any more. It's very difficult not to label because that's what we are programmed to do. But we have to avoid this if we are to allow people to stay themselves and to have normal human-to-human interactions with them. The second theme was the importance of time, and of ‘being in the moment.’ Healthcare staff often lack time to just be with their patients. A better example is hospital chaplaincy: chaplains are paid to have time for staff and families as well as patients.

Lastly the group conceded that although teamwork and trust within a team are vital and can be facilitated by mutual respect between team members, high turnover makes it difficult to develop trust over a long time.

Conclusion

Although compassion in healthcare is vitally important and improves outcomes for patients and staff there are formidable organisational, personal and professional barriers to putting it into everyday practice. Overcoming these involves personal reflection and relationship building as well as training, of which role modelling is a vital ingredient.

Discussion

What was your [Sarah] experience as a patient?

Last year I had a severe flare up of what had been many years of recurrent hip pain. My first encounter was with a surgeon, who said I needed both hips urgently replaced. When I saw him again after the first operation he asked me “how’s the hip”? I replied that the hip was fine but I was still getting a lot of pain, and his response was “not really my field I’m afraid – go and ask your GP – goodbye!” But I had been in a hospital where there had been a lot of Filipino nurses who were wonderful – really lovely, caring and compassionate.

But I did find that people had clearly defined ways in which they could help you, and if you fall outside these they are completely at a loss as to what to do. So when I went in for my operations and the recovery from the first was great. But after the second one I got quite ill [with what was eventually diagnosed as a flare-up of adult Still’s Disease] and they didn’t have a clue what to do as I was in the wrong department of the hospital.

I’m keeping a little book of my experiences but I’m not through my journey yet...

[Partly inaudible] I’ve just started a [?] compassion-focussed group for our pain team ... pain population shortly... it’s a very relevant approach for this group...

You need to include a Yoga teacher! I have been working mainly with cancer patients with very restricted movements...

You mentioned compassion for yourself: there is a need for compassion in teams as well; you have to look after those around you and working with you. I’m very fortunate in this respect.

My daughter’s experience in medical school is that there is so much competition for placements etc that any compassion they have for each other has to take back seat.

You mentioned a hands-on approach; we have moved away from actually touching our patients. We have had a serious discussion in the physio world about whether we should touch our patients – how on earth can you do physiotherapy without touching your patients? ...

...Patients have said – he didn’t touch me...or didn’t even examine me...

In Yoga when people go into postures it’s tremendously important you correct them as otherwise they won’t get any benefit and might even hurt themselves. Adjusting movement is a real art, but I have known teachers who are reluctant to touch their students lest they lay themselves open to litigation.

So many of the useful discussions take place outside this room...we were wondering why do people talk to their hairdressers? They are touching you ...grooming you ... you have a relationship which means you can talk about anything. I know intimate details of my hairdresser's life... Touch is so important but how we do it in a way that don't lead to – er – expectations... It can be difficult with male/female relationships. My teacher is a man. He continually has students falling in love with him! It's very difficult; he has to have an absolute barrier between student and teacher. He has had some students for 30 years but won't socialise with them – it's the only way he can protect himself.

I have a lot of patients come to the pain clinic who have had physiotherapy and been discharged because they are in too much pain...

[Paraphrase of barely audible contribution] the fast pace we have been talking about and reforms in the NHS with changes every day lead to burn-out and desensitisation; people don't have time to slow down and become more compassionate.

You were talking about what trickles down from the top. Two names come to mind: Nicholson [Sir David Nicholson, Chief Executive of NHS England.] and Sir Richard Sykes who is chairman of our board. I work in a noticeably uncompassionate environment which is so focussed on finance, care for patients takes second place. Nicholson probably leads from the top and doesn't seem to have any iota of care – he's only focussed on results and finance.

...The mid-Staffs affair isn't unique...

...We can all recognise threads in reports... if we ignore that...

I have done some work for an organisation called 1000 Lives Plus. It's part of NHS Wales and has been set up to reduce harm in the NHS. There has been some really interesting work – going through patient scenarios and training healthcare professionals in that way – asking them how they would feel in that situation – rather than telling people what to do, which tends not to change culture, motivating them to wanting to change their own actions.

[Look at their website – and be reassured that things can be changed – a good antidote to depression brought on by 'reforms' in NHS England. Ed]

I went to a 'monetary training day', which sounds awful, but there was something good in it. There was a microbiologist talking about MRSA and other hospital infections and the difficulty of fighting them. I felt there was some compassionate change there as they found that when they put the name and the photograph of the patient that was affected the message was going across. If you just publish numbers it's meaningless and no change happens. The moment they identified patients it changed peoples' attitudes and changes that people thought were impossible were taking place. There is a lot of hopelessness in what we have been talking about, but there are levels that we don't understand even in a big system and you can make changes if you try.

I think the Schwarz Round concept is one of these small things which don't have to be costly but can bring about change.

There was a meeting of NHS chief executives who were asked to come to a meeting bringing a photo of a loved one who had been cared for in the NHS. They were made

to sit in a circle, facing outwards, looking at these, while someone in the centre read the NHS constitution. At the end of this they were all in tears.

You talked about top down: in the Department of Health there have been directives for senior civil servants to spend a month or six weeks getting hands on experience in a hospital – how can this be done?

...It's like policemen having to be nurses...

... Jeremy Hunt [Secretary of State for Health] was in our hospital the other day shadowing an A&E consultant - like a little puppy...

Learning and teaching about pain: The evidence and the values

Ed Piele

“The best clinical decisions are based both on the best available scientific evidence and on the values relevant to the individual patient situation.”

The topics of pain and sleep [Ed’s area of special interest] are gifts to clinical educators. Everybody has a basic understanding of the topic but much more to learn. Everybody has personal experience of pain and sleep and have met people with problems in these areas. All the biomedical sciences, most social sciences and most clinical sciences can be included in teaching about both pain and sleep. They can usefully be brought into integrated education, both horizontally, linking the material that students are learning at a particular time, for instance integrating what year one students are learning about neuroscience and psychology; and vertically, as you can spiral back to it during the clinical years.

They are also ideal topics for students to learn what shared decision-making looks like. I like to talk about learning *with* patients; it’s important for students to realise that they learn as much from patients as they do from physicians. I started on the wards when a physician would drag you off to see their latest rarity – a ‘fascinoma’ – but I hope that nowadays that has gone and we teach around patients and not ‘cases’. The patient isn’t defined by the condition or his pain, and the rule ‘no teaching about me without me’ should be observed. The days of the secretive ward rounds where you could rubbish your patients’ stories and cast aspersions on their history are – or certainly should be – long gone.

Person centred healthcare

The recently launched European Society for Patient Centred Healthcare defines this as:

‘That which takes full account of patients’ values, preferences, narratives, cultural context, fears, worries, anxieties, hopes and aspirations.’

I would emphasise *hopes and aspirations*: when we are teaching about communication skills we tend to neglect the positive drivers – the things that can get you out of trouble.

I was thrilled to hear John talk about narrative. I believe passionately in the importance of narrative. One of my first jobs at Oxford was to design the clinical teaching for the new graduate entry fast track course. These were people who were having a day a week of clinical learning from day one before they knew anything about medicine. We decided we would just get them listening to patients. I have used this again and again even at the stage of postgraduate medicine. There is evidence that we actually harm students’ inherent capacity for communication. It’s not uncommon to see a dip in communication skills between years two and three. We give them wonderful models of communication skills but something as yet undefined damages their own inherent skills. I emphasise that people must learn to *listen* before they learn to *format*: for instance telling them that you must get the history of the present complaint before you get on to past medical history all gets in the way of

fluidity – our normal conversation with people. Medicine is about a person interacting with a person: one is the expert in their own condition; the other may be trying to become more expert in the management of similar conditions. Communication needs fluidity, not formats; these will come later if they sell themselves. I rarely down-rate a student because they have not formatted in a disciplined way; I down-rate them if they haven't heard the appropriate story or haven't facilitated the telling of that story. It's part of our human condition that we can do it quite well; all that needs to be taught is to check back that we have captured what they are trying to tell us and actually use the patient.

In teaching values-based practice we like to invoke the 'two-feet principle': the best clinical decisions are based both on the best available scientific evidence and on the values relevant to the individual patient situation. These are two very different paradigms. In a biomedically dominated world scientific evidence is generally gathered on populations and the RCT ranks very highly. Thinking about individual values means looking at an n of 1.

[The audience were invited at this point each to think of three words describing values. Suggestions included: integrity, important, belief, hope, meaning, passion, truth, direction, heartfelt, sincerity, worth, riches, quality and principles.]

Some of these are *examples* of values like integrity, hope, truth, and sincerity; some are *descriptive* words like beliefs, meanings, passions and principles; and some which emphasise a *quality* of values – their importance, their dimensions – such as direction, heartfelt, individual.

I hope to convince you of one overarching quality of these values, that they are 'action-guiding'. If we want to understand how a person might act or how we might want to act, or move in any particular direction, we need to look at values.

One of the three guiding principles laid down by the National Institute for Mental Health for England states that:

'The values of each individual service user or client and their communities must be the key determinant for all actions by professionals.'

This relates back to evidence-based medicine, which was defined as long ago as 2000 by Sackett as the integration of the best research evidence, clinical experience *and patient values*; the latter defined as the unique preferences, concerns and expectations each patient brings to the clinical encounter and which must be integrated into clinical decisions if they are to serve the patient.

To give you an example: you may remember that last year there was a lot of debate as to whether a patient should be able to request Caesarean Section. The Royal College of Obstetricians and Gynaecologists opined that:

'Healthcare providers have the responsibility to ensure the safest, most cost-effective method of delivery for women and babies *accepting that very occasionally women will request an elective c-section in the absence of conventional obstetric indications.*'

Here is policy-making influenced by values and recognition that EBM is not the trump card that we can beat patients about the head with in the way that we used to. It is no longer good enough to hide behind 'well the evidence is that you shouldn't have a

c section'. We are now expecting clinicians to balance evidence with values; to say to patients 'this is the evidence – what do you feel?'

A curriculum for the training of GPs requires that:

All General Practitioners should be able to:

- Recognise the ethical dimension of every healthcare encounter.
- Identify the values that patients, families and members of the healthcare team bring to a specific healthcare decision.
- Understand the nature of values and how they impact on healthcare.
- Demonstrate moral reasoning skills in the process of choosing an appropriate course of action or resolving conflicting values.
- Use knowledge, skills, and attitudes for effective communication in eliciting and understanding the values of patients, negotiating an acceptable course of action and justifying that course of action.
- Demonstrate knowledge of the professional ethical guidelines and legal framework within which healthcare decisions should be made.
- Recognize their personal values and their influence on decision-making.

So when we talk about respecting patient values do we mean medicine which is 'patient centred?' – or 'patient focussed?' – Or 'patient led?' – or 'patient empowering, or enabling?' – or in which 'anything goes'? It's only that last I would disagree with. I think we would be doing our patients an enormous disservice to change from paternalistically telling patients what they need to saying they need to decide and we'll go along with it. For me, values-based practice involves looking for balanced decision-making within a shared framework of values. All of us physicians (and other health professionals) are bringing some form of expertise that we believe is of help to that patient. We're not going to deny that.

Patient enablement and empowerment

'Patient Enablement describes the effect of the clinical encounter on a patient's ability to cope with and understand his/her illness, encouraging the patient to realize his/her autonomy.'

J.C. de Sousa

In the NHS most of us have to do patient satisfaction surveys – your archetypal tick-box exercise. Satisfaction is conceived as a consultation outcome in and of itself. And these surveys say very little about how we have actually helped people. This is in contrast to *enablement* which is conceptualised as an indicator of the self-efficacy benefits of consulting a doctor, and is expected to be associated with behaviours like treatment adherence and self-care, and is much more useful.

Patient Empowerment has been described as a multi-dimensional social process that helps people gain control over their own lives. This is of course very important in chronic pain. It is a process that fosters power in people, for use in their own lives, their communities, and in their society, by acting on issues that *they* define as important.

Values-based practice starts from a basis of mutual respect for a diversity of values. It makes things which are disrespectful very difficult in values-based practice. You can work with a racist but not around racist views, because a racist is disrespectful of others. All the ‘-ists’ – sexist, racist, ageist – need special skills to work with to achieve mutual respect.

We try to integrate two forms of values reasoning. Firstly principles reasoning: All students have been brought up on Beauchamp and Childress’s four principles of beneficence and nonmaleficence, justice and autonomy. But the vital bit, which their teachers tend to forget, and as Beauchamp and Childress themselves say, these principles will not of themselves answer ethical dilemmas. But they do help to define the parameters and give a really helpful format of reasoning. Ethics based on process are much more useful for decision-making than those based on rights. The other form of reasoning includes casuistry, or case-based reasoning. If you’re stuck with a patient who has come to you with a difficult dilemma and you are wondering how to handle them, you may want first to apply the four principles and then relate it to other cases that you or your colleagues may have seen. It can be very effective to use more than one approach. It’s easy for those who have been trained in critical appraisal to find knowledge involving scientific evidence; finding knowledge about values is more difficult but the resources are available.

Balanced decision-making within a shared framework of values

One of the great things about a shared framework, which I think will work in pain (although I’m not going to give an example from pain as I’m not familiar enough with the field), is exemplified by assisted suicide. Say a patient comes requesting this, and if as a physician this goes straight against my values, there is a conflict. The way I would tackle that in the light of values-based practice is to start by listening to a patient’s values and their narrative, and then demonstrating that all important understanding, showing that I have heard, that I am respectful in my hearing; that within the limits that one can understand what another human being thinks I have done my best to appreciate and respect the values they have revealed. I would then expose my own values and why I hold them, and clarify the differences between us. At that point we move into the world of dissensus, where we agree to disagree and constructively work around our differences: ‘OK, let’s look at what we do have in common: both of us want you not to suffer, both of us want you to have a death in which you lose neither your dignity nor the respect you want, and between us we can achieve a huge amount on that.’ It’s looking for that common ground. Our different values have been recognised and *worked with* instead of allowing them to become a barrier between us – using dissensus constructively.

Undergraduate teaching.

How do we communicate values awareness? I was debriefing a medical student who had been to see a patient with prostate cancer. When he had given me the history I asked what Mr Jones felt about his sexual function. “Oh,” he came back as quick as a flash, “patients with prostate cancer don’t care about sexual function.” “How do we know that?” “Mr Smith did a case study last week and the patient was quite clear he didn’t care about it.” He had taken an N of 1 experience and extrapolated it to everybody. We all do this and we all have a psychological bias to believe that surely everyone thinks like I do (‘surely’ is a red light warning word!) And we forget how impressionistic those early medical experiences are on students. So they should be but it’s up to us to balance that.

We can teach how to balance the two feet principles. You can relate this to your teaching about pain management.

To return to consensus and dissensus: when it comes to the evidence base we want to teach consensus. I would hope that if I am managing a patient with pain and you know a better way – if you cite a paper showing that the drug I am using is ineffective and so on – we are trying to achieve consensus. It's important for the patient to see that the people looking after them are talking honestly to them and that one is not rubbishing the other's treatment. But with values we have to learn a completely different skill, which is dissensus, working across differences, and that isn't emphasised a lot in conventional teaching. We don't notice values when we are all going in same direction, but when consultations go wrong it is more often because clinicians were not able to deal with the values than because they did not know the evidence. It is useful to allow learners to get it wrong and then demonstrating a better way.

[This was followed by a video clip of a role-playing teaching exercise with a GP, a medical student and a patient, played by actors. The student told the patient that the questionnaire demonstrated that she was suffering from clinical depression and immediately suggested antidepressants; an entirely biomedical approach. The GP tutor elicited the problem that this upset the patient as her mother had killed herself with these. He asked what help she herself would like, and agreed with her suggestion of 'talking therapy.']

There was some concern that exposing the patient to the mistakes of the learner might cause harm, but this was limited by the tutor and may have actually helped by bringing out the traumatic experience. It represented a very common real-life experience in teaching students at an early stage: they nearly all jump in with the biomedical stuff; they go into 'transmission mode' and completely forget everything they have received. It's important for them to recognise the bear-trap; we ask them to share information and they forget that this involves a two-way conversation. Not only have few early stage students failed to grasp this but I see many postgraduate learners who haven't got a two-way facility.

It struck me that there were two fearful people meeting; the body language of the student and the patient reinforced that fear. Fear blocks communication. But I liked the doctor – his body language... the way he spoke... Until you feel comfortable you can't transmit that transformative way of being with...

Yes ... there was tremendous compassion which was coming across in the role modelling. The student couldn't show compassion because she was fearful. It was more comfortable for her to stick to 'science' and 'facts.'

The tutor gave the patient space for the narrative and demonstrated how this can still be done within the time-constraints of the consultation.

Questionnaires are unhelpful and they get in the way of communication. So can science if you put it first – deferring communication until you have done all the tests and X-rays.

It also demonstrated the importance of non-verbal communication – the way they were sitting...

So we're talking about values awareness. In the context of pain, a values question might be something like 'What does your pain mean to you?' We've established the

nature, site, intensity and so on of the pain, and found out how it's restricting activities etc. etc, but it still remains to ask an open-ended question like this to establish whether there is any disassociation of values. We need to understand at a philosophical level what pain is about for them. For instance do they feel that they are being punished for something? We won't know unless we ask.

...There could be a cultural or religious underpinning, such as Roman Catholicism...

...Absolutely but we need to go beyond this. We need to be able to ask Roman Catholics about termination or Muslims about alcohol. We need to be able to ask someone from a different culture about their sexual practices without causing mortal offence. Cultural competence is important but can lead to assumptions, and assumptions are the enemy of values. The more we assume the less we find out.

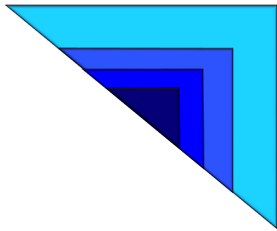
Keywords referring to values communication which appear in nearly all the important literature the three main models of communication skills are: ideas, concerns, expectations, strengths, aspirations and resources (which have acquired the acronym ICES_tAR). These are great but there is a problem that they may have become a tick-box.

You as pain experts would be able to teach the main world of communication these skills because it's something you do incredibly well when you have a patient whose pain is getting in the way of their way of being. You do look with them at their strengths: 'how did you overcome past obstacles – what did you bring to bear when you had similar trials and tribulations in your life – what are your aspirations – what are your resources – what else can you draw upon?' These are the underemphasised aspects of communication generally. If you reflect on the last time you were teaching anyone about pain do you think you identified the patient's values – the learner's values – your own values – the societal and institutional values in the background – as part of your teaching? It very seldom is but if you've got time it can be very good use of it. Perhaps you might try it next time you are teaching? Ask values questions and show how you bring values and evidence together when you approach your clinical decision-making. And never forget that role modelling has a significant impact on student professional attitudes.

Clinical decision-making

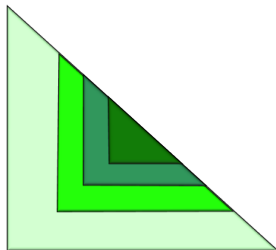
I'm going to offer you 'Ed's simple model' which I developed because I found that when we were talking about all the theory of clinical decision-making and using words like hypothetical, deductive, scheme-inductive reasoning, pattern recognition etc. etc. I was getting a load of blank faces around me and it was not really helping to move education forward. So what I talk about is the fact that we actually gather information about a patient in conventional ways: history, examination and investigation.

The Clinician's frame I: Diagnosis



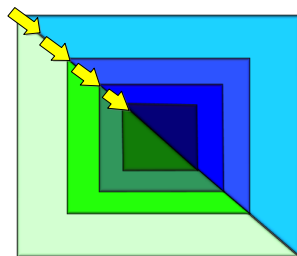
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Medical School

The Clinician's Frame II: Management



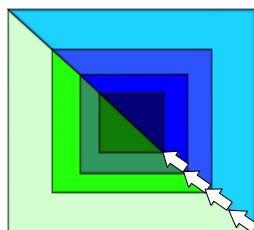
Warwick
Medical School

Clinician Process III: Evidence Basing



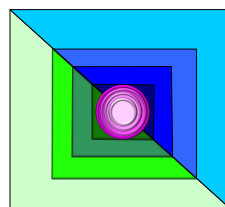
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Clinician Process IV: Values Basing



Warwick
Medical School

The Round Peg in the Square Hole



Where does it fit?
=
Professional
Judgement

Warwick
Medical School

Sometimes this information leads to immediate action and there is only one appropriate treatment, but I'm not concerned with that. What I am concerned with is how we interact with what we know about the patient. There are two frames of these. If you go to conventional medical teaching you would hear that there can be no treatment without diagnosis. As we work with our patient we are reducing the big universe of possible diagnoses down to likely diagnoses. But at the same time, and particularly in primary care, in between 50 and 60 per cent of clinical situations management decisions are reached before a firm diagnosis is reached. There's nothing wrong with that. You can start with all the possible actions but you might, for instance rule out surgery fairly early and arrive at much simpler possibilities of management.

But what drives the process of the 'squaring down' of management decisions and diagnostic decisions going together? We need both of these because you can't make a diagnosis without evidence, be it a science base for a structural diagnosis, or a 'social' diagnosis, but don't forget that evidence involves your clinical experience as well as all the thousands of trials that are published every day. And you also need values. People say to me: "hang on – I can see that values can guide management but what have they to do with diagnosis?" I think they have an awful lot. Let's go back to our patient with depression. How do we know that she has got sadness, depression, stress – what are we going to call it? All diagnosis is value-laden. So what we are trying to achieve is a professional judgment that involves moving forward with a plan based around our knowledge of the patient

Finally may I also mention the European Society for Person Centred Healthcare (ESPCH) which seeks to promote a person centred healthcare which takes full account of patients' values, preferences, narratives, cultural context, fears, worries, anxieties, hopes and aspirations, and recognises and responds to their emotional, psychological and spiritual necessities in addition to their physical needs.

(Contact Prof Andrew Miles, Secretary General, Andrew.miles@pchealthcare.org.uk)

Discussion

This links nicely with what Alex Cahana was saying at one of our meetings a few years ago about phenomenology. I never read a patient's notes until after I have seen the patient. It's amazing how wrong other people can get patients.

...Don't read your own notes.

[Further discussion relevant to this topic will be found in the section: 'General discussion of Tuesday's proceedings' on page 40]

Changing the Culture of Pain Medicine: A desirable and achievable international goal?

Clare Roques

“The problem is vast and very complex; it is easy to be overwhelmed by it and paralysed into thinking that we shouldn’t try to do anything at all.”

I am chair of the Developing Countries SIG. I recently completed a Master’s in medical anthropology and I’m now doing a PhD looking at social construction of pain management in India so I’m going to draw on some of these things for this talk.

Changing the culture is a somewhat abhorrent idea in the world of anthropology – it sounds a bit like going out to the Colonies with our pith helmets on and trying to change everybody into little Englishmen. So should we be trying to change anything in anyone else’s culture? I want to start with an overview of how healthcare and culture might interact, and ask whether it is desirable to do anything and what achievable in any sense. Then I want to talk about some of the initiatives and ongoing work in this field.

I’m not going to attempt any strict definition of developing countries except to say that the UN Human Development Index (<http://hdr.undp.org/en/statistics/hdi/>) focuses on the three areas of health, education and living standards, for which they use various markers. Within that the countries are marked in quartiles so there isn’t a cut-off between developing and developed. So it’s all relative and some countries have poorer resources for healthcare than others.

Culture

Culture is defined in my dictionary as a ‘state of manners, taste and intellectual development at a time or place.’ So it is not a fixed entity that you can examine and change; it’s a very nebulous concept, and it varies with time and place. My second definition is taken from an anthropology book: ‘Systems of shared ideas, systems of concepts and rules and meanings that underlie and are expressed in the way that human beings live.’ (Keesing and Strathern, 1998)

So there are two different ways of thinking about culture in relation to healthcare. First of all is the culture *in* healthcare. That’s not a million miles away from the biopsychosocial model: how the environment and culture that someone is in effects their experience, how their disease becomes an illness, how they conceptualise and think of it and how they understand it. That’s obviously very important, especially in an overseas environment; another person’s culture may not be as immediately obvious as it would be if we were working at home.

Secondly is the idea of the culture *of* healthcare, which is more the focus of this meeting – our culture and the culture of the healthcare system within which we are treating patients. But whether we are working overseas or at home we need to be reflexive; we need to be aware of our own culture and our own perspective that we are bringing to everything. So what may seem commonsense to us may not be so at all; it may be a socially derived idea that is completely alien to other people.

The way in which we need to think about the way in which the wider social environment and context might affect an individual's illness is illustrated by the example of a malnourished child. If we only look at the *proximate* cause with the Western biomedical model of illness we will perceive that the child isn't getting enough food, is predisposed to infection and will be vulnerable to a high mortality. So the instinct is to just give the child more food and think that the whole problem will be sorted. But you also have to look at *intermediate* factors in the child's environment, such as social practices which might lead to the food being distributed to the whole family, or to the young adult who is going out to work to bring more food in, instead of the malnourished child, and there may be as poor sanitation and hygiene. And behind this there may be economic, political, and natural *ultimate* contributors to the child's problem. It's easy to see this sort of thing overseas but it's probably true back home as well.

The need for change?

I'm going to come back to this in the context of pain management. But is it desirable to change the culture? I'm not going to question the benefits of treating an individual person's pain, but I do want to share some fairly shocking statistics. First: the World Health Organization (WHO) estimates that five billion people live in countries with low or no access to controlled medicines and have no or insufficient access to treatment for moderate to severe pain. In the same report they go on to list all sorts of conditions including cancer, HIV/AIDS, post-op pain etc. There isn't a huge amount of comprehensive epidemiological data but what there is suggests that the prevalence of untreated pain will be higher in developing than in developed countries. If we accept the idea that pain is something to be treated (which, it can be argued, is not necessarily a given) there are a lot of people out there not getting access to effective treatment.

There has been a lot of recent talk about human rights and I'm not going to talk in any detail about the philosophical debate about the universal nature of things as human rights but you are all familiar with the *Montreal Declaration* of 2010 which stated that 'Access to pain management is a fundamental human right.' With regard to palliative care, the campaign group Human Rights Watch also identified access to palliative care as a human right in their *Global State of Pain Treatment* report of 2011 (an extensive but interesting read which is easily accessible online). This reflects a focus on palliative care which is often seen within such organisations. The issue of human rights is probably contentious in some areas but nevertheless is how a lot of the debate is being described at the moment.

So is change desirable? I think so and that in an ideal world (which we don't live in) it is something we should be striving for, but that's just my perspective and not everybody would agree.

But is it achievable? With five billion people in need in a phenomenally difficult economic and social environment? We can't even treat chronic pain here, so we clearly can't sort out everyone's pain. But there probably is a fantastic opportunity for us to be looking at the bits of our work that we do do well and to build new models and new ways of doing things, and to learn back from some of the processes in action overseas.

A list of barriers to change taken from the *Oxford Book of Palliative Medicine* identifies the same ultimate, intermediate and proximate factors as I was talking about earlier. Ultimate global, society and policy barriers include such problems as

drug availability and funding and economic issues. Intermediate social barriers involve the influences of ethnicity, culture and religion which may lead to patients not describing or even reporting their pain, partly because they don't think there will be any treatment for it but also because they are living in a culture where they don't expect pain to be treated and regard it as something they have to put up with in life. Then there are huge proximate professional barriers, shared by patients and their families, associated with both mistaken attitudes and lack of knowledge, such as fear of addiction and of using opiates at all, and the stigma attached to many treatments.

The Declaration of Montreal summarises quite a lot of these points and suggests some of the areas that should be targeted. It identifies:

‘Inadequate access to treatment for acute pain... and failure to recognize that chronic pain is a serious chronic health problem requiring access to management...’

and acknowledges that there are:

‘...major deficits in knowledge of healthcare professionals...’

and

‘Most countries have no national policy at all or very inadequate policies.’

and

‘...severe restrictions on the availability of opioids and other essential medications...’

One of the key issues is that of essential medicines. A lot of the debate and published work has been about morphine and getting access to it, and it is on the WHO's list of essential medicines. The figure I quoted about five billion people earlier was taken from the World Health Organization (WHO) 2011 report *The World Medicines Situation: Access to Controlled Medicines*. In a lot of countries there is very strict legislation to control diversion and problems that are highly reported in the US and other Western countries. All countries have to report their drug usage to the International Narcotics Control Board (ICNB) who issue statistics.

In 2003 the ICNB reported that just six developed countries used 79 per cent of the world's morphine and 80 per cent of world's population, i.e. those in developing countries used only 6 per cent. In 2007 the consumption of morphine in the USA was 150mg per capita; in France it was 80mg. and in the UK 55mg. The global mean consumption was 6mg per capita. In 2010 Americans consumed 256mg of morphine equivalent per capita; in India the figure was 0.24mg.

A lot has been written about access to opioids, and this has been the focus of attention for several organisations including Human Rights Watch and WHO, and a lot of palliative care groups. Three key areas of problems have been described. The first is that of maintaining a balance between availability and control. Some countries have phenomenal amounts of legislation and bureaucracy for import licences; by the time you've got hold of one licence the first one has run out. Healthcare workers may be afraid of prosecution. A lot is being done (India is the country I know most about) to simplify narcotics laws but it's not an easy process. The second problematic area is availability, and is partly the responsibility of the pharmaceutical companies. It may be very difficult to obtain cheap oral morphine even though you can buy prohibitively expensive Fentanyl patches with relative ease. Thirdly there is lack of knowledge associated with attitudes which amount to opiophobia.

Organisations such as Pallium India, the group in Kerala led by Dr Rajagopal, and the Uganda based group Hospice Africa have done a huge amount of work towards making cheap oral morphine available – they actually make up the solutions themselves.

The Pain and Policies Study Group (PPSG) in the University of Wisconsin provides all the statistics and graphs for the WHO reports. Their tagline is to 'To improve global pain relief by achieving balanced access to opioids' and they do a lot of advocacy work. If you look at the WHO Collaborating Centre website you can get data out for almost every country. They award Pain Policy Fellowships. Their work is in general focussed on palliative care rather than more general pain issues.

So is it achievable? The answer is 'Yes'...but only to a certain extent and we do need to be realistic. The two areas where we could make progress are education and advocacy. And when I speak of education I mean sharing ideas about what works and doesn't work, and being honest about it, rather than trying to impose a model of what we do here – which may not even work here. And there's a lot we can learn in return.

As well as WHO and the PPSG, initiatives in this field have emanated from the World Federation of Societies of Anesthesiologists (WFSA), who have an education committee, the World Medical Association (WMA) and Médecins sans Frontières.

Palliative care

There is a lot of work in this field, and several organisations involved including the International Association for Hospice and Palliative Care, Help the Hospices, the Global Access to Pain Relief Initiative (GAPRI) (which is focussed on cancer pain) and the Worldwide Palliative Care Alliance (WPCA).

Extensive mapping studies have been carried out by the International Observatory on End of Life Care in the University of Lancaster with detailed reports of the state of palliative care in many countries. Teaching initiatives include the work of GAPRI who have produced an excellent series of short films called *Life before Death* which sum up a lot of the problems really well.

There are also models of something we may not think of as palliative care; specifically the group in Kerala run by Suresh Kumar called the Neighbourhood Network of Palliative Care (NNPC). Instead of classifying everything by disease patients are classified by their disability, whatever the underlying cause of their condition. It is run by volunteers supervised by healthcare teams who seek medical help when necessary. They may be dealing with a wide range of health problems such as mental health issues, dementia and paraplegia as well as palliative care. There are also examples of palliative care services looking after people with sickle cell crises so there is quite a lot of overlap.

A lot of the work of these organisations is directed towards access to opioids. This is an important area and one where a lot of gains can probably be made. But there are potential problems if we don't work closely with palliative care and build on the work that is already there. First of all there are going to be patients with acute pain who aren't going to benefit. I visited a hospital where they had practically no morphine available in theatre even for major operations and didn't think it was necessary or desirable. But in the same hospital oral morphine was freely available in the oncology unit.

The converse of that is that there may be patients who were getting access to morphine when perhaps they shouldn't, and for whom there may be other treatments which may be more appropriate. This may be reflected in education, practice, political lobbying and research.

There is also a potential for complacency if these big organisations have impressive headings like 'We're treating worldwide pain', which seems to imply that all pain is being treated which it is not, if they are only focussing on palliative care. It might even send out the message that some conditions are not worthy of treatment.

IASP activity

I want to move on to work that is being done more generally in pain rather than specifically in palliative care. A lot of countries have their own IASP chapters and their own initiatives. There are several regional groups: the European group, the South-East Asia and the South American group. IASP publications include a document on pain management in resource-poor settings as well as the other educational resources.

Advocacy work undertaken by IASP has included the *Montreal Declaration* and the various IASP 'Years against' (headache, acute pain, visceral pain etc.)

The Developing Countries Working Group (DCWG) was set up by Michael Bond in 2002 and he chaired it until last year. They carried out a survey looking at education and training in developing countries. They have been instrumental in setting up 'bottom-up' grants towards such projects as storage and use of opioids in Nigeria and Egypt, and education in cancer pain, and running clinical fellowships (with the cooperation of the WFSA) There is a very successful programme in Bangkok, and trainees have gone there from Cambodia, Laos, Vietnam, Mongolia, Sri Lanka, Bhutan and Indonesia. There is also a programme in Bogota and a pilot project in Cape Town. IASP has collaborated with other organisations such as the WHO, Hospice Africa Uganda, (HAU) and Kybele which is an African organisation looking at women's and child health.

The 2007 IASP survey of *Education and Training for Pain Management in Developing Countries*, which was sent out to all IASP members in such countries, had a low response rate (189 out of 927) so it is difficult to obtain comprehensive quantitative data. But it certainly provides some interesting suggestions regarding future targets, particularly regarding education which remains the main focus of the DCWG.

Another survey, *Desirable Characteristics of National Pain Strategies* (2011), which went to all IASP chapters so is not specifically directed to developing countries, produced some interesting comparative data again highlighting the need for training and increased governmental input into policy changes and integrating these into pain strategies.

The BPS Pain in Developing Countries SIG

This has been in existence for two or three years now. We have about 70 members. It has been difficult to know what such a small group can do with such a phenomenally large problem but there are some initiatives we can undertake. We try to keep these issues in the news with articles in *Pain News*. We recently did a survey of BPS members and DC SIG members to see if we can get together a database of people who are interested in working abroad, or have already worked abroad and

who might have ongoing links, and try to match up these people with any groups that might need the resources we can offer.

The first project we have got underway is a course called *Essential Pain Management* which is written by Australian and New Zealand anaesthetists. We are running this course in Uganda in a couple of months' time. It has been funded by the BPS and the International Relations Committee of the Association of Anaesthetists. If this is successful we are hoping to take on a longer collaboration with the Faculty of Pain Medicine and maybe others to set up a series of courses, mostly in Africa. *Essential Pain Management* is a lovely simple course written by Roger Goucke and Wayne Morriss from the Australian and New Zealand College of Anaesthetists. They wrote it originally to be used just in developing countries and started using it in the Pacific region but it is now becoming increasingly popular and they are actually running it at one of their medical schools. It's a one-day course; all the teaching materials are essentially there. It is very much a basic structure on which local groups can work out what treatments they have available and how they can best use this basic tool in their own environment. As well as teaching the basics of pain management there is a section on recognition of local barriers and how these might be overcome. It is often run as a series of three workshops, which is what we are hoping to do in Uganda. The first is the one-day course, the second is for training the trainers, and the third is another one-day course with a new set of participants which is basically run by the new local trainers. The aim is to encourage local handover very early on and to use the tools we give them as best they can in their own environment. It is supported by IASP and the WFSA and other groups and is run in many countries throughout the world and becoming more and more popular.

To get people thinking very basically about different types of pain it starts with a simple classification of acute and chronic, cancer and non-cancer, nociceptive and neuropathic pain. There is some basic physiology describing the steps involving the periphery, the spinal cord and the brain, ascending and descending pathways and the concept of modulation. This part is sometimes omitted if it seems too complicated but it tries to introduce the idea of a higher input which may modify pain and why it might be useful to employ psychological therapies including explanation, reassurance and counselling, and to encourage thinking first about non-drug physical treatments such as rest, ice, compression, elevation, surgery, acupuncture, massage and physiotherapy before resorting to drugs. Teaching on the latter [with a slide grading usefulness of drugs in different causative categories and severity of pain] involves getting people to understand that morphine may not always be necessary or appropriate, that simple analgesics can be useful, and that Amitriptyline and Carbamazepine (or whatever is locally available) can be used to treat neuropathic pain.

Conclusions

Perhaps we should be aiming for a better understanding of cultural context – becoming 'culturally competent' – rather than trying to change other people's culture. Indeed we need to be more aware of our own culture and the social context we are working in, and how our attitudes have been informed by the environment we were brought up in.

The problem is vast and very complex, and it is easy to be overwhelmed by it and paralysed into thinking that we shouldn't try to do anything at all. I don't think that is the right answer; there are things we can do but we need to be very realistic and quite specific about picking out the things we are probably good at and being aware

of the things we are not good at. We need to build on successful work already underway – for instance taking advantage of improved access to opiates for palliative care to use them for acute pain. The way forward lies in working together on education and advocacy.

‘The post-Cartesian world has very successfully out-descarted Descartes. It has perfected a pain so stripped down that it has almost no meaning and no social value at all.’

Morris. *'The Culture of Pain.'*

Discussion

That course (Essential Pain Management) should be required for all medical students and perhaps all GPs.

That separation of chronic non-malignant pain and cancer pain is artificial. One of my colleagues described our chronic pain patients as non-dying palliative care patients and you can make a strong argument for linking the two. One reason for not linking them is that palliative care is largely funded by oncology. But palliative care isn't only about oncology: their patients have other problems. Perhaps the developing world is the place to put this perception into practice.

It's interesting that we keep making statements that acute and chronic pains are different. There isn't a shred of evidence that the mechanisms underlying them are in any way different. There's a lot of social difference and a lot of social factors involved in chronic pain simply because it is chronic, but whether they are in fact different phenomena or not is still an open question.

I thought your talk was great and it's nice to see things that have been in gestation for a long time coming to fruition. IASP started trying to work with WHO in 1981. They are impossible to work with...

...You're not the first person to have told me that...

...They are riddled with internal politics. I hope that the current IASP project to try to get the WHO classification scheme to reflect more meaningfully what pains are will bring something to fruition but ...

...The WHO is very focussed on cancer pain – so they're missing a trick...

There is no question that the WHO is controlled by oncology. But if that's all you can do in a country it's better than doing nothing.

If you want to read more about IASP activity with regard to education in developing countries buy the transcript of the 2010 meeting and Michael Bond's talk on the subject.

There was also an article in the *British Journal of Pain* last year in which he wrote a summary.

Who's going to deliver this course in Uganda?

I'm going to lead it and there are two anaesthetists there and the Hospice Africa Uganda people, and a registrar from here.

The new Dean of the Faculty, Kate Grady, and Doug Justins who has already taught on one of these courses, are keen to get a comprehensive strategy to get things more organised to set up more courses. At the moment we have people like me going funded by the BPS and someone else with other funding. What we're going to try to do is to get some kind of European Pain Network (EPN) co-ordination, with a database of people who are interested in helping and of the people that need help, for running a course or whatever. So watch this space – we are going to be working things out over the next couple of months and making a plan.

I've done some of this with medical students who aren't taught much else other than the WHO ladder.

One thing that bothers me as a pain person is in the USA where you can see the following phenomenon: The National Institutes of Health have as their mandate 'to relieve the burden of illness from the American public.' The burden of illness due to back pain alone is more than the sum of cancer, heart disease, stroke and AIDS, if you measure disability, that is. Disability due to back pain swamps everything else. The NIH spends less than one per cent of its budget on pain research. The other organisation, which sits 200 yards from where I work, is the International Health Foundation which Bill Gates has funded with a 40 billion dollar from his trust. They too have taken on this mandate of relieving the burden of illness in the world. Their recent publication documents the burdens of illness in different countries throughout the world without one word about pain. There's an old rule in my country: 'strike where the money is', so it seems to me that people with the interest you have ought to come at the Gates Foundation and see if there is a way of getting them to provide money to relieve this burden of illness – not just infectious disease. They have lots of money – more than you or I could ever dream of! [Gates] has completely bypassed WHO and set up programmes to eliminate malaria and childhood diseases.

The other one is the European Union, if you can face all the bureaucracy. We got 2.7 million Euros out of them for empowering education in Malawi and Tanzania to tackle maternal and neonatal mortality working with non-physician clinicians who do all the work there. You have to research your approaches as you are doing it. But this would sit very nicely in terms of doing something sustainable in developing countries. You have to work with non-physician clinicians for it to be sustainable. (The work you do with doctors is not sustainable because you are giving them a passport to leave.) The EU likes that and you just need one other European partner and an African partner. There is another African call coming up next year.

There is a lot of money out there for a lot of projects. We are starting small but if we do get bigger and show what we are doing is workable there may be opportunities for bigger projects.

[Partly inaudible] ...Societal Impact of Pain ... got nowhere with the EU ... doesn't have votes in parliament ... it's a good idea what they are trying to do but the EU won't buy them.

You said something interesting which I personally observed in Egypt 30 years ago when Mubarak was president. At that time the only opiate available in Egypt was Fentanyl patch. What on Earth had happened? The answer is that an American business managed to bribe the minister of health into buying Fentanyl patches, but they didn't have morphine. How are you going to overcome that problem? Because generic drugs don't have any marketing associated with them, and are competing with the marketing of expensive drugs. This is a big issue in many developing countries: they have the expensive drugs but not the basics.

...India is one of the world's largest manufacturers of morphine...

We need a different word for pain. Pain's not sexy. People give money for people dying with cancer.

What about suffering? – The suffering clinic? It would make the point of what it was there for.

General discussion of Tuesday's proceedings

In the last sentence of the introduction to the programme I used the word optimism. Beatrice took me to task on that and said it was thoroughly unrealistic. I'm afraid she may be right, and I do think we must identify and face some of the objections and obstructions to progress. I would like to mention two which came to mind when Ed was talking. One we identified last year when we were talking about education was that because the process of qualification requires passing exams which are largely science-based the sort of thing Ed was talking about tends to take second place in people's priorities, if not disappear – indeed someone said they don't even bother to turn up for the classes if they don't perceive that it's going to be any use in passing their exams. The other related problem is that once you qualify, the system of postgraduate education – not just the education but the role models you work with who have inherited their attitudes from their role models – may be distinctly inimical to the sort of change in the culture of medicine we have been talking about. How can we overcome these obstacles? Do we have any grounds for maintaining optimism?

I think optimism is like hope – you don't want to kill it. They are both good. ...Like with our most despairing patients ... if you take away their hope you're done. It's the same with professionals – you've got to try and hang on to the optimism otherwise we may as well give up and go home.

There's a great tendency for all of us to believe that what we were taught when we were trained is the Truth so it is very difficult to get the providers in the healthcare system to change their way of thinking. In my country at least the great majority of physicians are biomedically fixated. I don't know how you get them to change that.

We must beware of a false dichotomy here. In looking at appropriate people for the job ... if you're looking for jet pilots you have a very small pool to choose from as you need people with superb hand-eye coordination and computer skills etc. The same is true of a lot of clinical subjects; just because we are choosing people with high grades that's not automatically wrong in the sense that we do want technical and rational mastery – that's what the public expect. But what they do want as well is humanism and compassion. If we fish in the pool of people who have reasonably high academic qualifications there are masses of people who are humane and compassionate. What we have to do is to actually make those qualities valued. There are two angles here. One is that we should start earlier – even the school education system can play a part – and looking at using arts and humanities as part of the subjects that we are choosing. It's our own fault that we are asking for grades in science. As well as scientific competence we should be looking at evidence of a broad outlook in arts and humanities. The second point is that the old adage that assessment drives the curriculum is not false, and it is up to us who run medical schools to change the way we rate success, and to prioritise – people will not get through if they cannot demonstrate mastery of the tools of interacting with their fellow human beings to a level which is every bit as high as their scientific mastery. I think it is possible – I just don't think we've got it right.

In our (American) medical schools the primary measurement of success is the student's scores in the national board examinations. These have only recently started to contain a few questions relevant to pain. The problem is that if the medical schools teach to the exams then you've got to figure out how to get the exams to change. Who writes the examination questions? The faculty of the medical schools all over the country submit questions which are then used to generate the national exams. It seems to me you have a tautology here. I'm not sure how a minority of faculty members, because that's what we are, are capable of effecting the change we need to see. We need to change the exams first and the faculties and courses will follow. Nobody really knows how people practice medicine – all they know is how they score on the exams and that's what they measure.

We can help from this side of the Pond in the sense that we have resisted the universal examination. We do not have national board exams here. The belief here is that the curricula of all the 31 medical schools in the UK are different, and therefore the assessments must be different. The GMC is concerned about standardisation because there is evidence of variation and that is being addressed by having a few components of final assessment for qualification in common. But it will still be individual. The advantage of that people can experiment with progressive assessment of development. One of the exciting things for me as an educationalist is that a lot of clinical skills have been assessed by the Objective Clinical Skills Examination (OSCE) which is a component test. It is very valuable; there are some superb OSCE's including some that can test really refined social medicine content etc. However, it is still a component test. One of the sexy new trends that is emerging in assessment is whole process examination. We're not going back to the long case, because the long case had its problems, but I think that – and the Dutch are leading the way – in terms of problematic assessment where every component of what patients want their doctors to look like is systematically assessed throughout the medical course. But in there will be a lot of task assessments, and if the pain people can write some very good whole task assessments that really don't just look at a two-minute clip of what you should be doing with someone who happens to have a problem with pain, but look at something much more systematic, pain will come in as a gift to assessment, whereas I believe that it is a gift to education.

At Imperial we are looking at psychometric testing on students to see what they would be best at. I don't know if they test anything other than mechanical skills if they want to be surgeons and that sort of thing and I don't know whether things like humanistic skills and empathy could be included.

Could you use some of the tools of modern neuroscience to validate the issues you are interested in? People now need evidence and measurability and hard data. I'm not a neuro nut but people like Benedetti are producing books on patient/doctor interactions and the brain changes you see with hope and expectation...

I thought you were going to suggest that all students should have a PET scan when they come through the door!

We've been talking about educating clinicians but we haven't said anything about educating society and patients themselves. A lot of people are waiting for something to be done to them. I think we need to educate people from children upwards to take responsibility for their own healthcare and what they can do for themselves. [Partly inaudible] ...they did something in Australia with public broadcasting...

There is a private university in Germany, Witten Herdecke University where they were using what may seem rather strange methods including anthropometric testing*

and to do anatomy you had to work with clay and put muscles on bones and all sorts of things you wouldn't do at a 'normal' university.

** www.uni-wh.de/en/*

It was a commendable attempt to teach medicine from a humane approach but they struggled very hard to be accepted by the mainstream.

One of the things I've noticed over the last five or ten years is that we seem to be becoming more extreme. Whereas before, most of us were in the middle doing a bit of intervention, a little bit of psychology and so on we're becoming more and more interventionist or psychological. We have heard how this is happening in the US but it seems to be happening in the UK and I don't know where it's coming from. The multiprofessional model I was brought up with seems to be disappearing. Or is this my misperception?

I think you're right. It's part of the fragmentation process. In our country it's part of competing for the healthcare dollar, and the insurance industry which has made funding decisions which have nothing whatsoever to do with outcomes data or patient data. It has to do with political agitation by groups of physicians who are trying to protect their piece of the action – not just their financial piece but their intellectual turf as well, because even if you have someone on a salaried system, not fee for service, if they haven't any business they are going to lose their jobs so people fight for what they do to earn a living. All of those factors are playing a role and it's really hard to maintain a multidisciplinary approach. This takes teamwork, financial and institutional support, and it's just much easier to do it all by yourself.

[Interviewing new students? - inaudible] The students who come are all very well prepared and if you test for compassion and humanity they will do that. They are all very intelligent. I've been more than 20 years in this field; I didn't have this ... when I entered medical school. Whatever test you keep doesn't reciprocate into practice; the culture change has to come from practice rather than testing.

*We're talking about selecting students at an early stage for empathy or motor skills ...but... we talk about patient narratives but all of us here have different narratives of how we come to be in this room. It's almost as if there is some sort of selection process going on within medicine. Years and years ago there was a very good paper in *Anaesthesia* on the personality of anaesthetists, and showing how – for want of a better word! – They deviated from the norm. So you had to ask: how has this happened? There was no-one there 40 or 50 years ago actually directing you into anaesthesia or heart surgery or whatever. So there are other processes going on which we haven't mentioned and which do concern me when I interview medical students. We're going down this route of trying to find out if they can empathise and we ask the standard questions and get the same stuff churned out; I want to cut my wrists sometimes! I remember seeing a guy who had come up for interview. He was very smart; he had a good degree and had worked in the City of London as a trader. He had a bottle of water by him and in 45 minutes he went through a litre – you could see him doing all this on the trading floor. We reckoned that although he didn't show much empathy he would probably have made a very good cardiac surgeon – he had that sort of drive and determination. But because he wasn't what we were looking for it was like... we don't think we want him.*

I once did a study with an anthropologist in Israel and I interviewed doctors from different specialities about their perceptions of people who had chronic pain. The

neurosurgeons liked patients who said they have 'pain there, there and there.' But the psychiatrists liked patients who said 'it feels like I have a stone around my neck.' I went through the whole gamut of specialities until at last I got what I wanted which was from the general physicians. The anaesthetists were different but the neurosurgeons stood out.

Social media in medicine: Benign influence or spin?

Trish Groves

“It’s like Chinese whispers – you tell somebody who tells somebody who tells somebody ... the great thing about Twitter is that you can eyeball it and see immediately if you are interested or not.”

My brief was to talk about agendas and spin and democratic debate. I’m drawing on two reports published in the last month. The first is on international trends in Internet usage and published by a consultancy called KCPB.

It’s about where we are now but they make the point that it’s difficult to predict the future and technologies often come out of the blue. We could never have expected to have more computing power in our pockets than the Apollo moon rockets. In the Sixties we had mainframe computing and now they are talking about everyday wearable computing and glasses that will project what you want for the Internet straight into your eye. They have already brought in rules to prevent you from searching for the person you are talking to.

This has driven how we communicate with each other. In the 1990s people danced at pop concerts – now they video, click, share and tweet each other. It’s not surprising that India is second in world internet usage; back in the 1990s I was writing articles in the BMJ about the need to get telephone lines to people in their homes and in hospitals so that doctors and healthcare workers could get easy access to information from books and journals by wired internet, but mobile phones have completely leapfrogged that. (The USA and the UK are well down the list and Japan, surprisingly, last.)

Social media have been variously defined as:

‘Applications that build on ideological & technological foundations of Web 2.0 & allow creation and exchange of user-generated content.’

(Alqvist T et al, 2008)

‘Interactions in which people create, share, and exchange information and ideas in virtual communities and networks.’

(Kaplan AM, Haenlein M, 2010)

‘Information tools that both exploit and celebrate our social nature.’

(Coiera E, BMJ 2013)

The first is about the technology but the second is about people and the third is about the tools that allow them to interact and to exploit and celebrate our social nature. These things are just tools; the medium is not the message – what’s important is what we do with them.

The GMC which rules how doctors are supposed to behave has a social media policy which covers blogs and micro blogs such as Twitter, internet forums such as doctors.net and the BMJ’s Doc2Doc which doctors use to talk to each other, content communities such as YouTube and Flickr and social networking sites such as

Facebook and LinkedIn. People can use LinkedIn to share their work profiles etc: it is used enormously in India and, apparently, increasingly here.

The same KCPB survey ranked the usage of various media internationally. Facebook, YouTube and Twitter came way out top and there were some at the bottom you may not be familiar with but are being increasingly used by the young, such as Tumblr which is huge amongst teenagers mostly for sharing images and blogs, and Instagram which is an app which allows you to share photos to which you can add effects. These things go in and out of fashion.

Twitter

The great and powerful thing about Twitter is that you can share links to articles and websites etc – I use it all day and everyday and get all my information from Twitter now – I've given up on reading journals. The way it works is you join and have your own profile (since I joined in 2010 I have sent 12,658 Tweets, am following 820 people and have 3316 followers). Unlike email, which is horrible, horrible – I am seriously thinking of deleting my email inbox, which always contains about 600 emails, and I simply cannot answer them all – the great thing about Twitter is that it is a stream which you can step in and out of. You can take it or leave it, and if something whizzes past and looks interesting you can click on it. It's the equivalent of a ticker at the bottom of the TV screen which gives you the news headlines. I think it's wonderful but you may not believe me. You can look to see who has picked up or re-used the tweets you have sent. It's not time wasting – it's actually parsimonious. People take Twitter seriously and the LSE has by far the best guide *Using Twitter in university research, teaching and impact activities, a guide for academics and researchers*, published in 2011. <http://blogs.lse.ac.uk/> It is concise but very informative and contains lots of different ways of using Twitter, not just the basic stuff. Twitter does tend to be rather device dependent: if your contact with the internet means you are logging on to your home computer morning and evening then Twitter probably isn't for you, and it is probably much more useful if you have a phone or a tablet that you can use 'on the go'.

Blogs and Facebook

There are lots of these: the BMJ has a very active blog site, Doc2Doc. We get bloggers from all over the world. People will share information through different media. The cardiologists in the US have a huge network with closed areas where they can consult one another about patients, as well as forums for discussing academic issues. I think there is an industry site where industry can get feedback from sponsorship. Discussions in Doc2Doc cover a wide range of subjects, recently including *Why do medical students behave badly*; *Why do doctors prescribe expensive drugs*; *Should castration of sex offenders be banned*; *Ignorant doctors and blood pressure* and *Should unconscious patients be tested for HIV?*

I only use Facebook for family but lots of companies, journals, hospitals and patient groups do use it and it is a great way to tell people what you are doing and then they discuss it.

Interaction

I want to talk now about the people aspect – the interactive aspect. We recently published an article by Enrico Coeira, who is a Professor of Medical Technology in Australia. He argues that we can use social media to improve patient care,

particularly with what have been called social shape diseases. He describes the concept of *social contagion*: that illnesses and health states can be transmitted socially – not like sexually transmitted disease but, for instance, it is known that people tend to marry others with similar rates of heart disease or diabetes. But it's more than that: it also includes things like poverty, education, diet, smoking and all sorts of confounding factors. There is increasing evidence that chronic, lifestyle type diseases do spread within social networks. This seems to accord with the concept of *Homophily*. People tend to have friends who are similar to them. Is this simply 'birds of a feather', or do individuals alter their behaviours to match those of their peers? Recent controlled experiments suggest both, with reinforcement. One such showed that diffusion of a simple diet diary, tracking calorie intake etc. was stronger in more homophilous networks, suggesting, perhaps not surprisingly, that our most similar friends have most influence on our behaviour.

Nicholas Kostakis has done lots of work using the Framingham cohort: following people in the USA over years and years, looking at all sorts of aspects of their lives and rates of heart disease to develop risk scores for dying with this. He has looked at these data from all sorts of angles and written on the spread of illness through social networks

Coeira avers that you can intervene in networks, using the tools I was talking about. You can intervene between individuals: champions central to a network can increase diffusion of evidence-based practices. If you want to intervene in groups, such as multiprofessional teams, for instance to improve hospital safety or perhaps quality of nursing care, you can look at social interactions as well as professional interactions to change behaviour. He also talks about network induction, how word of mouth, snowballing and viral interventions can spread information widely if you understand how the group functions socially, as with HIV prevention messages among peers. And there is network alteration, for instance in the management of alcohol or drug use removing someone from a group who is a particularly bad influence, or changing the nature of connections. This may seem rather obvious but here we have academic studies which show how to do this in a planned way.

Crowd-sourcing was used by astronomers without the time to analyse all the data from the Hubble telescope to enrol lots of amateurs in finding new nebulae using their home computers. It was used to define the structure of a protein, by putting images on the Internet and telling people what patterns to look for, and has been similarly used with great success in cancer research. An Italian patient did this with his own brain tumour: he had a rare one and there was something about his clinical test data that his doctors were puzzled about. So he put it on the Internet as a blog and asked if anyone could help solve the puzzle, and was successful in this.

Table: Online Physician Activities: Benefits, Pitfalls and Recommended Safeguards			
Activity	Potential Benefits	Potential Pitfalls	Recommended Safeguards
Communications with patients using e-mail, text and instant messaging	Greater accessibility Immediate answers to non urgent issues	Confidentiality concerns Replacement of face-to-face or telephone interaction Ambiguity or misinterpretation of digital interactions	Establish guidelines for types of issues appropriate for digital communication Reserve digital communication only for patients who maintain face-to-face follow up
Use of social media sites to gather information about patients	Observe and counsel patients on risk-taking or health-averse behaviours Intervene in an emergency	Sensitivity to source of information Threaten trust in patient-physician relationship	Consider intent of search and application of findings Consider implications for on-going care
Use of online educational resources and related information with patients	Encourage patient empowerment through self-education Supplement resource-poor environments	Non-peer reviewed materials may provide inaccurate information Scam 'patient' sites that misrepresent therapies and outcomes	Vet information to ensure accuracy of content Refer patients only to reputable sites and sources
Physician-produced blogs, micro-blogs, and physician posting of comments by others	Advocacy and public health enhancement Introduction of physician 'voice' into such conversations	Negative online content such as 'venting' and ranting that disparages patients and colleagues	'Pause before posting' Consider the content and the message it sends about a physician as an individual and the profession
Physician posting of physician personal information on public social media sites	Networking and communications	Blurring of professional and personal boundaries Impact on representation of the individual and the profession	Maintain separate personas, personal and professional, for online social behaviour Scrutinize material available for public consumption
Physician use of digital venues (e.g. text and Web) for communicating with colleagues about patient care	Ease of communication with colleagues	Confidentiality concerns Unsecured networks and accessibility of protected health information	Implement institutional practice and policy for remote and mobile access of protected health information

Source: Online Medical Professionalism: Patient and Public Relationships: Policy Statement
From the American College of Physicians and the Federation of State Medical Boards

Discussion

There's a generational aspect to this: if you're over 30 you are less likely to use social media than if you're a teenager.

There's a grey power thing – a lot of older people are...my dad died at 98 and the first thing he asked when he went into a nursing home at the end of his life was "have you got WIFI?" so he could use his Ipad. Things are changing – it's people with time. And our patients are using these things.

A lot of people are scared to put anything on Twitter because they don't want to be seen to be critical or whatever...

... Your Trust has a gagging clause and you're not allowed to slag them off...

...That sort of thing and people don't want to be seen hanging their dirty washing out...

It's easier for journalists and editors to publish because Twitter is essentially a publishing site. But there are doctors who use it and lots and lots of patients who do. There are rules: you must use your real identity – you may have a Twitter handle but your page has your real name and place of work etc. You mustn't be defamatory – basically you shouldn't say anything you wouldn't want published.

You can make it safe: you can pre-moderate and postmoderate things like blogs. You can have a private page on the Internet where patients can post their comments. I'm a bit worried about this – it might be a little too personal and you might not want it to be in the public domain. That's what we do with our rapid responses in the BMJ. We've published nearly 90,000 e-letters since the mid-Nineties and we pre-moderate them and don't post ones that are really stupid, defamatory or offensive. You can protect people in this way.

It's un-nerving when people pick up and re-tweet things – you sometimes find weird people trying to follow you. My god-daughter is in PR at Leeds and the first thing they do when they start their PR course is to teach them how to sanitise their Twitter and Facebook because employers know everything you've ever tweeted comes up comes up on search.

I run an online support group. We found we could improve people's self-confidence online ...[inaudible] ...recently put a survey online and got over 3500 responses... individual pain clinics can do that on a smaller basis...

The important thing is for people to realise they are not alone. For example we have one member who lives on a farm in South Africa with severe fibromyalgia and can't ever get out of the house. He hasn't got a hope of getting to a pain management programme but other members of the group share the information they have had. We actually find it more beneficial to have people with a mixture of conditions including some who are healthy otherwise the conversation can get a bit depressing.

People can be addicted to the positive comments they get on the forum ...go on line and say I'm really down this morning and five minutes later someone tells them you're wonderful...they can get addicted to that...

Is that necessarily a bad thing?

Well, you can tell that people are sitting there all the time depending on this sort of thing and I tell them they should be out doing things.

What about the litigation issue?

Yes it is an issue. Twitter is a publishing platform. You will remember the case of Sally Bercow, the wife of the Speaker of the House of Commons, who was convicted of Twittering libel. She has thousands of followers and should have known better, but people who were twittering us information were considered not to be worth prosecuting as they had very few followers.

We have a new libel law which is much more sensible than the old one, but nevertheless, the simple rule with libel is if you put something into the public domain

in any way that can lower the reputation of the person in peoples' eyes, that is potentially libel, and in the UK the onus is on the you to prove that it wasn't libel. In most other countries it's the other way round: the person libelled has to make the case.

I want to go back to what you were saying about the early days of communication strategies in Africa. I'm involved in an education project in Malawi and Tanzania. What we have found is that we have to use different solutions in different locations. For instance in Malawi we have found something which is commercially valid and sustainable whereby Skyband who use a lot of WIFI hot-spots around the country and provide scratch cards which purchase time on these hot-spots. They have been able to install hot spots specifically around the rural health clinics, hospitals and centres and provide free access to any of the sites that we recommend – the BMJ is one of them. People can have free access to any source of material that they legitimately need to improve healthcare provision. This is proving commercially viable for Skyband as although they aren't making anything directly out of their investment in installing hot spots, once people start using it professionally and buying their scratch cards to do their social networking they are doing quite well. We have had to use a different wrinkle in Tanzania and other places but it is possible.

I'm no technophobe but my biggest concern is the thought of having tweets going on all day which would drive me insane. I find how intrusive the technology has now become into the clinic. Patients tell me about the doctor who is looking at the screen and not looking at them. Electronic health records have been a curse since they brought them into our hospital eight months ago. These things all intrude into my face-to-face contact with patients. I don't want tweets all day – it's bad enough now with all the text messages I get on my mobile. It's all coming at us too fast and our way of working is changing as a result. I'm not sure we have a good idea how to control it actually within the clinic – it's a bit different for you in an office or on a train.

Yes – it's not going to stop so you have to find ways of managing it – or harnessing it. There need to be rules about where and when it can be allowed and so on. But it won't go away.

...I don't want it to go away but my problem is with the intrusion... and how we are going to control this thing which seems to be getting bigger all the time.

But it is fascinating how we do keep sort of humanising it. When my son was about nine or ten we didn't have any of the devices like X-Box and Playstation – he just had a PC with stuff like Tomb Raider and I thought – is he going to be glued to this stuff for the rest of his life? – I'd better set rules around it. He fairly quickly got fed up with that and went out and did other things. But my daughter who is two years younger just used it entirely socially – the equivalent of the way my sisters and I used to spend most of our evenings as teenagers in my parents' bedroom on the phone to our friends. Some of our friends' parents got payphones installed as they were fed up with their daughters running up huge telephone bills. Now they can do it for free and they can Skype their friends around the world. They are constantly talking to their friends and it reminds me of seeing people in warm countries sitting outside talking, and perhaps it isn't much different from when people in a village all knew each other and everyone knew what every one else was doing. They're at it again; these things have cycles and the challenge is to make them work, to keep them safe and appropriate.

Speaking from a perspective of total ignorance I really want to bring the subject into the context of this meeting, the purpose of which is to work out how to promulgate ideas and change people's thinking. How can the social media be used in this way?

You can tweet about the work you are doing. You can have a Facebook page. It's a very good way of reaching people. You can share articles that might be interesting to other people in the SIG. It's like Chinese whispers – you tell somebody who tells somebody who tells somebody ... I have used it to take part in a conference. I was once due to speak at a conference and I had proper 'couldn't get out of bed' flu, so I didn't go but I joined on Twitter so while they were running the session that I was in – a panel discussion – there were people in the audience and the panel who followed me on Twitter who could say that Trish has just mentioned this article that was published in Annals last week and is terribly relevant to what we're discussing – and there were people from all over the world joining in on the conference via my Twitter account. I was in a meeting at the BMJ: there were three of us there tweeting and in the two hours of the meeting there were tweets reaching 22,000 people all round the world.

The way people curate tweets is to use something called a hashtag which is prefixed by the hashtag symbol # so you could have something like #BPS SIG – you want to keep it short – and you could say that at the beginning of the meeting and people all round the world who are interested could join in. They could make comments, suggest topics for next year, say do you know about the work of this group or that article... That's how it works.

What's the difference between the hashtag and the @?

That's someone's name – their address – mine is @trished. So if somebody re-tweets one of my messages their message automatically includes it – they can delete it if they want to but you're supposed to include attribution. Or if they want to contact me they can put a message with that and when the thing that says 'connect' lights up you can click on it and see everyone that has been reading your messages. And there is also a direct private option. That would be 'want to know more about the philosophy of pain follow Trish, hashtag whatever that is for the meeting'. And if I was sitting here tweeting people could know what you are discussing. Now that depends on me giving a faithful account of what's going on, and not saying coo-er – they're a funny lot here! So there is that risk.

I read an article the other day saying the hashtag is incredibly powerful and is taking over from Facebook and the youngsters now are moving from Facebook to Twitter.

Yesterday we published a big investigation in the BMJ about the new diabetes drugs (Incretin mimetics) and I was tweeting about the article and completely coincidentally Diabetes Care published some similar stuff this month, so if you put in #Incretins on twitter you get wonderful comment, feedback, discussion and debate – serious scholarly stuff, involving a huge range of people, patients, academics, industry, GP's – extending the published work.

You might say you haven't time for all that but many people do and if you want to share what you are doing these tools are very powerful, and much more useful than a print newsletter as they are interactive.

It sounds very time-consuming – as a retired person I have no time!

Yes, but many organisations see it as an important role – it's a fulltime job for some people to manage the social media. In some companies they have whole teams doing it.

I tweeted this morning about this meeting and downloaded the programme PDF. I got an immediate reply from Sweden.

[Partly inaudible] ...a lot more we could do...to...reach more patients than we see in pain management programmes...

They can educate you too – its two way. People in psychiatry are using the Internet and social networks as cognitive tools, for instance, as they work terribly well.

And professional people use it to educate each other.

The trouble with emails is that you feel obliged to answer every one. I have a automated reply which says 'please don't be offended if I reply with a message and a header or yes thanks because that way they don't have to click on anything. And I ask for emails that are no more than a few lines and if people want to say something more to attach it as a document I can deal with when I have time, or if I need to act put 'please do this by Friday'. So I can at least prioritise what I see in my inbox. Whereas the great thing about Twitter is that you can eyeball it and see immediately if you are interested or not.

With the emphasis on brevity in so many of these formats do we know anything about the effect on narrative? Because it's really important that people should be able to tell their full stories.

Twitter can be narrative because within those 140 characters you can attach a link which can be as long as you want. There are also lovely tools: there is one called Storify which I use a lot. If you've sent a lot of Tweets, say at a conference, you can pull all of them into Storify and drag in your tweets and it turns them into a blog, and a nice story of the conference has written itself in seconds.

Are you worried about privacy?

That's one reason I don't use Facebook for work and keep it for family. Of course we have the US government watching us but I don't mind any more than I do the CCTV camera in the street – which I wouldn't want pointing at my front door. But I'm not worried about loss of privacy. All of these social media tools have privacy settings and it's important that you know how to use them. You can have a private Twitter account which only allows people you have chosen to follow you.

Summing up – The way forward

John Loeser

This has been a fascinating experience for me and I greatly appreciate the invitation to join you. The chance to participate in less than formal presentations and discussions is relatively rare. I have been to plenty meetings in my life and heard many plenary lectures and attended workshops etc. but you have a lovely format that is very satisfying for people to participate in. Some of the talks were much broader than the issue of pain. I see them mainly as a way of saying can we capture modern technology and apply it to what we are trying to do.

I would be the first to admit that when it comes to social media I am a Luddite and am driven crazy by the number of invitations I get every day to join people on Facebook and LinkedIn etc. Unfortunately when my granddaughter invited me to join her on Facebook I said yes and have I regretted that! But I recognise that that is going to be a major method of communication that we are all going to have to include and it's going to change the frequency and type of meetings that are going to occur. When I was young in order to find out what was happening in your field you had to go to meetings. Then a year or two later a manuscript based on the meeting would be published and you had to subscribe to the journal to see the publication. But we are going to have to make use of modern communication systems to accomplish our goals. Google has totally changed my life if I want to find out what is happening. So has Wikipedia, although half the things in it are wrong, but you can quickly get an answer to a question. So we need to incorporate all these things in a variety of ways.

The advertising world has taken over so we now know that if you want to have people look at your website it needs to be friendly, attractive and useable and I note that each medical department at home is hiring IT experts to help us to design these. There is technology coming in that we are all, including our institutions, going to have to participate in to keep us in communication networks. That is going to be a challenge especially when resources are limited because it costs money and doesn't provide any direct patient care.

As for pain: I think everything depends on education. Those of us interested in pain need to go back and start at ground zero and ask what shall we do to influence the education in medicine, nursing physiotherapy, social work – all the involved disciplines and figure out how to infiltrate the education system and get appropriate pain information into it. A movement has started in the US; a woman from Johns Hopkins spent a year surveying American and Canadian medical schools determining the curricular content relevant to pain and someone in Canada took those data and went to the veterinary schools in Canada. An article was published in Queen's magazine that pointed out that on average the veterinarians had eight times the pain education as the physicians. Her article, which I believe was published in Pain, started a snowballing effect. The American Pain Society has a SIG on education and many American medical schools have now started looking at the issue of how to get more pain education. It was facilitated to no small degree by the Institute of Medicine which published a huge tome on pain medicine in the USA and pointed out that 100 million people out of the 300 million people in the country had pain of some sort, acute or chronic, in any given year, and the cost to the country was 560 billion dollars. This served as a further impetus as the Institute of Medicine (IOM) report said that there was virtually nothing on pain education in any of the American health schools, whether in medicine, nursing or other things. It pointed out that although pain education in nursing schools was better than in medicine it was by

no means adequate. And so many schools including ours are trying to beef up their curriculum.

Curricular change is an interesting problem. I was the curricular dean in our school in 1977 for a five-year period. I would describe the medical school curriculum as the last vestige of the feudal system in the modern world. If you want to change a medical school curriculum it becomes a fight because for a finite number of years, no more than four, and in some places three, you have a certain number of hours and now we are much more concerned with the hours we make our students learn in than what they actually learn. So if you want to bring something new into the curriculum how do you get something out? If you're in the department of physiology and you have thirty hours and someone asks them to include six hours of pain you will say we can't stop teaching cardiac physiology or whatever. And as well as the problem of finding time for something new the people doing the teaching are oblivious to pain.

We have studied this and we do a pretty good job within the third year clerkship on family medicine in getting the family medicine faculty to teach about chronic pain and its management. Then they go out into the community and the practitioners undo most of the things the faculty did. How are we going to deal with that and influence the changes you want to see? I don't have an answer to the problem but I do think that if you're going to improve pain management you've got to improve the pain managers. And that means you're going to need more physicians, nurses and every kind of healthcare person reasonably educated about what chronic pain is and what chronic pain patients represent.

I think it is appropriate to make a dichotomy between acute and chronic pain. Most acute pain is either trauma or surgery. Numerically the major cause of pain in the US is surgeons. It's not hard to improve that kind of pain management. You do need people who care. We have seen that nurses providing feedback to the physicians can dramatically change post-op pain management. But if no one provides feedback nothing changes. That's really an anesthesiologic issue. In our system you have attendings, residents, interns and medical students and you might ask who writes the pain orders. If it's the student you're in trouble because they know nothing whatsoever about pain management and the attending surgeon couldn't care less, but it's not entirely facetious to suggest that there should be a rule to make surgeon do it himself and to care about it. As for trauma pain - we have a huge problem in our country with ER's prescribing opiates for chronic pain patients, but not enough for acute pain. It's crazy - you get someone with a busted femur in agony but the ER doctor says, "We don't want to get you addicted to morphine..." But if someone comes in and says they are on 300 mg of morphine a day but their doctor is out of town... the doctor falls for it and writes a prescription.

The remedies for acute pain are available and we just need to implement them. Chronic pain is a much more difficult subject. The multidisciplinary model is the best but hard to sustain in the current economic climate. We have to change our argument and say it's not just the best model but the most cost-effective model. You do that by showing what happens to people who get single modality treatment without appropriate diagnosis, and how much they cost the system if you track them over time; how many times they get recycled to have an epidural or whatever.

Although chronic pain often has a medical substrate it is so much more than a medical disease in the traditional sense and needs a very different approach. But it is part of the chronic illness spectrum. The population is aging; people who used to die of diseases at a younger age are now living longer and having more chronic problems. Watch out what's coming down the pipe as oncology gets better. It's

improving all the time and more patients are surviving for longer after diagnosis and – guess what – they have chronic diseases. But to treat them as if they have cancer is a mistake. And the treatment has to change from that of the acute pain during the acute phase of the disease to the fact that, for example, they now have a neurogenic pain due to the chemotherapy, and though in one sense they remain cancer patients their pain is not directly related to the cancer.

We are going to have many more educated providers, and that brings me back to education. Chronic pain patients just have so many more needs than the things physicians are trained to do, which is why we need multidisciplinary teams and you need to be able to address all those issues.

I do think that chronic pain is a disease in its own right and in order to put resources into managing chronic pain we need to say it's just like 'real' disease and we need to fight for the territory.

The pain world is fragmented and does not have a shared purpose or set of goals.

Those of us who begin with narrative and the individual provider-patient relationship need to keep presenting our way of looking at the problems of chronic pain to the health care system. We must, in my opinion, start with education, as this is the cornerstone of change. I suspect that change requires different mechanisms in different countries, as the health care systems are so different. Anyway, you have raised an important question and I hope that you will continue to pursue its answer.

Do nurses care?

Dr Janet Holt

“The problem is that we haven’t stopped to consider what we mean by caring or nursing and the relationship between the two.”

I haven’t been engaged in clinical nursing for a very long time but as an educationalist involved in teaching healthcare ethics this is a subject of great interest to me. I came into philosophy and ethics mainly through working in developing countries a number of years ago, in particular thinking about questions of social justice. Most of my academic career has been spent looking at the big ethical issues, such as end of life care and assisted dying, and it’s only recently that I have become concerned with ethical practice and the everyday ethical issues that effect practitioners. It would not be to deny the importance of the big issues to suggest that sometimes it is the everyday issues that have more resonance with healthcare practitioners. Since I became Director of Student Education I have been responsible for the quality assurance of all the education across 48 programmes run by the School of Healthcare, and teaching about these issues has become very important to me.

The image of nursing

Today I want to look at the public image of nursing, and the *Francis Report* and negative images it has generated. I will discuss the meaning of caring and nursing and the relationship between the two, describe Tronto’s theory of the elements of care, and ask if it matters if nurses don’t care. I am trained in an analytical tradition of philosophy, so I will be giving an analytical account of this.

What images come to mind when we think of nursing? I’m focussing this on nursing because that’s what I know about but I could have replaced nursing with ‘healthcare professionals’ or doctors – I don’t mean to be tribal or patronising about this so please translate it into anything that is relevant to you. I don’t want to fall into that well-trodden and rather tedious argument that nurses care and doctors don’t.

Is it about what nurses do? Or is it about what members of the public think that nurses do? This may be quite different from what they actually do. For many years nurses have been lucky in having a very positive public image of the nurse as angel. (There is also the image of the naughty nurse but we’ll leave that on one side – I’m sure none of you read that kind of magazine!) We see nurses as essentially good people so we seem to be much more horrified when we have images of nurses that don’t care. Take the example – the only one of its kind I have been able to find – of Beverley Allitt (a nurse who killed several children in the children’s ward at Grantham Hospital and is now detained in Rampton Special Hospital). The question as to whether she was just a criminal or mentally ill is at the heart of the matter but the fact that she was a nurse is completely incidental, apart from giving her the vehicle for her actions.

There is also some interesting work around gender, nursing being a female-dominated profession. So are we more horrified when women do bad things than when men do them? Helga Kuhse, an Australian philosopher who worked with Peter Singer, has written an interesting book about women and ethics and nursing in which she explores this in a lot of detail; it’s really a kind of backlash against an ethics of care philosophy which seeks to ‘genderise’ this and suggest that women care more

than men. These things do cause us anxiety and unfortunately I can only give you very colourful examples. Were Myra Hindley's actions worse because she was a woman? She seemed to be worse than Ian Brady because he was a man. As a society we seem more inclined to accept men doing bad things than women. Helena Kennedy wrote a book some years ago called *Eve was framed* which is an examination of women in the judicial system accused of crime who get treated in different ways. So there is an interesting subtext to the public image of nursing to do with the fact that most of them are women.

What then do we think the public image of nursing to be? When I looked for pictures of nurses on Google I found it very easy to find ones with nurses doing technical things but very few illustrating the 'softer' skills of nursing. This is important because it focuses on the practical skills of nursing and competence and although it would be foolish to suggest nurses don't need to be competent, when we are talking about what we mean by nursing we have to think about other skills.

The Francis Report

Nursing has taken a big hammering as a result of the *Francis Report* into the Mid-Stafford NHS Foundation Trust. The story it tells is of the appalling suffering experienced by many patients. We are living in a post-Francis world. The focus was really on the leadership within the Trust but issues around nursing are very much there.

Examples of the failings listed in the report included:

- Patients left in excrement in soiled bedclothes for lengthy periods.
- Assistance not given to patients who needed help with feeding.
- Water left out of reach – patients drinking water from flower vases.
- Patients not helped with toileting despite repeated requests.
- Filthy wards and toilets.
- Privacy and dignity even in death not respected.
- Triage in A&E done by untrained staff.
- Patients and relatives treated with callous indifference.

I don't know if any of you have read the report; it is a huge four-volume document and the executive summary runs to 125 pages. If you've got the stomach for it it's worth dipping into the testimony. It's very hard for me to look at that and see that it's the fault and failings of the Trust. It's very difficult for me to understand as a nurse why one could blame anyone else but the nurses on that ward for patients having to drink flower-water, or not helped with feeding. When we see this publicised in horrible detail in the press we have a problem if people perceive that nurses don't seem to care when they can treat patients with such callous indifference.

This quote is from the report:

‘As a result of poor leadership and staffing policies, a completely inadequate standard of nursing was offered on some wards at Stafford. The complaints heard at both the first inquiry and this one testified not only to inadequate staffing levels but poor leadership, recruitment and training. This led in turn to a declining professionalism and a tolerance of poor standards. Staff did report many incidents which occurred because of short staffing, exhibited

poor morale in their response to staff surveys, and received only ineffective representation of concerns from the Royal College of Nursing.'

What it says about standards is particularly important. The RCS came in for quite a bit of hammering as a result of the *Francis Report*, mainly because of its difficult dual role as a trade union as well as a Royal College. But I do think there was some misunderstanding of that in the report. It's not really surprising that 'representation of concerns from the Royal College of Nursing' was not good enough for the staff that made complaints because that isn't really their role; perhaps it should be but you could argue that it is not here. But whichever way we look at this it is talking about nursing standards. It isn't talking about Trust policies or management; it is only talking about what nurses were or were not doing on the ward. But it does go on to say that:

'It is now clear that some staff did express concern about the standard of care being provided to patients. The tragedy is that they were ignored and worse still others were discouraged from speaking out.'

– which expresses this whole idea of a negative culture. I am concerned about this concept as it could be a very easy excuse. We could say that the reason for the poor standards was that these were really good nurses and really good people, but because of the culture they weren't able to speak out or do anything about it. We all know what it is like to work in difficult environments or areas where you can't speak out. But for me there is something about individual responsibility that we shouldn't allow nurses to abdicate from. It's not just about saying 'it's just a bad culture and if you work in a poor culture you'll inevitably be practising poor care, and if you worked in a nice place you would do all the things you wanted to and that would be fine.' But at Mid Staffs it wasn't every place or every environment. It could also be argued that they were unlucky because they got caught; perhaps they could be described in places you are working in now and it may well be widespread. So although I don't believe it can just be excused by poor culture at the same time you don't want to demonise individual nurses. I'm sure all of you in this room could give at least two examples each of good and bad nursing care. T'was ever thus; there are good, not so good and downright bad people out there. We have to deal with that but not try to hide behind the idea that it is just to do with culture and the environment people find themselves in.

We have had a lot of interesting discussions about this in the University and about the 'too posh to wash' debate that has appeared in the media. These are the sorts of things that journalists have been saying about nursing:

'Nursing is no longer the caring profession. As they rise through the ranks to a desk job, many see patients as a nuisance to be ignored.'

Cristina Odone, *Telegraph* 28.08.11

What on earth does she mean? Not many nurses want to 'rise to a desk job'. And it's not the case that it's no longer generally regarded as a caring profession.

'Nurses need to clean up their act. The nurse's once-spotless image has been tainted by recent revelations of neglect.'

Libby Purves, *Telegraph* 28.8.09

‘A crisis in nursing: six operations, six stays in hospital – and six first-hand experiences of the care that doesn't care enough.’

Christina Patterson, *Independent* 10.04.12

A good set of articles and worth reading. They are based on her own experiences and quite thoughtful.

The Daily Mail screams to us:

‘Why have so many nurses stopped CARING?’

Daily Mail 09.02.13

(I have tried not to quote exclusively from the Mail but an awful lot of the criticism of nurses has been in that paper)

All this is important because it is what people are saying about our profession. They don't read the *Francis Report* or academic articles – they read this. That may give people a fear of coming into hospital. Francis talks about a negative culture and a negative culture in the media reinforces this perception. I'm not worried so much about the public image of nursing being destroyed just for the sake of it but I am worried that patients will feel that that's what it's about. And as an educator it has huge implications for my practice. I have people queuing up to tell me (a) that I'm recruiting the wrong people into nursing and (b) you don't need a degree to nurse and (c) even those people who do have degrees don't have to carry it out.

Caring

I want now to turn to some of the more theoretical perspectives on this. The idea that nurses don't care is fundamental but the problem is that we haven't stopped to consider what we mean by caring or nursing and the relationship between the two. John Paley sums this up neatly:



“There have been repeated attempts, especially during the last 20 years, to say precisely what caring in nursing is. Authors who undertake this task usually begin with the observation that the concept of caring is complex and elusive, and suggest that their contribution will help clarify this most confused of notions. However, they are always followed by other authors who do exactly the same thing. We seem no closer, now, to a clarification of caring than we have ever been.”

Paley (2001, p188)


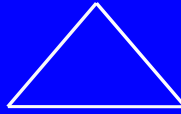
(Paley is a philosopher, not a nurse, but has some interesting – and sometimes caustic – views about nursing which are very challenging.)

Let's try to unpack some of these concepts a little more. One of the things I want us to think about is what we mean when we try to define something – I'm back to philosophical basics here – about how we decide what something is. A definition describes characteristics, features, qualities or properties something has to have in order for the word to apply to it. We tend to have two types of characteristics: the defining characteristics – part of the meaning of the word, and accompanying characteristics which assert facts about an object.

An example which is often used is that of a triangle, defined as a plane figure with three angles and three sides, so the one on the right cannot be a triangle, because it has lost its defining characteristic.

Definitions	
Triangle = plane figure with three angles and three sides	If a side is removed is the object still a triangle? Defining characteristic
	

Does the colour of the background make any difference? Clearly not, because colour is an accompanying characteristic.

School of Healthcare FACULTY OF MEDICINE AND HEALTH		UNIVERSITY OF LEEDS
Does the colour affect the definition	Colour is an accompanying characteristic?	
		

Can we then apply that to the idea of nursing? If we label one side of the triangle as caring, and take it out, does it cease to be nursing?

Nursing

If caring is removed is it still nursing



A defining characteristic?

Is caring then considered to be a defining characteristic of nursing? Are we saying that you can't even carry out nursing without the caring element? (You will notice that I am neatly sidestepping defining what caring is, and assuming a lot of things about it.) I think the commonsense approach is to say that it can't be nursing if you remove caring. There seems to be something odd about saying nursing is just the practical skill. Does exercising the practical skill involve some caring? So even if we don't know what caring is and don't define it can we still say it's nursing if care is removed?

Some have talked about care being the 'essence' of nursing but this is very easily dismissed as an incorrect use of the word essence; it can be refuted because care may be an important facet of nursing but is not unique: if you use the word essence it has to detect uniqueness (a bit like the difference between vanilla essence and vanilla 'flavouring') So caring can't be the essence of nursing as many other people do it as well – you do in your practice and even in your families. Nevertheless it is important to nursing; it seems pointless to say otherwise. In the same way that someone described as nursing should be relied upon to perform caring acts, so we talk about the caring professions. If we describe someone as engaged in a caring profession we are loading that in that we expect a certain amount of behaviours; we are not expecting someone not to exhibit some of the facets of caring as a result of that.

I think there is a real difference between saying that caring is essential for nursing (or medical) practice and asking whether it is essential for *good* practice. If I'm a patient I don't want to rely on just good nurses or doctors; I want to rely on nurses and doctors in doing the job they need to do. What I don't want is to feel is that I might get the good ones or the less good ones; I want to believe that there is some kind of universal standard here. It isn't about being good; it's about what we do. I'm not using 'good' in a kind of virtue ethics context; not so much being morally good as being good at something...

...Competent?

...Yes – but it's broader than competent, but I don't want to use it in a Virtue Ethics sense for reasons I will come to.

May I interrupt? You talk about the caring professions. The original sense of professional was 'one who professes a vocation.' So you could argue that if nurses

are true caring professionals, caring is essential to the profession of nursing because you profess that vocation of care.

It's the word vocation that somewhat worries me in that. That may have been the original definition of profession but is that necessarily universally applicable? People talk about trait theory for professionals ...it's an interesting point you raise because there is a whole body of literature about...for example, when nursing seemed to have lost it's roots because of taking on more technical skills, as with the rise of the Advanced Nursing Practitioner, it was seen to be losing the idea of that vocational element – the 'bedside' element – in seeking professional recognition.

But what to come back to and look at in a simplistic way is what people feel they can rely on when using that term; what they should be able to expect from a caring professional. I was struck by a theory put forward by Joan Tronto in her book *Moral Boundaries: A Political Argument for an Ethic of Care* (1993) regarding the different elements of care which others have used in developing an ethic of care. But I want to do something much simpler than that – not, as other writers have done, translate Tronto's theory into an ethic of care or relate it to an Aristotelian idea of Virtue Ethics – but simply to help make the distinction between a nurse and a good nurse, and between nursing and good nursing care.

Tronto talks about five elements of care. The first is *caring about*: attentiveness, being observant of people's needs and receptive to that. That's pretty straightforward and so is the second, *taking responsibility for taking care* of somebody. Thirdly she talks about *competence*. She's not falling into the trap of saying this is simply about technical skills – she's talking about the whole realm of competence in *care giving*. She thinks of all these things as interwoven. France and Gallagher give a very good example of the nurses looking after a patient who had been diagnosed with lung cancer and was very anxious about this, being able to reassure and care for her without using sedatives by using different skills and empathy. Her fourth element of care is *responsiveness*: how the person being cared for responds. This is not just a matter of reciprocity: I'll care for you and you'll care for me. It's more to do with recognising the vulnerability at the hands of caregivers; something reflected in the Francis report. She wraps up all of this in her fifth element which she calls *the integrity of care*. Good care requires all five elements and involves the context of the care process and making judgements about conflicting needs and strategies. *Moral Boundaries: A Political Argument for an Ethic of Care* is written in a broader context than nursing alone.

Many authors have translated this into Virtue Ethics and the idea of the 'Good Nurse'. I want to consider this in a much more simple way. Is it possible to consider it as a fundamental premise for what caring is? Does it tell us what we require as a minimum standard? That changes the focus; we don't need to get into an ethic of care or the area of obligation and moral responsibility – I don't want to minimize this but I want to make it more fundamental and a reason for action rather than simply a matter of the Good Nurse. I think this does matter hugely because, as Hallam reminds us: "the images of nurses constructed by the media are not value-free accounts, but have implications for practice and/or policy". We've got all sorts of people jumping on this now. Last week I had a request from our local authority to 'detail the admission procedures for students demonstrating how I am testing them for exhibiting caring behaviours' – my goodness, if only life was that simple!

In an interesting paper looking at nursing images on YouTube, Kelly et al. suggest that:

“Nursing identities can give rise to nursing behaviours in interprofessional working and clinical decision-making, and identities can also influence the way the society behaves towards nurses, [so] as a social practice, nursing is inherently problematic, with great variance between nursing image and the nursing role.”

So it is important for us to determine what we mean by saying that caring is an essential quality of nursing per se and not just a quality of the good nurse. There is a big gulf there between the idea of what nursing practice is and a Virtue Ethics interpretation of that which involves talking about ‘good’ nurses as opposed to ‘ordinary’ nurses; what I want is a better definition of ordinary nursing practice. That might be about changing culture: that’s where Francis started talking about understanding care as a defining characteristic of nursing and not just ‘good’ nursing.

I have mentioned the implications for nurse education. You will have seen how this gives politicians carte blanche make suggestions like obliging people to have a year in practice before they come into nurse education – practice before practice? – an odd idea. Then there are the issues around nursing leadership particularly those involving the Royal College of Nursing, and the dreadful disarray that the Nursing and Midwifery Council has found itself in, which has been cringingly embarrassing and may see the end of self-regulation of the profession as a result.

So before we start talking about changing the culture and what we mean by concepts such as compassion, caring and courage we really need to define what we mean by nursing. For me there is too much attention to the attributes rather than the fundamentals.

Discussion

One of the issues which is becoming increasingly important in the NHS is the requirement to reduce staff, particularly nursing staff. I find a lot of wards are barely functioning with the allocation they have. So even if you have brilliant nurses, if there are not enough of them they can't be that good at running a ward. And I suspect that what may happen, if as a consequence good nurses find themselves in an environment where patients aren't getting proper care, they will become frustrated and leave to find work elsewhere.

Francis also talks a lot about Assistant or Associate Practitioners, and this is a big issue. Some of you will remember Enrolled Nurses and this is beginning to look like their return. It's almost astonishing, but there is no regulation and no agreed training curriculum for them. So for example, in the University of Leeds we offer people wanting to become Assistant Practitioners the first year of a degree programme, but in other places there is only 'in house' training with no kind of accreditation whatsoever. A lot of the 'fundamental' care is now being done by these people. That's the reality and a really serious issue that we do have to tackle. It's no use saying that's not what we want. There are never going to be enough registered nurses doing fundamental care simply because of economic factors.

It's a big transformation. Last week I was teaching a new group of healthcare assistants and five of them had been working in Tesco's the previous week. To give them the skills to wash and turn people in bed, and comfort them, and help them to

feed seemed like an enormous mountain to climb. Patients can't get their heads around the situation that someone who is wearing a uniform and looks like a nurse may have very little skill or training. Unless we have a proper system for training and skill support for these very important workers things won't improve and as Mike says good nurses will go elsewhere.

But surely the antidote to this is that a lot of these attributes of compassion and caring are human traits and most people that go into nursing would have those. I wonder how much of this needs to be taught?

There are two answers to that: one is that in theory we should be able to teach people from Tesco's to wash and turn etc. but how do you know they have those traits – how do you assess them?

I interview these people but it's a complete lottery – some come over as very kind but...Can you maintain your characteristics whilst learning a new skill and trying to clean someone...

We've moved away from individual interviews for that very reason. Some of the applicants are very smart and know what to say. We've been trying group exercises and things like that.

One of the things that exercise us is the fees backlash, as although most of the healthcare professions still come under Department of Health funding, nursing students don't pay fees. What worries me is that applications to universities are down in every area except healthcare. So there are some smart people who know how to exploit that. Obviously I want to recruit good, well-qualified inspirational people into the profession but need those skills as well. At the same time you might say that you've done it in medicine so why can't you do it in another profession?

If you teach medical students you know their academic background and standards whereas the entry to nursing is quite complicated, now we are moving to an all graduate profession, as applicants might not have the qualifications that you might expect to start a degree programme. And that tells at various parts of their training and right through their career.

I'm still concerned about the number of people coming into nursing from the academic side. I go around a lot of the wards and see a mixed culture of people from other areas: Portuguese, Filipinos etc. and some of them are very good. I still see a lot of nursing auxiliaries who would make fantastic qualified nurses and quite capable of running a ward, but don't have the necessary academic background. I see others with good qualifications and exam results put into positions where they just haven't got what it takes.

...But is it mutually exclusive? This is the sort of essence of the 'too posh to wash' argument that just because you're bright it doesn't mean you don't have those characteristics...

...No but what I am saying is that a lot of people who were enrolled nurses would think: I couldn't get to that standard so I'll have to do something else, so we are losing a lot of people who could be good nurses.

There was article in [?] in the Nineties which predicted that by 2010, even if every female in the country became a carer there still wouldn't be enough, so we have to accept that that there aren't enough women, and now women can do everything and

have wonderful opportunities that is the reality that we are facing already .So we're going to have to accept that we have to accept women from other countries which is sad because the counties they come from need them...

...Or men!

... There are still relatively few men in nursing...

...Why not...

We are seeing a rise in the number of men applying to become healthcare assistants, possibly as a result in the downturn in the economy.

I have been very struck with the way that people applying for the Assistant Practitioner programme are such a mixed bag, including men, and not necessarily what you might expect, for example we had someone with a PhD who after five years of university wanted to try this to see if it was what they wanted to do. So we can't stereotype...

[Inaudible contribution regarding ward and classroom teaching]

In nursing education we seem to be good at not just throwing out the baby with the bathwater but drowning it at the same time – someone has a bright idea and then we decide it wasn't very good so we must do it completely differently. Those of you who remember Project 2000 ...when you look back on it you can't imagine what they were thinking of – you do everything on the wards? ...You do *nothing* on the wards in the first year! Your average student wants to get into practice. 50 per cent of a nursing programme has to be spent in practice, and that may not be enough, but you need the theoretical knowledge as well.

...In medical schools...start clinical teaching in first year... bringing back tutors on wards...

Can I bring up the subject of role models? We discussed these last year in the context of educating doctors. They can learn medicine in all sorts of ways, but they can only learn how to behave from their role models, both before and after qualification – if they are good that's wonderful; but many of the bad elements in caring seem to be passed down from bad role models, and they may pass these on in their turn. And the same applies to young nurses. How can we break into that self-perpetuating process?

I think that's probably what Francis meant when he was talking about the culture of care in that you have a ward situation where the leaders aren't exhibiting the right sort of values it's very difficult to say I'm going to carry on my good care regardless. This is partly what the Chief Nurse's policy is focussed on. These things are very hard to do – it's partly about personalities.

We have had a PhD student looking at role modelling and it transpires that the thing we don't put enough emphasis on is educating the modelees. It's the same in nursing – we're putting a huge amount more work on how to role model effectively but we need to introduce more into the basic education of medical and, I suspect, nursing students about how to interpret the role models you see, and how to learn from negative role models as well as positive ones.

One of the things I do is teach critical thinking skills, particularly to help them identify good and bad role models, and explain why they find them so. People can't just do this by immersion. Some of my third year students tell me that they get their essays back with the comment: 'this grade would be improved by demonstrating more skills of critical analysis', but nobody has ever told them what that is and how to do it. I spent six years studying philosophy and I know how hard that is. I think it's incumbent on all of us to challenge people and say 'what do you mean by this?' and 'why do you think that?' And that's how they gain the courage to say 'I know what I'm talking about.'

I think the discipline has gone. When I was a houseman the matron or the deputy matron would make a round of the hospital at 9 o'clock every day and if I was summoned by the cardiology ward sister I would go quaking wondering what I had done or not done.

And there was the other archetype of nursing which was Hattie Jacques – an image which is still in the mind of the public and of politicians as an essential component of nursing...

... And the idea of 'bring back the matron'. I recently read something about making sure that sisters and nurses are on ward rounds...

...As I mentioned earlier doctors do ward rounds on their own, and when they ask for a nurse the nurses say we're not your handmaidens. They should be working together as a team...

...This should be part of the central role of the nurse...

There is a move to make our ward sisters supernumerary, as they haven't been able to go on ward rounds because they are physically administering care.

Another problem is that firms are scattered across different wards.

There are social implications I am not qualified to comment on. Something with which we struggle with our students is wanting them to feel they are university students and have the university experience. We do masses of work with the students' union to help them to think that. They spend so much of their time in practice it's quite hard for them to think of themselves in this way. They have tons more work to do than other students because they have to get a licence to practice as well as a degree.

When I trained I very much felt I was part of a clinical environment; was that a better culture than being part of an educational environment? Did that help me with my socialisation?

As a houseman I worked with nurses and they stopped me killing patients and vice versa but now we seem to be two different tribes.

Nurses also are great communicators. They have to be the advocate for the patient. On ward rounds they can communicate really valuable information to the doctor and have a critical role in decisions about the care of the patient.

I would want to be little cautious about saying that all nurses are good communicators, and about putting the advocacy tag on nurses.

When Project 2000 arrived nursing care disappeared.

The late professor of nursing at Edinburgh University, Annie Altschul, was very despondent before she died and said the end of nursing came with Project 2000. The current professor, Kath Melia, did a very interesting PhD study called Show and Go.

I don't think anyone would want to defend Project 2000. There are too many fundamental issues to address but the question of where nurses are best educated is still up for discussion. Perhaps the most useful lesson we can learn from the past is just because we did it one way which wasn't good doesn't mean that everything we did was necessarily wrong. But we do have a tendency in nursing education to pitch everything out and start again.

‘Know-what-I- mean?’

Do we hear what is said and know what is meant?

Karin Cannons

“We hope we have developed an open culture of communication that helps us share information and improves the care of our patients and the support we can offer the other professionals we engage with.”

I am going to talk about developing a common culture of communication in a chronic pain team. I am going to look at some of the things we have used and share some of the things that have happened along the way. When I prepared this talk I used an excellent paper on the subject by O’Daniel and Rosenstein (2008).

Communication

So what is communication? We all think we know and actually I think it is something almost autonomic; like breathing, we do it without thinking. Even now those of you not speaking are communicating.

The word Communication is from the Latin *communicare* ‘to share’. The OED defines it as the ‘imparting or exchanging of information by speaking, writing, or using some other medium’. 93 per cent of communication is more affected by body language, attitude, and tone, leaving only 7 per cent of the meaning and intent based on the actual words said. Whereas the spoken words contain the crucial content, their meaning can be influenced by the style of delivery, which includes the way speakers stand, speak, and look at a person.

However, in organisations like the NHS, critical information is often transmitted via handwritten notes, e-mails, or text messages, which can lead to serious consequences if there is miscommunication. Collaboration in healthcare is defined as healthcare professionals assuming complementary roles and cooperatively working together, sharing responsibility for problem-solving and making decisions to formulate and carry out plans for patient care. Collaboration between physicians, nurses, and other healthcare professionals increases team members’ awareness of each other’s type of knowledge and skills, leading to continued improvement in decision-making. Effective teams are characterised by trust, respect, and collaboration. Deming is one of the greatest proponents of teamwork. Teamwork, he believes, is endemic to a system in which all employees are working for the good of a goal, who have a common aim, and who work together to achieve that aim. When considering a teamwork model in healthcare, an interdisciplinary approach should be applied. Unlike a multidisciplinary approach, in which each team member is responsible only for the activities related to his or her own discipline and formulates separate goals for the patient, an interdisciplinary approach coalesces a joint effort on behalf of the patient with a common goal from all disciplines involved in the care plan. The pooling of specialised services leads to integrated interventions. The plan-of-care takes into account the multiple assessments and treatment regimens, and it packages these services to create an individualised care programme that best addresses the needs of the patient. The patient finds that communication is easier with the cohesive team, rather than with numerous professionals who do not know what others are doing to manage the patient.

When I joined my present team I felt as if I had fallen down a rabbit hole into a different land. The team I had been recruited to lead consisted of a series of individuals who seemed to rarely see each other let alone speak. They all did clinics in different parts of the Trust and were like 'ships passing in the night'. From my perspective it was like reading runes or solving riddles. So if I can borrow from Lewis Carroll...

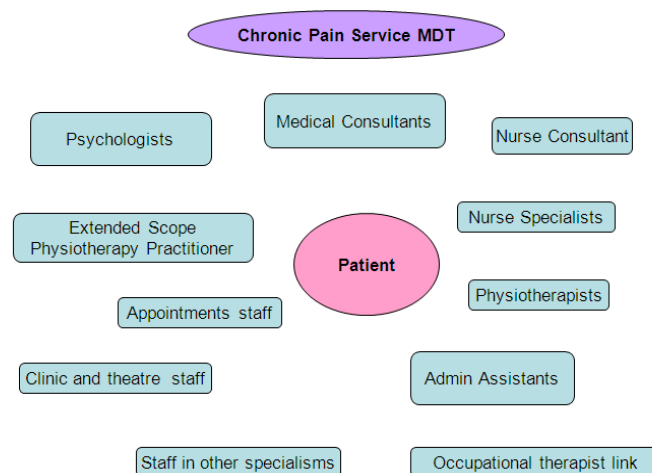


'Come, we shall have some fun now!' thought Alice. 'I'm glad they've begun asking riddles. I believe I can guess that,' she added aloud. 'Do you mean that you think you can find out the answer to it?' said the March Hare. 'Exactly so,' said Alice. 'Then you should say what you mean,' the March Hare went on. 'I do,' Alice hastily replied; 'at least--at least I mean what I say--that's the same thing, you know.' 'Not the same thing a bit!' said the Hatter. 'You might just as well say that "I see what I eat" is the same thing as "I eat what I see"!' 'You might just as well say,' added the March Hare, 'that "I like what I get" is the same thing as "I get what I like"!' 'You might just as well say,' added the Dormouse, who seemed to be talking in his sleep, 'that "I breathe when I sleep" is the same thing as "I sleep when I breathe"!''

On a more serious note, this is what the academic literature tells us are common barriers to interprofessional communication and collaboration:

- Personal values and expectations
- Personality differences
- Hierarchy/Historical inter-professional and intra-professional rivalries
- Disruptive behaviour
- Culture and ethnicity
- Generational differences
- Gender
- Differences in language and jargon
- Differences in schedules and professional routines
- Varying levels of preparation, qualifications, and status
- Differences in requirements, regulations, and norms of professional education
- Fears of diluted professional identity
- Differences in accountability, payment, and rewards
- Concerns regarding clinical responsibility
- Complexity of care
- Emphasis on rapid decision making

This slide shows the scope of the issue in terms of who is in our team.



Within a multidisciplinary team, like any group, communication is subject to influences by culture. There have been a few instances over last few years that have illustrated to us as a team that we have not always been on the 'same page' when communicating information amongst ourselves, with patients, our organisational management and with commissioners of our services. We have put a huge amount of work into communicating with patients in their own language and have a robust interpreter and telephone based system. Leaflets are available in foreign languages and support is available for those with visual and hearing impairment. Equality and diversity initiatives in the Trust seek to ensure that no one, staff or patient, is disadvantaged by gender, race or disability.

Learning from mistakes?

A good place to start is provided by the fact that most health professionals have at least one characteristic in common: a personal desire to learn; and at least one shared value: to meet the needs of their patients or clients. How can we learn and grow as a team? In my organisation learning from complaints is a standing item on the agenda of every meeting. We had to try and find a way to make this mean something and work in reality so that it added value.

Traditional medical education emphasizes the importance of error-free practice, utilising intense peer pressure to achieve perfection during both diagnosis and treatment. Errors are therefore perceived normatively as an expression of failure. This atmosphere creates an environment that precludes the fair, open discussion of mistakes that is required if organisational learning is to take place.

Trying to learn from complaints and incidents is part of the culture of our organisation. What can we learn from looking at other industries? A large body of literature shows that because of the complexity of medical care, coupled with the inherent limitations of human performance, it is critically important that clinicians have standardised communication tools and create an environment in which individuals can speak up and express concerns. This literature concurs that when a team needs to communicate complex information in a short period of time, it is helpful to use

structured communication techniques to ensure accuracy. Structured communication techniques can serve the same purpose that clinical practice guidelines do in assisting practitioners to make decisions and take action. Research from aviation and wilderness fire fighting is useful in healthcare because they involve settings where there is a huge variability in circumstances, the need to adapt processes quickly, a quickly changing knowledge base, and highly trained professionals who must use expert judgment in dynamic settings. Research shows that in these disciplines, the adoption of standardised tools and behaviours is a very effective strategy in enhancing teamwork and reducing risks.

The US Forest Service uses the acronym STICC:

- Situation: Here's what I think we face.
- Task: Here's what I think we should do.
- Intent: Here's why.
- Concern: Here's what we should keep our eye on.
- Calibrate: Talk to me. Tell me if you don't understand, can't do it, or see something I do not.

The aviation industry and its no blame culture is one we have examined. No blame is an important concept. With patients so quick to complain and increasingly quick to sue it is a hard concept to preserve! The Crew Resource Management is as follows:

- Design of systems to absorb errors through redundancy, standardisation, and checklists
- Movement from placing blame to designing safe processes and procedures, i.e., applying a systems approach
- Assurance of full immunity while implementing a nonpunitive approach
- Debriefing of all events, including near misses, that have learning potential.
- Focus on the severity of the potential risk rather than on the severity of the event's final outcome is more conducive to establishing effective prevention programmes.
- Institutionalisation of a permanent programme for risk identification, analysis, and dissemination of the lessons learned throughout the professional community.

Team working

So what are the components of successful team working (and no I don't think we have it right all the time)? Team working/building is a life-long process and journey in my view. We are striving for:

- Open communication
- Non-punitive environment
- Clear direction
- Clear and known roles and tasks for team members
- Respectful atmosphere
- Shared responsibility for team success
- Appropriate balance of member participation for the task at hand
- Acknowledgment and processing of conflict
- Clear specifications regarding authority and accountability
- Clear and known decision making procedures
- Regular and routine communication and information sharing

- Enabling environment, including access to needed resources
- Mechanism to evaluate outcomes and adjust accordingly

Within our MDT we realised that each professional group had their own approach to debriefing on incidents, and response to criticism. Our clinical psychologists had a highly evolved model of clinical supervision; our nurses were using reflective practice. There were a number of patient complaints that highlighted the perception that communication between team members, patients and GPs or other specialisms was not always working. An audit into consent taken for procedures showed variation in practice in terms of information given to patients. Even when information is given sometimes it is misinterpreted by patients or staff. For example, one of our patients rang our procedure unit to enquire about the date for application of an eight per cent capsaicin patch. The clerk said 'ah yes you are in the Qutenza trial' rather than you are having a trial of Qutenza. The patient cancelled her treatment as she didn't want to be a 'guinea pig in an experiment'. Unpicking all of this took a lot of time not to mention having to diffuse the complaint the patient had begun to make about not being told her treatment was experimental.

Reflection

'We decided to look at reflection as a tool to improve team communication and encourage collaborative working. We figured maybe...do reflective practices offer us a way of trying to make sense of the uncertainty in our workplaces and the courage to work competently and ethically at the edge of order and chaos?'

(Ghaye 2004)

So what is reflection and how can you do it? Can I have a show of hands in the room to see who currently uses formal reflection in practice? OK yes – as one might expect – the nurses and psychologists are familiar with the concept and doctors less so. Here are some quotes from the literature as to what reflection is:

'The throwing back of thoughts and memories, in cognitive acts such as thinking, contemplation, meditation and any other form of attentive consideration, in order to make sense of them, and to make contextually appropriate changes if they are required.'

(Taylor, 2000)

'Different from simply recalling an event, or even discussing a day at work with a colleague. The benefits of reflective practice are many and varied. It can lead to an analysis of (nursing) actions in such a way that it can become evident how things might have been done differently, or equally the recognition that things are done well and should be repeated.'

(Hogston and Simpson 1999)

'A process of looking back on what has been done and pondering on it and learning lessons from what did or did not work.... The act of deliberation, when the practitioner consciously stops and thinks what shall I do now?'

(Conway 1994)

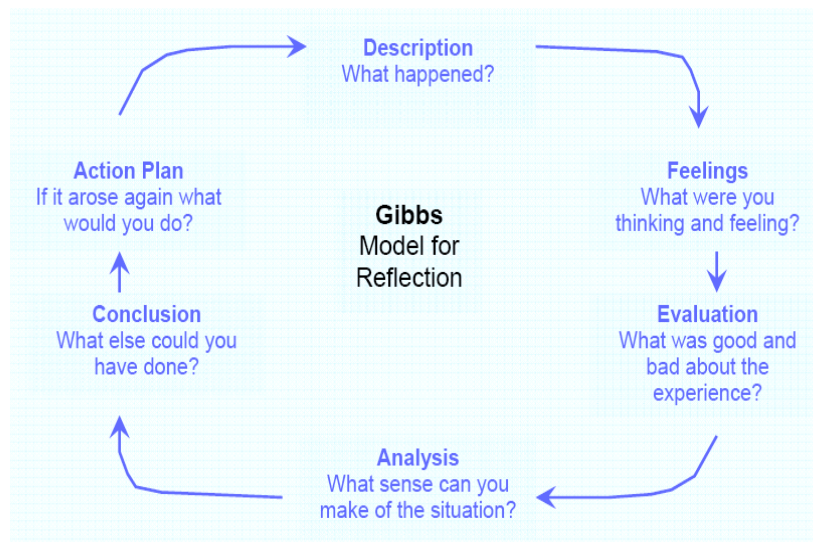
Boud (2006) describes why reflection is relevant for us today:

1. The Need to be a Lifelong Learner: Individuals need to develop their professional knowledge and competency to manage new and expanding roles and technological advances.
2. Information Explosion: Become comfortable with the widening evidence base and range of sources that inform practice.
3. Globalisation: Rapidly changing practice shaped by local and world events.
4. Increasingly Networked Society: Interprofessional practice requires cooperate and communication with colleagues within and beyond your own profession.
5. Risk and Audit Society: Critical reflection contributes to the ability of a professional to account for their practice within current benchmarks and standards.

Reflection is:

- A Conscious activity
- Learning from experience
- Understanding something that has happened in a different way

It is something the practitioner can do swiftly and at the time but in terms of improving team communication and collaboration we have been sharing our reflections with each other at team meetings using this model from Gibbs (1988). The time is ring fenced. No minutes are taken. Nothing is off limits but the meeting is private to team members only. Only the learning leaves the room in the action plan not the specifics of the situation.



What have we found most useful about reflection and our discussions? Obviously you would have to ask the team and as with any group of individuals some of us are more 'into' sharing and reflecting than others. Everyone is free to contribute as much or as little as they want to. For me a highlight is the companionship of my colleagues. We in the pain clinic rarely have solutions to our patient's problems. Rather we accompany them in their distress. We work face-to-face and on the phone with patients mostly alone (except when we have our pain fellow and trainees sitting-in on clinics). Even our inpatient work can be isolating as we are called as the 'expert' to troubleshoot a pain issue and again the quest for analgesia may not be simple. Reflecting with my colleagues on episodes of care enables me to get their support

and their fresh perspective. Reflection enables you to look from another's perspective and share their journey with their patients to 'walk a mile in their shoes'. It can be comforting, challenging, uplifting, and sometimes forces you to accept that you could indeed have done something differently or better. It has never been a negative experience for me, though, and I do believe that reflection offers a 'psychological safety net' for practitioners. Our work can be emotionally taxing as it is for anyone working with patients who have long-term conditions.

So...are we there yet? Is our communication perfect? Of course not. I don't think we have turned into a *Borg Collective* (only Star Trek aficionados will recognise this allusion) and, as I said, participation in reflection is always optional. Communication is central to culture and culture is rarely uniform. The culture and performance relationship is complex with no quick fixes to changing culture. One runs the risk of dysfunctional consequences like mid Staffs if you get it wrong. We use gardening metaphors not engineering ones in that it is an organic approach sensitive to local conditions. We hope that by holding people in psychological safety we use reflections to manage the complexities of culture and context and encourage communication. Getting that time ring fenced is a challenge with one always having to justify to management why time for MDT meetings and reflection have value.

Do we understand each other better? We think so. From that better understanding we hope we have developed an open culture of communication that helps us share information and improves the care of our patients and the support we can offer the other professionals we engage with. Incorporating reflection into our daily work helps us to share the good and bad swiftly. Nothing anyone brings is insignificant and everyone gets an equal chance to share if they choose to. Personally it has enabled me to look at things from the perspective of others. For the future, to facilitate true interdisciplinary team working, it occurs to me that if we could get patients who have complained to join in with the reflection that might help with complaint resolution. Where reflections have led to action plans, these have sometimes been shared with patients with good effect. With reflective practice we start from what is working rather than what is not and I think if you met us now you would think we were a cohesive group with common goals who are self-aware and aware of the needs of others within the group.

'The highest activity a human being can attain is learning for understanding, because to understand is to be free.'

Spinoza

[Unfortunately the discussion of this presentation was not recorded]

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Getting the right hand to work with the left hand. Knitting together: A future for healthcare?

Betsan Corkhill

“Knitting can help you to integrate a biomedical approach with care and compassion.”

I gave up physiotherapy in 2002 because I became frustrated at not being able to give my patients the time and treatment I felt they needed. Many of the patients I visited on my community rounds had become demotivated by the system they found themselves in and I knew with certainty that they wouldn't do the exercises I taught them or carry out the lifestyle changes I advised. Mrs. Smith wasn't getting out of her chair because she had no reason to. These patients needed to develop an interest in the world, to develop social contacts, and to develop an aspiration to improve their wellbeing before we had any hope of getting them to manage a complex long-term condition. So after much soul-searching I left my career as a physiotherapist and became a freelance production editor for a range of computer magazines. I ended up working on the craft portfolio of feature publishing, and one of my jobs was to look after the letters pages of all the magazines which involved reading the hundreds of letters that came into the office every day. About 98 per cent of these letters talked about using knitting as therapy. The striking thing was that there were large numbers of people from different backgrounds and cultures saying very similar if not identical things about knitting. It was then that a little light came on my head and I wondered if this could be used as motivation for all the people I used to see on my community rounds, to act as a springboard to other activities and bring them back into the world. The magazines let it be known that I was interested in researching this further so people from all round the world started sending me their stories. And it was then that I realised that there was something potentially really important here, and something that could change the way we treat people with long-term conditions.

Stitchlinks

So in 2005 I set up Stitchlinks. This is a non-profit community interest company and is an online support group for people who enjoy the therapeutic benefits of crafts and particularly knitting. It's also a resource for clinicians, teachers and other professionals who would like to use it.

I approached the pain clinic at the Royal United Hospitals in Bath to ask them if they would be interested in setting up a social knitting group to test my theories and to my surprise they said yes. I then had a major panic because I realised I was going to have to learn to knit! I now do one day a week on an honorary contract. I have a weekly group and also see individual patients who have been referred with complex problems.

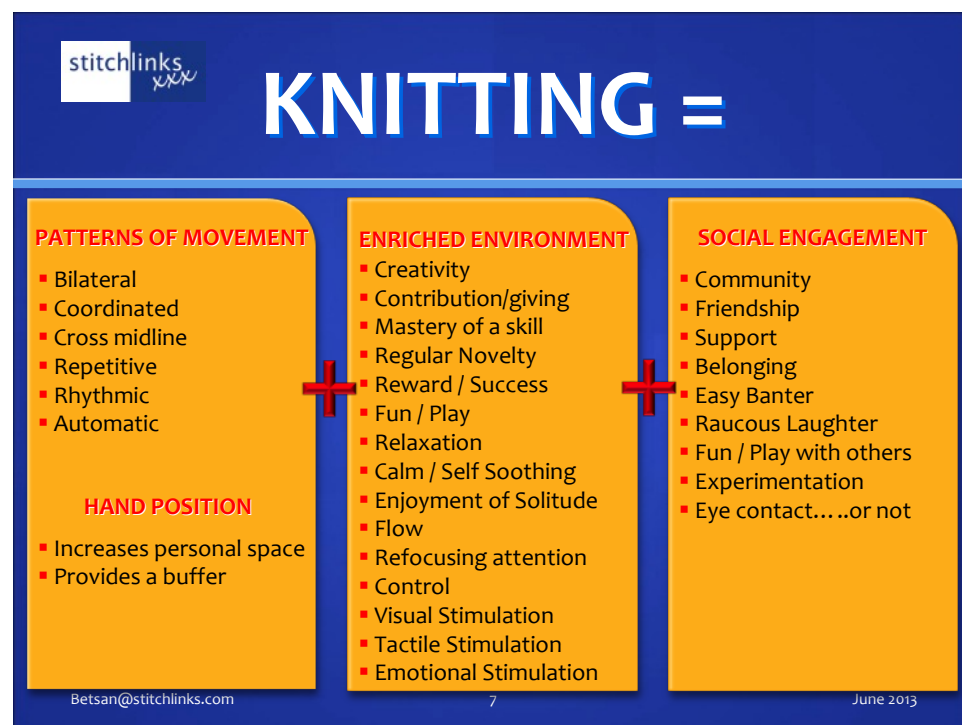
When people started sending me all their stories I became really intrigued by the way that some people cope with huge problems in their lives including pain and seem to stay afloat, and have a reasonable quality of life, and others seem to sink under minor issues. Five themes came up time and time again:

- Social isolation and loneliness
- Lack of rewarding occupation
- Low self-esteem, lack of confidence and feelings of worthlessness

- Worry, fear and stress
- Loss of identity and other identity issues

So the context within which people suffer ill health plays a huge part in how they manage their symptoms, and has been brought up many times in the last couple of days the other things that happen in their lives are very important.

I want to make a distinction between rewarding occupation and dutiful purposeful occupation. Housework is purposeful but not many people enjoy it. What I have found with our patients is that many of them prioritise chores over activities for their own wellbeing because they feel guilty about not being able to contribute – to society, to their families – in other ways. So life becomes as list of chores and pain. These issues feed each other and also cause physical symptoms: muscle tension, pain, poor posture, sleep problems, bowel problems, migraine – which all feed into this cycle of problems. Knitting and knitting groups can help you deal with these issues at very low cost. I don't need to tell this group that with chronic pain you can't just treat the symptoms and expect success. As well as looking at the whole person we've also got to look at the environment, the context, within which they experience pain. We know that changing the context can change the pain experience. And we also know that we can influence the top-down modulation to turn down the volume of the alarm signals coming up. And knitting can sit quite comfortably beside the science to enable you to enable you to provide a really effective psychosocial approach at low cost.



We all have our preconceptions about the word knitting. If you feel uncomfortable or sceptical about it you might like to call it a *bilateral rhythmic psychosocial intervention!* And that's how I started getting people interested, and what I want to do now is to get behind the knitting word and see what it contains. Knitting entails patterns of movement, which I am going into in a little more detail later, a hand position that makes people feel safe, an enriched environment, and social engagement. Very importantly it is portable and gives you a tool that you can use any

time and anywhere: doctors' surgeries, in bed or on public transport. It enables socialisation and management of symptoms out and about, on the go. People are telling us that they are learning transferrable skills; they are beginning to look forward, to visualise and use their imagination, and to learn patience, perseverance, planning, goal setting and pacing. They are also discovering that mistakes are not catastrophic and can be undone. You can still achieve your end goal despite a number of detours on the way and often the end goal is richer as a result.

The importance of being successful is shining through in this work, and that's an important part of it. But also there is a re-awakening of emotions they may not have felt for some time. We are turning round that vast juggernaut of negative backward thinking negative thought cycles. And this begins to change their perspective on life and on the world and help them to manage pain. Giving our patients something they can be successful at is a vital first step in helping them to accept pain and self-manage it successfully. We are giving them a tool that they own. And being able to do this has made me feel good. Are we sparking the reward system into action? The patients I used to see on my community rounds had nothing in their lives that they felt successful at.

Knitting makes people happy!

We did a survey at Cardiff University of over 3000 letters from 31 different countries. We found that the more frequently people knit the happier and calmer they feel. 81 per cent of the people with clinical depression who filled in the survey said knitting made them feel happier and 54 per cent that it actually made them happy or very happy. One respondent noted that "antidepressants numb all my senses. Knitting makes me happy." Texture and colour play an important part in this, and touch and texture are more effective than colour in improving mood. It appears that touching something that feels good makes you feel good. It also grounds you in the present.

It has become clear from this work that there is a very important link between creativity and wellbeing, between creative ability and psychological flexibility, and the ability to self-manage. It is a matter of being actively creative as opposed to being a passive recipient of a destructive force. If we want to be successful at something we need to take action. Most of the people that I see are waiting for something to be done to them. Often patients will tell me that this is the first constructive thing they have done for years. But they are also afraid of giving new things a try and they need a safe structure within which to operate. Knitting gives them that and then we can withdraw that gradually and encourage them to experiment. So we are seeing people move from being very closed down to being much more open and able to experiment.

These questions need to be addressed:

- Can creative thought act as ongoing distraction?
- Does improving creative thought and lateral thinking improve ability to self manage?
- Does improving creative ability improve your psychological flexibility?
- Does creative thought give your brain new tunes to play?

My answer would be yes to all of these.

Social benefits

We all know that social engagement is good for you but it's not just a nice positive add-on. It has actual physiological and chemical effects. John Cappioco has written that 'Loneliness and isolation increase the pain experience. The feeling of loneliness sensitises the nervous system and is as detrimental to health as smoking 15 cigarettes a day.' He has also shown that you need to address both emotional and social loneliness. This in my mind is where care in the community falls down. Knitting groups address both these issues. A study in rats showed that social contact can ease pain related to nerve damage by reducing inflammation. 'We believe that socially isolated individuals are physiologically different from socially paired individuals, and that this difference seems to be related to inflammation.' (Courtney deVries and Adam Hinzey, Ohio State University) and can also reverse the consequent brain changes. It has also been shown that active social engagement plays an important part in preventing dementia and that there is a 40 per cent lower chance of developing dementia if you stay mentally active and socially engaged (Michael Valenzuela, University of Sydney) The more you can engage in this sort of social contact the easier it will become to tune up the body's natural healing system.

But it can be quite difficult to go into a group, even for the most self-assured of us, and for patients with low social confidence and low self-esteem it may be well nigh impossible. None of the people who come to my knitting groups would have gone to a group without the activity. We found a synergistic relationship between knitting and the group. It provides a self-soothing tool for managing emotions. Also the hand position increases the personal space and provides a buffer to the outside world. We have a patient who had been to the pub for the first time in five years because she can take her knitting which makes her feel safe. It is one of the few activities that allow you to have eye contact while you are performing it – *or not*, as you wish. The *or not* is really important because if you want to sit and knit quietly you can and it will be perfectly acceptable and that puts the knitter in complete control over their participation in the group. So they will keep coming even though they are not feeling 100 per cent. You can use the group as a tool for enabling participation and socialisation. Indeed you can use it for absolutely anything: I use it for pain education; you can use it to socialise ethnic minority groups, and to move patients towards that decision line where they need to take action. I have a couple of ladies with learning difficulties who have never been in social groups in their lives. Knitting groups seem to provide many of the important things that are missing from our patients' lives. They enable them to just 'be with' other people. And many of them won't have experienced laughter and play in the rest of their lives. What I have found is that many of them are afraid to be seen to be enjoying themselves; there is a sort of belief that I can't be in pain if I'm laughing, or perhaps someone will take away my benefits if I'm seen enjoying myself. This has been a particular problem with the change in the benefit system.

People make very firm friendships in the group; we have weekly meetings but they meet and ring each other in the meantime and support each other. They egg each other into learning new skills so you have no problem with introducing regular novelty and we know that this may save lives, and together with exercise and good diet is one of the cornerstones of neuroplasticity.

So we are enabling people to learn that they can savour individual moments despite pain.

Knitting alone is just as important as knitting in a group. You can use it to change the home environment. We are looking at the context of the whole of life. You can use knitting in the home to improve mood, distract from pain and to improve sleep. It can enable people to enjoy moments of solitude and be less troubled by loneliness. It can be used to enable people to 'switch off' on a regular basis. Improved sleep and reduced nightmares have been particularly helpful for people with fibromyalgia. People can experience the feeling of flow and calm, and remember a feeling they may have forgotten: that of being truly relaxed. That all works together to give them the experience of control, and this changes their outlook on life. You can use the anticipation of praise in the following week's group as a goal and something to look forward to.

Specific benefits of knitting

I want to bring back the issues in this equation (see below) into centre stage.

stitchlinks

KNITTING =

PATTERNS OF MOVEMENT

- Bilateral
- Coordinated
- Cross midline
- Repetitive
- Rhythmic
- Automatic

HAND POSITION

- Increases personal space
- Provides a buffer

Betsan@stitchlinks.com 20 June 2013

It is these plus its portability that raise knitting above other activities. Our patients start telling us some very interesting things, for instance "I don't know what it is, but I feel different. I've been able to go out into crowds or the supermarket and not feel as if I'm going to bump into things." I have learnt from this project that changes in peoples' spatial awareness is a much bigger problem than I had realised, and something we should be doing much more about. This may even be tied into their identity: I don't know where I am in the world or who I am. The movements of knitting do seem to improve spatial awareness and thus the sense of self. Could they be changing brain maps? We have found that bilateral, rhythmic movements appear to facilitate a meditative state more readily than unilateral ones. Co-ordinated, bilateral movements that cross midline take up a lot of brain capacity. We know from the work of Giandomenico Iannetti and Lorimer Moseley that the midline is an important reference point in the brain for perception of pain as well as spatial awareness. Barry Jacobs has shown that repetitive movements in animals enhance the release of serotonin, but this hasn't been reduplicated in humans as yet. Many ancient cultures have tools, such as worry beads or the rosary, that involve repetitive hand

movements to induce a meditative-like state or to calm. The Chinese have worry balls and Native Americans worry stones. I find that when I get nervous I polish my glasses!

The important thing seems to be the rhythm of these movements. It is this that the knitters control, and which they alter according to their moods. The rhythm facilitates a meditative-like state which is instantaneously familiar and calming, and induces a sense of deep relaxation. Knitting is an excellent tool, which people can carry around in their bags, for achieving this instantaneous effect and we are successfully using it for managing panic attacks. This also all works together to reduce the experience of pain. Perhaps knitting could enable a wider population, including children, the elderly and learning disabled, to experience the benefits of regular meditation, without having to accept or understand it, because it seems to be happening as a natural side-effect.

I didn't fully understand the importance of the automatic nature of the movements at first but now I think that movements you don't have to think about seem to 'get in under the radar' of the pain system and avoid kicking in fear of pain. We have had a lot of success with CRPS to move in this way: Can automatic movement facilitate access to the subconscious? They appear to interfere with rumination and giving the mind a break from that constant chitter-chatter that happens between the conscious and the subconscious. If you give the brain a background automatic task it seems to facilitate intimate conversation, perhaps because it switches off self-monitoring and we are using this very successfully with people who find it difficult to talk. In Birmingham they were using it with a group of Somali women who had been badly tortured and found it very helpful. Emily Holmes's group in Oxford have shown that performing a repetitive visuospatial task during or shortly after a traumatic event significantly reduces the risk of flashbacks. We have found from listening to many of the patients' stories that many of the people having real problems managing pain have got some sort of hidden trauma or issues they haven't addressed in their backgrounds. All but one of my knitting group were having nightmares – not full-blown flashbacks – and these were reduced significantly. Is there a link with EMDR? (Eye Movement Desensitisation Therapy, used by psychologists for post-traumatic stress).



Picture: Soldiers being treated for shell shock after World War One



Picture: Soldier knitting in full combat gear

When personal desire prompts anyone to learn to do something well with the hands, an extremely complicated process is initiated that endows the work with a powerful emotional charge. There is something uniquely healing and unifying in the combination of movement, thought and feeling. Frank Wilson, a neurologist at the University of California, San Francisco, and author of *The Hand*, puts it very nicely:

‘People are changed significantly and irreversibly, it seems, when movement, thought and feeling fuse during active, long-term pursuit of personal goals.’

Knitting in the pain clinic

Perhaps you can begin to see how knitting can help you to integrate a biomedical approach with care and compassion at low cost. It can enable you to give whole-person care; you can use it as a tool with a specific aim in mind, for instance to teach and facilitate meditation and relaxation or manage stress and encourage movement. It’s much easier to engage men with this approach. Men are terrified of becoming knitters but quite happy if you prescribe it as a tool with a specific aim. You can use it to change someone’s perspective on life, and to enable them to be successful at something they can do in an armchair. It works very well as part of a self-management plus support approach. An ongoing clinician-led group can help you to motivate, monitor, support and educate your patients at very low cost. It is very practicable: the learning process doesn’t involve any wasted materials, it is deliverable in kit form to the armchair, it’s not messy to set up or clear up, and it doesn’t require any artistic talent – anyone can do it and if you get stuck at home there are plenty of DVD’s and videos available on YouTube to help. And it cuts across class, culture and educational background.

Knitting creates strong, resilient flexible fabric. What we are seeking to do with therapeutic knitting is to create strong, resilient flexible minds in the process.

There is much more information than I can give you in 20 minutes on the Stitchlinks website: www.stitchlinks.com

The therapeutic knitting conference we held in Bath last year was hosted and funded by Paul Dieppe, and was attended by 60 academics and clinicians.

[Betsan's talk was concluded with a brief audio recording of a conversation with a woman who had injured her back at the age of 18 and had been virtually bed-bound and home incarcerated for the whole of the intervening 20-odd years. Despite severe initial difficulty with simply holding the needles membership of the group had transformed her life.]

Discussion

[Some of this was made difficult to hear due to a subdued buzz of animated conversation – perhaps evidence of the high level of interest stimulated by this talk]

Every now and again I go away from these meetings thinking – yes I must do that... This will really revolutionise... next time everybody will be coming with their knitting needles!

I normally teach people to cast on because the most important thing is the process of it. I then teach the knit stitch which most people pick up in about fifteen minutes. I teach them to get their minds into the flow of movements, and that's all I do at this stage. Some, particularly the men, don't go on to an end product – they just knit for the process. Some group members help to teach...

How many are there in the group?

It's an on-going group – I had to fight for that as at first we were told we couldn't do that on the NHS and we would have to discharge people after twelve weeks – and this works well as people know that if they have a problem they can just drop into the group. We've probably got about 45 or 50 people on the books. We have a core of about eight who come in every week but it can go up to 20 or 25. I also work with individuals and I could be there seven days a week...

We have two sales a year that the members set up, but we also give sackfuls of stuff to charity. Knitting for others, like babies with AIDS in Africa, in more need than themselves helps a huge amount.

We started a group in our hospice about 15 years ago... the act of giving it to somebody else was very important...we linked to a charity that was sending stuff to Romania... and we arranged an outing to see the depot where everything was packed. This feeling that they were contributing something even as they were deteriorating was very... our group was self-limiting because they all died but there were always new people coming in...

...There's something symbolic about wrapping somebody up in something warm and cosy...

The first slide showed a long list of therapeutic gains from one intervention which was mind boggling... this is all we want from any therapeutic intervention... we ask what is the ideal intervention for someone suffering from a chronic illness and there's probably nothing missing from your list.

... Are people needing less analgesia...Talking about getting people off opioids...

Yes ... perhaps the reward system gets involved...people working with addicts... use it as a way of getting them off hard drugs, alcohol and smoking. It keeps the mind and the hands busy but it may also be replacing the chemicals. There is a group running in Sheffield for heroin addicts, for example. You can use it for that time when the medication is wearing off. We have one lady who has come off morphine completely.

What was the reaction to your article in Pain News – have people been taking you up on the idea?

We had a bit of negative feedback, to be honest – from a group of Occupational Therapists – actual hate mail... ‘Get off our territory’. They argue that you get psychological benefits from any activity and I would agree with that, but there really does seem to be something important in the movements of knitting and the fact that it’s portable. We have looked at other activities; we want people to do as many as they can, and you can use knitting as a springboard to other activities. Once you are successful at knitting you want to try other things. I don’t want people sitting down knitting all day. We haven’t found anything portable but Tai Chi fits in with this. African drumming is another but though obviously not portable it does involve bilateral movements and rhythms. There is some research on baking bread but you can’t do that in a busy clinic!

These all have virtue in their own right but none are so comprehensive.

Even crocheting doesn’t compete as it is much more one handed and people with hand problems may find the grip and the repetitive turning difficult. We are getting people with hand problems to knit using a specific kind of needle and specific support.

Have you come across a situation where knitting causes pain?

When they do it too long – people with hand or neck problems will have to pace it.

It’s a wonderful vehicle for teaching pacing skills...

...Yes, five stitches today and ten tomorrow...and you can see whether they’ve done anything or not between clinics...

I teach Yoga to people living with cancer. People think of Yoga as something you do standing up with strong static postures but the Yoga I teach is bilateral and emphasises small and precise movement; and it’s portable. I’m seeing the same thing as you which is that people come to a group ... they all have something different – apart from cancer but the group isn’t about cancer – they might not ever have met because they are different age and come from different social backgrounds, but they are very supportive of one another. It’s the bilateral movements... people report that their balance is improved, although we don’t do anything standing up, and that they are walking better and feel steadier.

As the editor of Pain News I like to encourage debate. There were people who didn’t notice your article at first but the opposition which came from a large hospital and your excellent reply brought the issue to more people’s attention and there was a very good debate.

May I suggest two additions to your very comprehensive list? The word mobility doesn’t appear. As in your story of the lady who had been housebound people are

being enabled to mobilise, to go out shopping, and perhaps be less reliant on a wheelchair. So maybe you could highlight that. The other thing, as we heard in the recording, is the effect on speech and the ability to take part in conversation for people who have been isolated and stumm for years. You do have communication on your slide but perhaps you could highlight that as well.

I wanted to stress that point. Endemic loneliness is a terrible indictment of our culture. So often in the pain clinic I pick up the lack of meaning in people's lives. So many patients are introspected, isolated and lonely and perhaps what they need is the idea of exo-spection, like the lady in the recording who was doing things for her children and grandchildren again. Also we've lost that idea of creativity.

When you started off with your group did you supply the needles etc? – And how many were there in the group?

I went to a charity shop and got some needles and yarn. We'd made the decision to run it as a normal social knitting group; people had to pay for their transport so that was their responsibility and they brought their own materials. But now we do buy materials out of the money we have made. It took about six months to build it up to a core of four people that worked in 2006 and we have built it up since then.

My aim when I see people individually is to work them towards coming to a group. These are people with the most horrendously complex problems and some with psychiatric issues as well who don't fit into any groups.

Do you do it in hospital or outside?

When I first thought of it I thought it would be a good idea to do it outside the 'sick' environment. But the clinical psychologist and the nurse practitioner said that they had a very large group who were so insecure they wouldn't attend anywhere outside this safe and secure environment, and we were lucky to have the use of a large seminar room in the pain clinic. But I also run a group on a Wednesday night in a pub!

In the area where I work where there is a large population who don't speak English and are consequently isolated. This could be a way of integrating them and for them to contribute

I was talking to Trisha Greenhalgh who works as a GP and has a large population of ladies who only speak Gujarati. They first came to England when they were fifteen and are now in their mid-fifties, looking after elderly men in arranged marriages and they are stuck in high-rise flats. They've all got diabetes and are all grossly overweight, and she had no way of getting to these women to give them health advice. So she wondered if their husbands would allow them to come to a social knitting group, which could be used to talk about health education.

Tales, stories and memories: A pain clinic compendium

Beatrice Sofaer Bennett

“It’s because of our own frailty that we are able to be healers.”

I would like to share a poem with you that I put at the beginning of my book *Pain, principles, practice and patients* (1998). It was written in 1994 by Sacha Rabinovitch who was born in Egypt in 1910 and lived in southern Europe. One day she was told that the Nazis were coming, so she took her little boy and walked with him for days and days until they were out of danger. (That little boy is now a professor of English at Sussex University)

Unwelcome guest

Pain, that seasoned émigré,
has come unasked to stay.

Since courtesy forbids
probing and questioning

there is no way to know
when or if he will go.

By day he’s on the prowl
seeking to gain control,

then creeps with clammy feet
by night between my sheets.

There at daggers drawn
We toss and turn till dawn,

for he will not retreat
nor I concede defeat.

The first chapter of my book is based on patient narratives, one of which concerns the effect of chronic pain on the life and family of a patient with chronic pancreatitis. He said: (describing the attitude of some medical and nursing staff):

“What they (doctors and nurses) ought to understand – well, psychologically – it can be very damaging and that is how I found it. I was at my lowest ebb when I was in there (hospital) and they certainly didn’t appreciate that. They don’t appreciate what it is like to have pain every second, 24 hours a day. They have no idea and therefore you don’t get much compassion whatsoever.

As regards my life, it’s totally destroyed. I mean I’ve lost a company, it’s been a terrible strain on the children, for instance both of them have been crying themselves to sleep at night saying ‘we wish we had our daddy back the way he was before’; my wife has a very demanding job as well and it’s been a terrible strain on her. Tempers are short with each other, and then bursting

into tears on many occasions. But we can't see a way out of this. It's something we have to live with and have to adapt to."

Before I invite other people to share their stories I thought I would tell you a few of my own. 1983 was a very important year for me; I was just finishing my doctorate at the University of Edinburgh, and I was invited to teach at St Mary's Hospital in Paddington. I got on the train at Waverly Station and finished up at King's Cross. A taxi drew up and the driver sprang out and said "your place or mine?!" I told him 'St. Mary's Hospital' in my most professional voice... We were stuck in stationary traffic and he opened the glass divider and asked, "Why are you going to St Mary's Hospital?" I explained that I was going to teach nurses about pain management and he said "I know all about pain – when the pain's gorn it doesn't 'urt any more!"

That year I was working as a counsellor in the pain clinic in Edinburgh with Murray Carmichael. One day he came to tell me about a patient with migraine. "I've tried everything: acupuncture, all the medications I can think of, she still has pain and I don't know what to do." I agreed to see her – I was too naïve to refuse. She was a woman of about 40, primly dressed. I asked how I could help her? She replied "I canna understand it – I go to bed at night, I roll over and gi' ma husband a chaste kiss, and I wake up in the morning with a headache." So I said: "have I got this right – you give your husband a chaste kiss..." and she said "I've just realised – I dinna want tae give him a chaste kiss – I want the whole thing!" So I said, – "so you want sex?" – " Oh I do, I do..." – "so what's stopping you?" – and then the story came. She lived in a council house with paper-thin walls and she had two teenage children. If she had sex the children would hear and she was embarrassed about it. I asked, "do you ever argue with your husband?" – " Oh aye, we do ..." – "well wouldn't you children like to hear you doing something you weren't arguing about? – "I never thought about that". So I directed her to Smith's in Princess Street and the shelf where the sex books were. She came back a couple of weeks later and said everything was wonderful. And she never saw Murray Carmichael again.

After I finished my doctorate I went to Jerusalem and things there were very different. People had different types of pain. It was a time of friction between Israelis and Palestinians. I was paid by the Israeli health ministry to go and teach in Rumala which was Palestinian territory. I made a lot of friends in the hospital and one of these was a very handsome doctor from South Africa. He asked me to see a patient on the wards with chest pain – nothing including opioids was touching her. She was in a bed in the corner of the ward sobbing her heart out. I took her hand – she had a very little English and I had very little Hebrew at the time, but I managed to explain who I was and that Dr. Mohammed had sent me to her. She kept telling me, every second sentence, what a wonderful doctor he was ... but she kept on crying. It eventually came out that she was a German Jewish immigrant who had escaped from the Nazis; she had one beautiful daughter in her twenties who had fallen in love with a Palestinian man. This, she said, had brought shame on both the families, and was causing heartbreak and pain etc... but Dr Mohammed was wonderful! After two sessions I thought I had better tell him that the trouble was that as well as the problem with the daughter, the patient adored and worshipped him. He was so upset with me for telling him this that didn't speak to me for two months. Just as I was about to leave I met him and he said: "I don't know what you did for that patient but she got better – no pain, and I discharged her." I have told you this story as it seems to illustrate the healing power of listening, because what is on the outside may not be what is on the inside, and the latter may be what is important.

It was autumn in Jerusalem. The director of the hospital sent for me and I wondered what I had done! But she sat me down and told me that her husband was dying with pancreatic cancer and needed talk to someone. I went to him and this is what he said: "I'm dying. It's not nice to die and I don't want to die. I have made my will. I have bequeathed my body to medical science. And I don't know what to do now. I've put out the rubbish and I've even done the shopping in case I die tonight..." I wondered what on earth I could say. So I asked: "have you prepared your wife for your dying?" He hadn't. So he spent the next two or three weeks preparing his wife so that when he died she knew what to expect and what to do. And he died with peace of mind; all the practical things he had done hadn't provided this. I think one thing we can do for people is to give them peace of mind whether or not they are dying.

Betsan

"My story is about my mother but it's relevant to all elderly people and indeed anyone in chronic pain who finds themselves committed to a hospital ward, and it's about the need to put an underlying chronic pain problem on the clinicians' agenda when a patient is admitted for something else.

Mum had two emergency admissions in the last eight months of her life, one for a pacemaker and the other for bowel resection, and she found herself in an acute surgical ward on both those occasions. In neither was her long-time chronic pain on the list of priorities – in fact it wasn't on the list at all. She was a typical little old lady with osteoporosis and a curved spine, and she had polymyalgia as well. Like many elderly people she didn't tolerate drugs very well. At home she managed her pain with paracetamol and heat packs and had a very good quality of life with that. Every day when we went to see her we would find her sitting in one of those big plastic hospital chairs curled up with her head on her knees in terrible pain, totally unsupported day after day. When we asked if we could bring in her heat pack they said no as it would be a cross-infection risk in the microwave.

So we asked if we could buy a new microwave and they said no, it would have to be PAT (Portable Apparatus Testing) tested. So we then asked if the physiotherapist could supply a heat pack but they said it wouldn't be practical. So they replaced the heat packs with Tramadol, and that knocked her for six. I asked for a more suitable chair – they only had them on the geriatric ward. So I suggested a beanbag insert or pillows to support her which was very helpful. So the solution was quite simple at zero cost.

The message I wanted to get across is that there is a huge need for educating clinicians working in acute areas about the underlying problems of chronic pain in patients admitted to an acute ward."

I've been hearing something so familiar: this barrier to common sense. The pain course I teach to newly qualified nurses starts by asking: what do people normally do for their pain? One of the reasons why we don't run an acute pain service any more is that we see so little acute pain compared with the baggage patients bring with them. When you normally sleep with two pillows and lie on your side, and if you have a hip replacement and have to lie on your back with one plastic pillow, no wonder your back pain flares up. Replacing practical, non-pharmacological things with drugs like Tramadol which is always bad for older patients...yes, there are always barriers...

I'm sick of cross-infection arguments. You can take their heat pad into your electronics department and get it PAT tested and then you can take it back to the ward and the patient can use it. You have to have someone in the organisation who is prepared to be a pest. It frustrates me that common sense and kindness which are almost the same... it's not being clever it's just getting what the patient needs.

My mother was also told that having a pacemaker inserted was just a 'minor procedure' – it may be for the cardiologist but for an elderly woman it was very traumatic because although she was sedated she had to lie on a very hard surface for more than an hour and a half and had no explanation during that time. All she could hear was the cardiologist saying these are very narrow veins etc. and it took much longer than she was told to expect so she thought there was a problem. She was unable to move or cough, afraid to speak - he kept putting cold instruments down on her stomach without telling her. There was no communication or consideration of her background pain.

Did you feed back to them?

Oh yes. Her story was the subject of a white paper for NHS Wales which was published last week.

There is an awful lot of cruelty around and sometimes it's under the guise of being helpful. When I had an open cholecystectomy I was returned to the ward with an epidural infusion which was fine until the night nurse turned it off – having said she had read my book! And so I lay all night in dreadful pain until the anaesthetist came in the morning and insisted that the epidural was turned on again.

We hear a lot about the bad things but there is good practice around, too, though. We have had family experiences of the NHS in the past year and some of it has been inspiringly good.

That's brilliant but the bad experiences live with you a long time.

That's true – but why is that – why do we remember the bad things better than the good? ...

... Good news is bad news is good news...

A simple practical point: at one stage in my many years in palliative care I spent half a day a week as complementary therapy coordinator for the unit. One of the things that kept coming up was that of heat packs and wheat packs and things and not wanting to put them in the microwave. The solution was simple – just to put them in a disposable microwavable bag, so nothing got contaminated.

There is a barrier to that if you're not allowed to put non-food items in the microwave

I first started coming to these meetings because I wanted to find out for my students, who are experiencing a lot of pain, how doctors think and come to their conclusions. When people are ill doctors tend to think of themselves as the primary caregivers, but quite often they are not. It's often the daughter and the vicar and a spectrum of people that are helping. As I have listened and talked to people in the group I have more and more encountered the archetype of the wounded healer. The people who come to this SIG are big on self-reflection: am I doing the right thing? – Am I doing enough for my patients? – Could I do more – work more hours - what else can I do? Why are my patients still suffering? It's because of our own frailty that we are able to

be healers. So I'm going to tell you a story which I heard in rather special circumstances. Some of you may remember Andy Graydon who spoke a couple of years ago – he is a wonderful inspiring speaker. When he was growing up in West Yorkshire, my husband was growing up two streets away, and also my husband's best friend Kevin. Kevin is one of the loveliest people you could wish to meet. Twelve years ago he went to bed with a headache and when he woke up he was blind because of a pituitary tumour. His life was destroyed – everything changed. But from the ruins he has made a new life. He told me this story, which is about the law of unintended consequences:

"Many, many years ago a woman lived in a little village. Every morning she used to walk down to the river to fetch water with a bucket in each hand. When she got back to the house – and it was quite a long way – one bucket was full of water but the other had a split in it, and it was only half full. This went on for years. One day the bucket with a split in it spoke to her. "Why do you keep using me", it asked, "I'm useless. You should throw me away." So she picked the bucket up, went out of the door, held the bucket up and said, "Look down the path". One side of the path was dusty and bare. The other side was full of flowers. "It's your split – your frailty – that caused that beauty to grow and has given so much pleasure to other people."

We never know that even with our frailty the effect we have on other people. So never give up – never surrender.

To end with two quotations. The first is Plato:

To be a true doctor would require that anyone who wanted to practice as such should have recovered from all the illnesses which he claimed to cure, and have gone through all the symptoms and conditions on which he would seek to give an opinion.

The second is John Dryden from the Indian Emperor:

For all the happiness mankind can gain
Is not in pleasure but in rest from pain.

Allegories of change: The poetry of Ted Hughes and images of the natural world

Ian Stevens

“...in some aspects of healthcare and illness attempting to find solutions solely through logical algorithms often reduces our possibility of finding fresh or novel solutions to a problem.”

First a few words of self-disclosure.

I grew up in the West Midlands. My father was a butcher. He is also a very skilled artist; he had a place at art school but because of his background he couldn't go. I sometimes think in the clinic of all those years watching my father and his handling of inanimate, dead objects, and now I have a hands-on profession in physical therapy. Perhaps some of this early background may have subconsciously influenced my interest in movement and tactile perception.

After a traditional orthopaedic dominated under and post-graduate education, I worked in outpatients and moved into the world of pain where I have remained. An interest in the 'no mans land' of healthcare and the humanities developed and I completed a MA in Medical Humanities at Swansea University. Swansea allowed me to consider many issues relating to the human condition such as the role of narrative, meaning and medicines role in understanding and alleviating suffering.

I am interested in the arts/science interface and completed my dissertation on the topic of placebo a subject that still fascinates. I looked at the topic from the standpoints of both neurophysiology and topics drawn from the humanities including symbolism and meaning.

This talk aims to explore some aspects of the art/science interface. Some of the photographic images shown alongside the talk draw on my longstanding interests in movement, exploration of the natural world and illustrate the theme of reflection, exploration and change as do the words of this poem by Ted Hughes:

Go Fishing

Join water, wade in underbeing
Let brain mist into moist earth
Ghost loosen away downstream
Gulp river and gravity

Lose words
Cease
Be assumed into glistenings of lymph
As if creation were a wound
As if this flow were all plasm healing

Be supplanted by mud and leaves and pebbles
By sudden rainbow monster-structures

That materialize in suspension gulping
And dematerialize under pressure of the eye

Be cleft by the sliding prow
Displaced by the hull of light and shadow

Dissolved in earth-wave, the soft sun-shock,
Dismembered in sun-melt

Become translucent – one untangling drift
Of water-mesh, and a weight of earth-taste light
Mangled by wing-shadows
Everything circling and flowing and hover-still

Crawl out over roots, new and nameless
Search for face, harden into limbs

Let the world come back, like a white hospital
Busy with urgency words

Try to speak and nearly succeed
Heal into time and other people

By Ted Hughes, *River*

As young man, prior to having any interest or experience in healthcare I escaped physically into the world of adventure and rock-climbing in North Wales. It was there that I brought an anthology of Ted Hughes poetry. I dipped into the book over many years and it accompanied me on my subsequent moves and career change. Growing up in an industrial, fairly deprived area my senses and imagination were stimulated by an inspiring English teacher. Ted Hughes poetry – the natural raw elemental landscapes, animal themes and in some cases such as the allegorical journey described in *River* have influenced me greatly.¹ Ted Hughes uses the allegorical river journey using Celtic symbolism of water, turmoil and a process akin to a shamanic ritual of immersion and renewal. I used the poem as a vehicle to reflect on aspects of change and stasis typically encountered in many aspects of chronic pain management (at least in my own experience). Hughes' poem may illustrate the embodied nature of the allegorical shamanic journey. Crucially it is through the experience of 'losing words' and being consumed by the overwhelming (and often isolating) process that transformation occurs. Turmoil and the journey into the unknown seem to be at the heart of this shamanic journey and it is only at the end of the process that it is possible to be reacquainted with the world.

Context and pain

The poetic journey described is probably not a feature of the conventional biomedical diagnostic pathway. However, in many cases of chronic pain and unexplained somatic distress understanding the human condition and aspects that conspire to either enhance or suppress the healing instinctive capacity of an individual may prove fruitful.

In terms of pain science we all know but probably still find it difficult to accept that the activation of nociceptors is not 'pain' – that tissue damage is not 'pain' and that pain is largely a threat response dependent on meaning and context. When I reflect on the science of pain and the evidence gleaned from neurobiology I am often reminded of a pain story, which changed operational policy in my hospital in Glasgow. Many years ago, as a newly trained physiotherapist, I was asked by an orthopaedic surgeon to see a young man who couldn't walk. He was a prisoner from Barlinnie Prison near Glasgow where all the hard men are sent. He was thrown from an upstairs gantry and had bilateral os calcis fractures. I was asked to put him in a pulpit-walking frame but, as any rational person would expect, his heels were too painful to put any weight on. I was being nagged by the surgeon for not getting him out of hospital quickly enough and because he couldn't walk, the prison officer took off his handcuffs. I came back after lunch and asked where he was. It transpired that while the officer was engrossed in his paper he had crawled under the bed, got out by the fire escape, climbed over the wall, summoned a taxi and escaped! So the power of context in pain cannot be overlooked!

Similarly we heard Betsan Corkhill describe through her own reflections and the voices of patients, that contextual change was the catalyst for recovery in many patients.² I have often reflected on how the environmental context (in terms of setting/interactive process and empathy) may often be the source of the alleviation or amplification of suffering in many chronic pain problems. Bernd Strathausen told us about the vulnerable isolated patient with severe Rheumatoid arthritis who on the Jumbulance disabled holiday inadvertently became separated from her strong pain medication in the underside of the bus, and didn't miss it at all. It seems that a window view, friends, kindness and care are as powerful as opiate medication in some instances.

Movement and change

'From a whisper in the forest, to the felling of a mighty tree, 'tis all movement'
William James (brother of the novelist Henry)

My greatest interest in life is movement in nature. More and more of us live out of contact with nature and often-prolonged pain and suffering seem to encourage isolation, immobilisation and stasis. Environmentally, urban environments may encourage repetitive limited, stereotypical motor repertoires. As we age in this environment our ability to react and interact may diminish. People often lose or have limited proprioceptive, balance, exteroception and interoception and sensory experiences. Positively these physical sensory experiences are not set in stone and many non mainstream approaches that involve mindful movement such as tai chi, 'feldenkrais', forms of yoga, dance or even deliberate walking practice may modulate and alter 'defensive' motor activity.

We have increasingly come to forget that our minds are shaped by the bodily experience of being in the world, textures, sounds, smells and habits as well as the genetic traits we inherit and the ideologies we absorb all affect the brain neuromatrix. As a population we are losing touch and becoming disembodied to a greater extent than in any previous historical period. For example, a leading pain researcher and former physiotherapist Lorimer Moseley did a very simple experiment with patients with complex regional pain and a pair of binoculars. When the image of the painful and oedematous limb was inverted (and the perceived threat 'shrank') a patient's physiology changed- inflammation, oedema and reported pain all decreased. This

simple experiment and sensory manipulation proves that 'pain' and perception are 'neuroplastic' phenomena and are potentially malleable.

Nan Shepherd, a Scottish novelist, saw this process starting more than 60 years ago. She wrote, 'One should use the whole of one's body to instruct the spirit. This is the innocence we have lost: living in one sense at a time to live all the way through.' Sensory experiences changes people.

The poem by Ted Hughes dramatically reveals that the loss of words and immersion in a dangerous unpredictable environment leads to transformation. It has been my rare experience that some individuals seem to have replicated this allegorical narrative. In some instances it has been necessary to cease believing in the medical process, inadvertently nocebo as this may sometimes prove, and to seek fresh challenge and commit to activity. As a physiotherapist I have seen patients embark on this process and thrive.

This scenario of seeking challenge and responding to the vagaries and challenges of fate was described by the evolutionary psychologist Nick Humphrey.⁴ Humphrey suggests that change can occur when people are given a push in a different direction. He was walking through a park in London when he saw a balloon caught in a branch. As the wind blew it, it kept on hitting the same branch, until the wind changed and it floated up into a higher branch. This seems to be a good metaphor for chronic pain: you can bounce on the bottom branch over and over again, but to experience big change you need a different stimulus. As Humphreys suggests; 'we too need to have a whirlwind blow through our lives before we will start over again and give ourselves the chance to move on to a new level. Human history is full of examples of how seeming catastrophes can in fact be the catalyst for profitable change.'

Change therefore often requires a spirit of experimentation, a change of heart, as well as risk and in some cases reflection. Approaching a complex multifactorial problem such as chronic pain and suffering with linear reasoning and solution (either as a patient or clinician) is probably akin to the schizophrenic world described by Iain McGilchrist in his seminal book *The Master and his Emissary*.⁵ Linear thinking, stereotypical motor activity, an inability to understand allegory and metaphor or to see the value of poetry and fiction, or respond to rhythm in music, are synonymous with excessive left brain lateralization and are extremely common in chronic stress. The way out of this situation is not more of the same or a repetition of the metaphor of the balloon on its lower branches. Clinically this is akin to the repetition of procedures and approaches which have failed previously. This scenario is all too common where the dominant ethos is 'doing' rather than understanding and interacting with patients in chronic pain. The 'way out' of complex defensive strategies such as chronic pain often needs a 'whole brain' approach. Iain McGilchrist suggests narrow focused attention – the effects of excitement, fear and stress actually inhibit the neuronal spread of information into the right hemisphere. This state of brief excitement is often necessary when vigilance and concentration is needed. The danger in the modern world is that the prolonged activation of this response without respite prevents the scene being experienced afresh or for new information to be processed or healing/recovery to occur. In terms of poetry and metaphorically or illustrative derived knowledge – the harder we try to understand a poem literally the less likely we are to make sense of it or gain any value from it. Similarly, in some aspects of healthcare and illness approaching a problem head on or attempting to find solutions solely through logical algorithms often reduces our possibility of finding fresh or novel solutions to a problem.

Esther Sternberg⁶, a rheumatologist who developed an autoimmune disease after a period of intense stress and coping with bereavement, describes her own journey of self discover and healing in her books *The Balance Within* and *Healing Spaces*. Doctor Sternberg described the temples of healing in Greece. Her opinion, which I tend to share, is that we often worship the wrong gods. The two gods of healing are Aesculapius, the god of intervention whom we tend to over-worship and Hygeia who is more concerned with self-care. Perhaps in the modern era we need to value Hygeia a little more and understand in many cases that the certainties promised by 'techno medicine' are often illusory.

Certainly we know through research that patients who face a window often require less medication and that natural scenes are beneficial and promote calm. Pain clinics I have worked in the past are often airless and windowless. I remember the sinking feeling I experienced seeing only a chair, plinth and silver hospital trolley when I was asked to meet highly distressed complex chronic pain patients. The scene was far more similar to Barlinnie than a healing temple of Hygeia!

My own experiences through photography, climbing and the humanities is that high levels of concentration and situations demanding creative solutions often lead to unexpected consequences and experiences. In dealing with chronic pain, perhaps insight from the humanities, poetic allegories and lessons from nature may lead to experiences being experienced afresh. My education and subsequent training (and still the dominant model today) emphasized a mechanistic 'operator mindset' – where the modus operandi is to adjust and interpret bodily dysfunction mechanistically.

Healthcare is an interactive process and pain may be conceptualized as verb not a noun in many situations. I wish to illustrate my perception of healthcare and particularly ongoing pain based on the metaphor of water. I want to use the picture of a river in spate as an image of biomedicine. When you have to hand over yourself in trauma or acute disease, (as you can't do anything to stop that huge flow of water,) biomedicine is appropriate and works well. But another picture of smooth water running over a weir is a metaphor for chronic pain. If you are a canoeist on a 'natural rapid' and are in danger of getting caught up in the middle of the turmoil the only escape is to get to the side and find natural respites or 'eddy'. Manmade weirs often offer no such respite and are more like a washing machine stuck on a perpetual spin cycle. In some states of chronic pain, medicalisation and iatrogenic disability people often get caught up in the middle of this 'weir'. The way out of this common scenario is to embark on a journey using different path sometimes with a guide or helper who follows a different narrative.

Ted Hughes' poetic imagery suggests that when words cease and forces overwhelm you who are the allegory of the shamanic journey when you move from the known into the unknown and subsume the forces that you can't control. Many shamanic stories and religious rituals are about change through experimentation. My own experience with body therapies and meditation is that when words cease senses change; that can be metaphysical and complex or very simple.

McGilchrist quotes Heraclitus:

'The nature of things is intrinsically hard to seek out using the tools with which we normally equip ourselves for the task. Our natural assumptions and our common ways of thinking will lead us astray and we need to be both wary and indefatigable in our seeking of the truth. All things flow; stability in the experiential world is always stability provided by a form

through which things continue to flow. As they step into the same rivers other still waters flow upon them. One cannot step twice into the same river; it is always different and always the same.'

In this too our bodies are like rivers. Stasis, which is the allegory of chronic pain and the opposite of flux, is incompatible with life and leads only to separation and disintegration.

So be optimistic; neurogenesis is possible with the right mix of ingredients be it watching images or Tai Chi. But sitting still ruminating about our problems doesn't achieve very much. So get out there and do something different - give it a go!

*[This presentation concluded with a slide show of photographic images of nature, many of exquisite beauty, to be found by following this link:
www.flickr.com/photos/ianstevens/sets/72157638243787946/]*

Footnotes

¹ The poem is described in more detail here <http://ann.skea.com/cairo.htm>

² Getting the right hand to work with the left hand. Knitting together: a future for healthcare? Betsan Corkhill

³ <http://blogs.discovermagazine.com/notrocketscience/2008/11/27/pain-in-the-eye-of-the-beholder/#.UtmKZRY4lok>

⁴ [http://cogprints.org/2215/3/14.DeformedTransformed\(pics\)2.pdf](http://cogprints.org/2215/3/14.DeformedTransformed(pics)2.pdf)
(page 8 in particular)

⁵ http://www.iainmcgilchrist.com/brief_description.asp

⁶ <http://www.esthersternberg.com>

The early days in Seattle and the birth of the IASP: A history of the pain movement

John Loeser

This was an informal 'extra' session enjoyed over a glass of wine in the lounge after dinner one evening, but it was arguably the highlight of the whole meeting, and a great privilege to listen to someone who had played a major role in the beginnings of the pain movement, and was intimately acquainted with its founder.



The pain world started with one person. It was a one-man project. That man was John Bonica. He was a fascinating person. He was born on the island of Filicudi near Sicily and brought to the USA by his family when he was ten years old. He worked from the age of ten but managed to get a scholarship to go to college where he became a successful college wrestler. He then went to Marquette Medical School in Milwaukee Wisconsin and graduated just before the United States entered World War Two. He was drafted into the army and had an internship in a big army hospital not far from Seattle in Madigan called Fort Lewis, where they told him he was going to do anesthesia. He literally self-taught himself what there was of anesthesia at the time and spent the entire war at Madigan. He became concerned there about issues of pain as Madigan received a lot of injured soldiers from the Pacific theatre, and there were a lot of problems like phantom limb pain and neuropathic pain. His interest in pain was rapidly doubled by the fact that when his first child was born his wife almost died from the anesthetic, and he decided that he had to do something about the management of pain in childbirth. This remained one of his lifelong interests. He went into private practice in Tacoma and was there for about 15 years. The University of Washington was founded in 1948 and in 1960 John Bonica was appointed as its first chairman of anesthesiology. By that time he had started a pain clinic which he ran but he brought in other types of physicians and nurses.

There are lots of legends about Bonica but the family story is that they lived in a three-story house and on the third floor was his office. He would come home from the

hospital, say a few words to his wife and children over dinner and go up to his office and work until 3 or 4 in the morning, and go off again after two or three hours of sleep. So in 1953 he produced the book entitled *The Management of Pain*, which to my knowledge was the first comprehensive look at pain. There was, interestingly, a book entitled *Pain* published in 1918 by Behan from Philadelphia. I got this and found that it talks only about pain as a symptom of disease of the body and not about pain as a subject.

When he came to the University of Washington in 1960 he immediately set up a pain clinic in cooperation with a neurosurgeon, Bud White, and a nurse, Dorothy Crowley. It was a fascinating organisation. I was a resident from 1962 so I saw the early days of the pain clinic. Bonica hired a primary care practitioner whose job it was on Monday to see two new referrals and decide what consultations were needed to make an appropriate diagnosis. On Tuesday, Wednesday and Thursday they were seen by other consultants in neurosurgery, orthopedics and psychiatry. There was a psychologist in the clinic then – there was also a Freudian psychoanalyst and listening to the two of them go head to head was sometimes very interesting! After every consultant had seen the patient, and if appropriate some sort of diagnostic blocks were done, on Friday at noon the group would convene and the GP presented in brief the patient's story, each of the consultants had their say, and a group formulation of the problem was arrived at. Dr Bonica would make his formulation; he would sometimes agree with the group – it was an interesting form of democracy; there were two votes, Bonica and everybody else! Then the patient and his or her spouse was brought into the conference room and Dr Bonica would explain to the patient what the group felt and what treatment options were available and what should be done. To my knowledge the group never again saw the patient. They went off to the surgeon or the psychiatrist and there was very little feedback. It was really a diagnostic operation.

The pressure to see more patients in the Sixties and early Seventies led us to try to figure out how to put more people through the system. By the early Seventies Bonica had not only established a reputation for the pain clinic but he was also at the same time secretary general of the World Federation of Societies of Anesthesiology (WFSA). He used that as a platform to go all over the world talking about how he was doing pain management – a good example of marketing. People came to visit from all over the world, in some cases to train with Dr Bonica, although these were the days before there were fellowships, to spend a week or a month or a year in the department learning about pain.

The International Association for the Study of Pain

By 1973 Bonica – and I really think it was just him – decided that it was time to organize the world to do something about pain. He raised money, including \$10,000 from the dean of our school (which was a miracle), some National Institutes of Health (NIH) money, mainly from the National Institute of Dental Research, which was the primary institute interested in pain in those days, and money from various drug companies. Then he sat down with his knowledge of people all over the world and those of us in his orbit and decided whom he should invite. I was asked who were the neurosurgeons we should ask, and the orthopedists, psychiatrists and others asked the same question. He then invited some 300 people, every single one of whom accepted. A meeting was held in Issaquah, outside Seattle, in a former nunnery which had been converted into a residential education centre. Bonica was a genius – this place was totally inaccessible; the only way you could get there was by a chartered bus or a taxi. So he had 300 people there *and they couldn't leave!* The

locals had cars and we could get away but the rest of them were captive for five days. We started at 8.00 am, broke for dinner at 5pm, and met again from 7 till 10pm. Everything was scheduled. Ron Melzack showed a movie of a person in some African country having a treatment for headache consisting of making a hole in their skull with a sharp rock; there was of course huge amount of blood and a psychologist in the front row passed out and someone shouted 'is there a neurosurgeon around?' This meeting brought together people Bonica and his colleagues thought would be suitable to start an international pain society. The last event on the Friday was an assembly in which the question was asked: where do we go from here? At that meeting we agreed that we should start an association which should have a journal, and Pat Wall agreed to be its editor. This was wonderful as there were very few people in the pain world at that time who had reputations as scientists or clinicians that could add colour and strength to the organisation. Pat was a well-known neurophysiologist by then and the seminal Melzack Wall gate theory was already well known. Bonica was a very clever man, and realised that one of the problems was that if this organization remained a Bonica/Seattle organisation it was never going to become internationally acceptable, and he had to do something to make them feel invested in it. And so it was agreed that we would form a society, that we would incorporate it in the US (that was because Bonica had just incorporated the WFSA and knew the lawyers in Washington DC who would do this for a relatively low fee.) We agreed that the first congress would be in Florence two years later. All the necessary committees were appointed and Bonica of course managed and organized everything to get just the results he wanted. So the IASP was launched and took off like a rocket, in no small part because of Pat Wall and the journal *Pain* which was a high status journal and at that time the only journal with the word pain in its title; there had been one with the title *Schmerz* published in Germany in the 1930's but most of the people involved in it were Jewish and they disappeared, and the journal died.

The first IASP congress was held in Florence. The question was who was going to be president? Everybody assumed that Bonica would want to be and everybody would vote for him. But we set up an organisational plan that said you are president-elect for three years, then president for three years and then past president for three years. And it was fascinating the way Bonica fixed things. One of the problems we had in the early days involved the French, led by Mme. Denise Albé-Fessard, a distinguished neurophysiologist and a good scientist. She and Bonica decided that she would be the first president. So she would be president for three years, past president for three and then she's gone. So who would be president-elect? John Bonica, so he got nine years of basically running the organisation. The first council meeting after Florence was held at a town near Innsbruck, and I will never forget – Denise Albé-Fessard stood up and said that there were not enough French people holding office in this organisation. And Bonica looked at her and said: "Madame, when the French do something worthwhile we'll get them into offices."

The second IASP conference was in 1975 in Montreal because Ron Melzack had added his name to the organization and we were getting both Melzack and Wall.

[Karen Loeser] And after it I had to entertain 50 Italians in Seattle with four days' notice!

By the early eighties there were pain clinics springing up all over the world. One of the first was in Oxford; there were early ones in Jerusalem, Sydney, and Los Angeles – about a half-dozen around the world by the early Eighties, and then it took off – it just exploded. One of our concerns early on in the Seventies about getting the IASP launched was that if we launched the American Pain Society at the same time, and

most of the workers in the early IASP were American – indeed from Seattle – we didn't want the two to be competing. In the USA we had regional pain societies that were started in the mid seventies. We made a deliberate policy of not letting these coalesce into an American Pain Society until after the IASP was successfully launched, so the APS was started in 1978 or 1979, and this has also prospered.

IASP has learned some lessons the hard way. In the early days we said we're going to have a governing council with the elected officers: president, secretary etc. and then we'll have a council consisting of six elected councilors and six regional vice-presidents. But although representatives for Europe, Africa and North and South America were acceptable, when you go to Asia (which includes Australia) none of the major countries would accept vice presidents from others, so it fell apart and we could not get a regional vice-president for Asia. So we abolished the VP's and just had twelve elected councilors, and we schemed – and still scheme – so there would be adequate representation geographically, discipline-wise, gender-wise and we have a good balance.

Bonica the man

Beatrice wanted to say a few words about John Bonica:

He wasn't just a clever man, he was a lovely man. At my first IASP meeting in Edinburgh in 1981 he and all the famous people I had been reading about were there. But John went around talking to people – and he talked to me – a first-year postgraduate student! He asked me what I was doing and when I told him it was a PhD in helping health professionals about pain management and measuring it on surgical wards, he grasped my shoulders and kissed me! John Bonica kissed me!! It was such a moving moment in my life and gave me so much encouragement to get on and do what I wanted to do.

That's a great story and very true of John Bonica. Nobody was too low in status to deny his attention. He paid attention to anybody who was interested in pain. He'd talk to students, nurses – if you were doing anything to do with pain he was interested in you. He was a very multifaceted person. He could be the most arrogant sonofabitch you ever saw. But that was in a different setting. He did not tolerate snobs at all, and if he thought you were pulling rank or whatever he was merciless. There was one phrase of his that if you heard it you would know it was time to get out of his way. If he ever said, "*listen friend ...*" you knew the trigger was about to be pulled.

He was not only a college wrestler but when he was an intern and in the army he wrestled professionally to make money. When he was at Madigan the Commanding Officer said that it was unbecoming conduct for an officer to be a wrestler – professional wrestling has always been a bit of a fake activity – and told him to stop wrestling as it was bringing disrepute to the US army medical corps. So Bonica became the Masked Marvel! He continued to wrestle with this identity for several years and won many prizes. He stopped when he went into practice. He paid a price for his wrestling as he had terrible hips, knees ears and other damage that cost him dear in later life.

John's wife Emma was a saint. John's family were Sicilians; Emma was born in Connecticut but her family were from Venice, where her mother had sung in the opera house. She took care of John; they had four children and she waited on John like no other wife I have ever seen, and took care of everything he did other than his profession. She raised the children as he was never home. She cooked, she

cleaned... she waited on him hand and foot in every way. My wife Karen would like to comment on this:

I grew up in a different family setting from Emma. My father was killed in the war so my mother was a single parent; things were tight and it was a very simple life. I was out of the country for a while and married when I came back, and then the pain game proliferated like mad... I got to know John and Emma both of whom I adored but Emma particularly. If I was ever in a quandary about what to do about entertaining or managing the home I would ask myself: "what would Emma do?" – and often asked her advice. She would occasionally sigh and say – "you know, taking care of John is at times a piece of work."

He loved her very much in terms of kindness and respect but as they were growing older some of us thought that it would be nice if John died first so Emma could have a little time to herself. But unfortunately Emma died first by a few months.

The saddest thing was at Emma's funeral was when she was being interred John approached the casket and said – "ciao, Emma".

There was no way he could survive without her, although his children waited on him too – not to the same degree as Emma, of course. He had three daughters and a son, and Emma taught the daughters exactly everything so if she was ill or out of town they would take over and minister to all his needs. John very much wanted his son to go into medicine and anesthesiology but he just didn't have the horsepower and it was unpleasant to watch this young man trying to carve out a career for himself with a domineering father who was pushing him to do what he didn't want to. Fortunately he did OK and lives in rural Washington where he edits a small newspaper and runs a restaurant, cooking as his mother taught him.

Although John wasn't very tall, his aura – his impression – was huge. And for a man like that his focus was on something other than the mundane and the business of day-to-day living. To make the contribution that they so you need a wife and family and the support system that allows you to do it.

She was an example of the adage that behind every great man is a great woman.

Oh she was – but she had nothing whatever to do with his profession, other than that she entertained everybody in the world. They had a nice, very large home with good entertainment facilities and he was always having visitors.

We were fortunate to be at their fiftieth wedding anniversary and his seventy-fifth birthday party, which were amazing events, and the emotional communication the two of them had was just amazing. They were an amazing couple and we felt privileged to be a little part of their world.

You said you were privileged to have known John Bonica but I think we feel very privileged this evening...

I was one of Bonica's foot soldiers. I was fortunate in that I was not in his department and boss me around because he could definitely exploit people whose lives he controlled. He worked twenty hours a day and would be angry with you if you didn't work as hard or didn't get a job done as fast as he could. He liked to call junior members of his faculty to go out to his house to inject his hip after work. I tried very hard not to be his neurosurgeon as he had back problems and terrible degenerative spine disease. So I schemed for one of the orthopedic surgeons to look after him,

and shortly before Christmas one year he acutely herniated a disc and had major neurologic deficit and this guy was out of town. So I had to operate on Bonica, and for the next twenty years I was his spine doctor! He was not a good patient!

Things evolved and in late '78 or '79. He got the president of the university to establish the pain centre, implying real existence and not just a group of people. With that came two faculty positions for the pain centre. So he went out and hired two full-time psychologists, one of whom, Judy Turner, is still with us. That catapulted up the pain centre in terms of the resources we had available. They were part of the training program and we had residents and fellows in psychology and psychiatry.

Bonica retired from clinical activity in 1978 and passed the running of the pain centre on to a couple of his colleagues. Suffice it to say that it didn't prosper the way John wanted it to. In 1982 when I finished a period as curriculum dean I became Director of the pain centre. I was very fortunate because Bill Fordyce who was without doubt the psychologist who did the most to put pain into a reasonable perspective was looking for an opportunity to expand his activities. He and I got a whole ward in a hospital and we constructed an inpatient and outpatient service with a group treatment program of some 20 patients for three weeks at a time. That served as a model for pain clinics all over the world. Bill and I decided that we had to make sure that the physicians and psychologists were equals. So we were going to have the psychologists on call for emergencies the same as the physicians, and we got them both pagers. One of the anesthesiologists said to me "this is crazy – you're never going to get psychologists to respond to pagers." Shortly after this one of the psychologists said "you'll never get the physicians to treat us as equals". The end of the story is that these two people got married and have been married for thirty years! This is a good parable!

You were saying about the small number of clinics which sparked off the pain movement in the 1980's. But where I work in Great Yarmouth there was an embryonic pain clinic in 1971 or '72 and there was Mark Mehta in Norwich just down the road. In a way the word had gone out and there were a lot of embryonic pain clinics getting going – some people with only one session a week, in back room in the anaesthetic department...

One thing that helped was that Bonica was the secretary-general of the World Federation of Anesthesiologists. And that put him into every developed country in the world.

He wrote a textbook on obstetric anesthesia and analgesia. He wrote the second edition of the *Management of Pain*, and I edited the third edition because six months before he died he made me promise that I would bring out another edition.

Is there an endowed chair at the University?

Yes. It is a research chair and is held by Dennis Turk who is a psychologist. The second chair of the department of anesthesia was the first American to stand on the top of Mount Everest, Tom Hornbeim. If you met him on the first floor and went with him to his office you had to run up the stairs to the fourteenth floor!

Pat Wall had an office on the sixth floor... When I went to see him first as a PhD student he asked me when I last went to a concert and reminded me that there was life after a PhD...

Pat Wall was also an interesting character. In 1989 we were in Australia; I was secretary of the IASP and Mike Cousins was the president. He and I decided to spend every Wednesday afternoon working on IASP activities. Mike, who always thought big, said: "The IASP congress is going to be here in Adelaide and I'm going to get Pat Wall and Ron Melzack the Order of Australia." To do that he had to provide the government with information from them, about how valuable they had been to Australia. Ron replied that he had so many graduate students from Australia, he'd been so many times to Australia lecturing etc. etc. Pat wrote back: "I've never done a damn thing for Australia!"... With one exception: when he was in the RAF he was assigned to an airfield somewhere in England and there was an Australian anti-aircraft battery there. "One day they shot down one of our own planes. Their CO was almost suicidal so I took him to the pub and got him so drunk he forgot about his misery – and that's what I have done for Australia!"

He published some qualitative research of mine in Pain – I had asked him whether they ever published qualitative research and he replied, "we do – we just put numbers in front of it."

I was the clinical section editor for the first 15 years. We tried very hard to get articles submitted by people other than Americans, Canadian and British. It was difficult. There were language problems and there were not enough people in the developing world writing scientific articles. One day I got a paper on acupuncture from a Nigerian anesthesiologist who had been on Council. I spent many hours correcting his English and editing the paper to make it look presentable and we published it. About a year later Pat got a letter claiming that the article had been plagiarised. It had been originally published in a Chinese journal and the co-author of the Nigerian one was Chinese and had simply translated it. When challenged, the Nigerian author resigned from Council and was never heard from again. So that's what you get from helping to get articles published!

Of the people you have mentioned who is still alive?

I am! Ron Melzack is alive, so is Harold Merskey... Bill Fordyce is dead, so are Pat Wall, Ainsley Iggo, Ed Charlton... Procacci has died – now there was an interesting man. Paolo Procacci was professor of medicine in Florence. His ancestors collected timepieces. He had 400 years' worth of them in his house – it was a museum and he knew all there was to know about them. He could tell you the exact date a historical house was built by the style of the shutters. He was a wonderful man.

To me the most rewarding thing of the whole IASP story was going to some country where they were trying to start pain clinics and societies and helping them to get things going. When that succeeds their gratitude is wonderful and you have made friends everywhere. I was able to do that in China and the Philippines, Thailand, Bulgaria, Rumania and what is now the Czech Republic. And there was a wonderful group of people in the IASP who shared a common purpose and a common goal. We were a family. As it has evolved and the original family has died or left office it has been sad.

Who have I forgotten? Mike Cousins. He was a big force in IASP and of course the Australian Pain Society. Ron Dubner, Howard Fields, Alan Bassbaum, Sam Lipton ...and of course Michael Bond.

I ran into Michael in Milan last year at the IASP conference. You could see he was struggling to identify me and all of a sudden he said "Woodbridge!... Notcutt" (where my family nurseries are) He told me that he and his wife had taken the train from

Helsinki to St Petersburg. When they got to the border the Russian guards came on board. They both took a long look at their passports, closed them up and handed them back with the words "Welcome to Russia, Mr Bond."

[Karen] We went to the IASP meeting in Milan which is a wonderful city. There were over 6000 people, and you could hardly find the people you wanted to. In the early days there were only a few hundred and you all had dinner together.

The numbers have grown from about 500 in Florence to 1100 in Edinburgh and straight upward since then. We had policy of rotating between Europe, America and someplace else.

One person in the pain world who was not actually a provider but who orchestrated everything was Louisa Jones. IASP would never have been the same without her.

Louisa was originally Bonica's manuscript secretary. She did a lot of organising for the Issaquah meeting and after it she asked him what she should do with all the material and he said, "you're going to take care of it". So she progressed from being John's secretary to becoming the administrative secretary of IASP and ran it until she retired about five years ago or so. She was amazing: first of all IASP's overhead costs were incredibly low because she organised everything so efficiently. She was the mother of the society – seeing to everybody's needs.

Why has it moved to Washington?

I will give you my answer – I don't know if it's the right answer. I was told, and this tells you something about the people currently running it, that it would be closer to most of the action. I don't think the Chinese would agree with that! The membership is mostly in North America and Europe, and Washington is a lot easier for Europeans to get to than Seattle. (If they should by any chance want to visit the secretariat). It is also claimed that by purchasing a whole floor of an office block in Washington money is being saved compared with the rent in Seattle. And it is probably easier to find well-qualified people there.

Michael Bond pushed IASP into helping developing programmes all over the world and although I know he is personally committed to that IASP is doing as much as it was when he was president. Each president gets to push the resources towards the things they feel are most important; mine was to establish chapters all over the world.

The journal *Pain* is still the best pain journal measured by the conventional criteria and it's harder to get something published in it than anywhere else. The mission of the publishing arm is to produce cheap books - we have learned how much profit a book publisher makes and we can do it much cheaper. We distribute books and journals in developing countries on a free basis.

The challenges we face today are very different from those you faced in the Seventies. How do you see that?

In the Seventies it was like being a pioneer pushing westward in the US to try and bring roads, railroads and civilisation into the wilderness. What we were trying to do was new and unheard of. It's still true in some countries but by and large the ground has changed. Now the question is how do you bring modern knowledge be it technical, psychological or whatever and information about pain to people that don't have it. Pain management is part of healthcare and we have learnt the hard way that you can't go to someplace where there is no healthcare and try to bring them pain

management. You don't have the infrastructure and providers. So the focus has changed from bringing the issues of pain to people who never saw them to getting people to allocate resources to pain management that are appropriate to their system. You can't just export sophisticated pain medicine.

And the other issue is that young men and women want to come to the USA for training. The question I always ask them when they apply is what are you going to do when you're done with your training. If some guy from Nigeria says he wants to train as an interventional anesthesiologist so he can go home and practice as this, we don't accept him because you can't do this sort of thing where there isn't the infrastructure. Either he's naïve or he's lying to me and he really wants to stay in the US. Why the US should suck up all the brightest and best of every other country of the world I don't understand. So the challenge is to fit in your concept of pain management into someone else's culture and the resources they have. On the other hand Eastern Europe was a totally different issue. When the Iron Curtain fell there were plenty of people who understood the technology and the equipment issues. Every country has a different problem.

I don't think the IASP has squarely addressed the opiate problem.

There are lots of people you can talk to now – pain is not some unheard of thing. The exclusively biomedical approach is diminishing. There are a lot more psychologists and social workers involved.

Further reading

First Steps: The Early Years of IASP 1973-1984. Louisa Jones

www.iasp-pain.org/AM/Template.cfm?Section=History1&Template=/CM/ContentDisplay.cfm&ContentID=11411

Celebrating 25 Years

www.iasp-pain.org/AM/Template.cfm?Section=History1&Template=/CM/ContentDisplay.cfm&ContentID=7643