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Saving starfish – integrating care and compassion into a system based on business ethics. Is it possible?

Reflections on Philosophy & Ethics SIG meeting at Launde Abbey

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> *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

This was my first visit to the British Pain Society Philosophy & Ethics Special Interest Group's (SIG) annual conference, which is traditionally held at a retreat. This year, the group was meeting at Launde Abbey, which is set in 450 acres of beautiful, green, open parkland on the borders of Leicestershire and Rutland.

In preparation, we were asked to read a paper by esteemed American neurosurgeon and elder statesman in the world of pain medicine, John Loeser and his co-author, Alex Cahana, a professor in pain medicine. John was the conference's special guest. Their powerful paper, *Pain medicine versus pain management: ethical dilemmas created by contemporary medicine and business*,[1] discusses the conflicts that arise when business principles are applied to health-care systems. 'The world of health care and the world of business have fundamentally different ethical standards'[1] and consequently not only produce conflicts in the physician and patient's mind, but directly affect the actual treatments offered. The paper talks about the state of pain medicine in the United States, but there are many parallels with the United Kingdom and other countries. What you get is not necessarily what you need, but rather what is dictated by financial drivers, pressure from providers of devices and drugs and an incorrect belief that chronic pain is a result of a broken body part which can be fixed.

The conference's agenda reflected the approach we were seeking to promote for the treatment of persistent pain – it focussed on the whole person. Each day began with a session of Tai Chi on the lawn, followed by breakfast, a morning of talks and discussions, lunch, a long country 'walking and talking' session, afternoon tea and cake, evening lecture and discussion, then supper and chat in the lounge and grounds of the abbey, a format which nourished us in many ways.

Changing culture

In his talk *Can we change the culture of pain management?*, John Loeser spoke about the conflict of interests and values which have arisen as a result of business ethics being imposed on health-care systems. I was struck by his comment that 'Patients get what the provider does, not what the patient needs', and how there is no time in the system to hear the patient's story because of the requirement to measure success by throughput of patients rather than by successful outcomes.

The management of persistent pain by a multidisciplinary team of specialist clinicians has been shown to be more effective, in terms of helping the person in pain to manage his or her symptoms over the longer term, than direct interventions. However, this is often overlooked. John and Alex's paper states that 'As hospitals are also searching for revenue generation, they have facilitated utilisation of revenue-producing procedures and removed support from multidisciplinary pain clinics'.[1] In John's opinion, '*Money always trumps ethics … Profits are the bottom line, not efficacy or humanity of care*'.

John also spoke of the huge opioid problem in the United States which we are beginning to see reflected in the United Kingdom and other countries. More people in the United States die from an overdose of opioids than from heroin. His co-author, Alex Cahana, put it more starkly in a TEDx Bellvue video (http://www.youtube.com/watch?v=VF_WQK0eWik): '*Today (in the US), 50 people will die from an overdose of pain killers. Painkillers kill*'.

Saving starfish – integrating care and compassion into a system based on business ethics.

Morphine is neither a desirable nor an effective solution for persistent pain, yet in many developed countries, it is hugely overused for this purpose. Alex Cahana made it clear in his TEDx talk when he said, '*Pain is not an opioid-deficient state*'. Opioids play an important role in managing acute pain but are often under used in this area, so there needs to be a shift in thinking and practice on a number of levels across the world. This point was reinforced by Consultant in Pain Medicine and Chair of the British Pain Society Pain in Developing Countries SIG, Clare Roques, in her talk entitled *Changing the culture of pain medicine: a desirable and achievable international goal*. Alex Cahana illustrates this in his video with photographs of badly injured soldiers – morphine enables us to deal with the acute pain of stepping on a mine, but months down the line, when injuries have healed, it has no place to play in pain that persists.

This belief that morphine is an answer is a huge problem and leads to a false expectation that a pain specialist can fix all pain. I have encountered patients unable to keep their eyes open or be a part of life because of their high morphine intake; so it is food for some thought that these are prescribed by doctors who have a duty of care. The conflict is that they are also trying to fulfil their patient's expectations that their pain can be fixed, so there is a wide-ranging need for education across many levels.

Education, education

There is a need to educate populations about the true nature of persistent pain to change the focus away from short-term fixes in favour of longer term management. John called for a move away from the belief that chronic pain is a by-product of disease – the belief that if you fix the disease, you fix the pain. This biomedical approach promises the abolition of pain, which is currently not possible. John and Alex both stress that pain should not be considered as a 'THING' – a noun. Pain is a process – a verb, so perhaps we should be saying that people are 'paining' rather than people have something called 'pain'. Alex Cahana argues that we have developed a culture of medicalising life.

John went on to discuss how pain and suffering have become synonymous in our culture and language – the language of pain is used to describe all types of suffering. As Alex Cahana put it in his video, '***Pain is mandatory – suffering is optional***'. Many people in pain will find this a difficult concept to grasp. Again, it comes back to education and changing our cultural beliefs about pain. It also highlights a need to change the message and language the media promotes and the benefits of making research articles more widely accessible and readable. We need, however, to be careful that the message that persistent pain isn't the result of a broken part which can be fixed isn't interpreted as, '*I'm sorry you have chronic pain so there is nothing we can do for you*'. There is a lot we *can* do to change the experience of pain and alleviate suffering, but this needs to be done from a baseline of accurate knowledge.

Success needs action

Patients who hold the belief that pain can be cured by the doctor 'doing something to them' are passive in managing their pain. Long-term success depends on the patient taking an active role in their treatment, physically and mentally – being involved, owning a way forward. Being successful at anything requires action. That decision to change and take action needs to be made before any progress is possible.

I emphasised this in my talk on knitting as a tool in health care. I spoke about how knitting can be used as a springboard to action – becoming involved in the world. About how enabling our patients to be successful at something was an important first step in helping them to accept their pain and successfully manage it so that the process of change can begin.

Change almost invariably needs to involve lifestyle changes, changes in mental attitude as well as increasing levels of physical movement. In John Loeser and Alex Cahana's words,

> *Chronic inactivity has been shown to be deleterious for every organ system in the body. Certainly if rest and inactivity are prescribed by the physician, the patient acquires a disability that may not be driven by the underlying injury at all.*[1]

I see this frequently – people with persistent pain who haven't moved or exercised for years, so their pain and disability is accentuated and perpetuated by being generally out of condition and unfit.

Making changes to deeply rooted ways of life isn't easy, so people need ongoing support to achieve this. The culture of measuring success by throughput doesn't allow for ongoing longer term support, so it should be no surprise that patients keep bouncing back asking for help. Perhaps we should take a message from successful weight-loss organisations which recognise that ongoing support through groups, run by an expert, is an effective long-term strategy. Praise and reinforcement of success have been shown to minimise the risk of failure.

Long-term conditions need a longer term view, although within this model, it is important to recognise that an effective multidisciplinary approach may require a short-term interventionist procedure (such as an injection) to enable movement to begin the journey along that longer term path. These decisions should be made within the multidisciplinary team with a specific desired outcome in mind, and then be monitored appropriately and happen within a system which enables ongoing support and motivation. It's all too easy to fall by the wayside and develop other problems without support along the way.

This is exactly what thriving businesses do, and indeed, there are many good

practices we can take from business models, so I would caution against turning our backs on ideas just because they have come from the business world. Successful business strives for and depends on customer satisfaction. A thriving, successful health-care system should strive for patient satisfaction.

Are we compassionate?

Giving clinicians time to reflect and talk about difficult cases enables them to improve their care and manage their own personal mental health. A stressed out clinician cannot offer a compassionate ear to his or her patient. As Yoga teacher Sarah Dixon emphasised, to show compassion, we have to start with ourselves.

BBC Radio 4's programme *You and Yours* on Tuesday, 20 June 2013, discussed quality of care and compassion. I was struck by the comments of one caller who said, 'Without compassion there is no dignity or respect'. He also said that no matter how compassionate individual carers were, imposed time constraints forced compassion by the wayside, 'Without time there can be little compassion'. This is also my impression; measuring success by throughput of patients introduces time constraints which can seriously impede the clinician's ability to show compassion and therefore the quality of care they provide.

In her talk, *Compassion in healthcare: report of the Royal Society of Medicine meeting*, Sarah Dixon told us that the psychologies of threat and compassion are incompatible. In a situation of threat, it is difficult to be compassionate. When the threat level is high, threat focus takes over leading to threat-focussed solutions. If threat level is low, collaborative relationships and creativity flourish.

This highlights how the structure of organisations and the status of pain education create conflicts: the values of business versus the values of effective health care; the values of clinicians versus that of the system; the patient, who enters the consulting room with an expectation of finding a fix, versus the clinician who is unable to deliver.

Meaningful message

The importance of finding shared values was reinforced by Ed Peile (Professor Emeritus of Medical Education, University of Warwick) in his talk, *Learning and teaching about pain: the evidence and the values*. He focussed on improving the clinician–patient relationship by exploring shared values. I think this can be expanded to include the system within which the clinician/patient relationship occurs. If we have a system which builds on shared values, ethics and goals, then surely this will be beneficial for everyone – management, clinician and patient. Knowing what our focus is as a whole will help to create order from the chaos that John described. Managing order must surely be more cost-effective than managing chaos.

Ed Peile spoke about the essentials of values-based practice, where the best available scientific evidence is combined with clinical experience and knowledge of the patient's individual values. He argued that the most effective approach is to explore values which are shared by patient and clinician – the need to ease suffering is a good place to start – and build on these. He stressed the danger of making assumptions and the importance of realising that not everyone thinks alike – 'Not everyone thinks like I do'.

These shared values should guide actions. By knowing what really matters to their patient, clinicians will be aware of how these values may impact on their clinical approach. This process of empowering patients by using the thoughts and beliefs they deem important gives the process meaning, and in so doing makes it more likely that guidance on managing pain is adhered to. The message was that we should be learning to listen before learning to format.

According to John Loeser, this is exactly what is not happening in health care in America, and we are seeing this trend spreading. To reiterate his statement, 'Patients get what the provider gives, not what the patient needs'. Is there any surprise therefore

that we're unsuccessful in our treatment of persistent pain?

Do we care?

Janet Holt (Senior Lecturer, School of Healthcare, University of Leeds) in her talk entitled *Do nurses care?* asked what we mean by 'care' and discussed whether we thought 'care' was a defining characteristic of nursing. Should we be choosing prospective nursing candidates by their ability to care? Should this take precedence over competence? How do we ascertain whether a person is caring in an interview? She got me thinking how difficult it is to get it right. It's easy enough to say that nurses should be more caring, but what do we actually mean by that? I think reassuring touch plays an important part in showing we care, but in a society that doesn't encourage touch, how do we train someone to do so in a way which conveys they care?

Janet identified the elements of care as Attentiveness, Responsibility, Competence and Responsiveness. Good care requires all these elements and involves the context of the care process plus the ability to make judgements about conflicting needs and strategies. So in the context of health care, 'care' goes much further than ensuring someone is fed, washed, watered and comforted.

In the follow-up discussion, the training of health-care assistants was raised. How do you develop those caring skills in such a short period of time? How do you move someone from operating an inanimate supermarket till to touching caringly and giving intimate care to sick people in a few days? Can we teach compassion, I wonder? Do we only train those people who demonstrate a propensity to be able to practise it? How do we measure that? Confusion can also arise about who is a nurse and who is a health-care assistant, so perhaps we expect too much of these 'carers'? Where is our duty of care to them?

Patient people

There was an interesting discussion on whether the patient should be referred to as a patient or a person with pain. I don't think the two are mutually exclusive. My personal view is that there are millions of people who have pain, but at some stage, some of them require our help. I think at this point they also become patients. A patient is still a person with pain in the same way as the pain specialist is a person with knowledge about pain. When a person with pain seeks our help, we enter into a mutual contract, the relationship changes and needs to change. This point was emphasised by General Practitioner (GP) Bernd Strathausen. The clinician–patient contract enables the clinician to touch and examine the person with pain. It gives us a duty of care which we don't have to all the other people who live with pain in society, apart, of course, from having a duty of care for them as fellow humans. Therefore, in my view, we need a word which describes the person with pain who seeks our help, and for want of a better word, I am happy to 'patient' for the duration of their treatment.

Musings about pain

After supper on day 2, we were treated to a wonderful few hours of reminiscence by John Loeser who spoke about the early days of establishing the International Association for the Study of Pain (IASP) and its journal, *Pain*, in 1973. It was a privilege to sit with a small group listening to him talking about the great names in the world of pain medicine. His lovely wife Karen chipped in with tales of her own, which brought the stories to life.

Beatrice Sofaer-Bennet (Honorary Fellow, Clinical Research Centre, University of Brighton) added her own amusing anecdotes of her experiences in this early era of pain management. She expanded on this in her session, *Tales, stories and memories: a Pain Clinic Compendium*, on the last morning of the conference. It is thanks to clinicians like John and researchers like Beatrice, who are passionate about their subject, that pain medicine has advanced as it has, so let's hope people will take heed of John and Alex's paper which warns health-care systems around the world against continuing on the path of using business ethics.

Chaos versus order

John spoke of the chaos currently present in pain medicine. It is my view that without an agreed standard for treatment or makeup of clinical teams based on outcomes, there can be no consistency of treatment. How, therefore, can we expect consistency of care or success? Several people rightly pointed out that there are areas where the level of care and competence is wonderful and works well. I would agree, but in my opinion, this is down to some remarkably hard working individuals who manage to provide exemplary care despite the

broader, target/numbers driven system they find themselves in.

As a reminder of these good things, Clare Roques spoke about advances being made in pain management in developing countries. She is working to educate clinicians in these countries to enable people to access effective pain management.

Consultant Nurse Karin Cannons has crafted order from chaos in her Department in Frimley Park, London. In her talk, 'Know-what-I-mean? Do we hear what is said and what is meant? Developing a common culture of communication amongst the Pain Multidisciplinary Team using reflection', Karin described team meetings in which clinicians are encouraged to reflect on their work, patients and problems, and how it had been a fight to secure these non-clinical hours. Again, the conflict between business ethics and those of health care raised its head but, despite this, she has been successful in securing this non-patient (zero revenue-making) time for her team to meet. We can learn from her example and perhaps begin to bring order to the chaos. Learning from areas that *are* functioning well is also what good business practice does.

Knitting it together

The third morning pulled together many of the issues raised over the conference. My talk on *Getting the right hand to work with the left: knitting together – a future for health care* was well received and other pain clinics will be setting up Therapeutic Knitting groups as a result.

I focussed on the importance of the 'other things' going on in people's lives and the benefits of listening to and hearing the patient's story which was an underlying theme of discussions. This was reinforced by John when he reminded us that a major cause of persistent pain is poverty and this situation is worsened when those who are 'paining' have to give up work and rely on the uncertainty of handouts. This is a situation we've seen made worse by the recent introduction of a new benefits system in the United Kingdom.

It is my opinion that we *can* address many of the issues raised over the 3 days at low cost if we change the focus of our delivery. We can influence positive change in the body's physiology by applying the principles of positive psychology to change the chemical processes that cause us to feel the way we do. We can exploit the fact that our amazing nervous system changes with experience to influence positive change. This point was reinforced by physiotherapist Ian Stevens in the last talk of the conference. We need to change the belief that all medical conditions require medication. Sometimes there are easier, cheaper options.

Ian Stevens has a special interest in the interface between arts and science, so his talk on *Allegories of change: the poetry of Ted Hughes and images of the natural world* was a fitting way of winding up a conference that had debated wide-ranging, serious issues in such beautiful surroundings. Ian spoke about how context and meaning can dramatically change the nature of pain. His first slide reminded us of the difference between pain and suffering. It showed a graphic image of a painful ritual where the cultural context completely changed the degree of suffering. The meaning had changed, so it was a great way of reinforcing the importance of hearing the patient's story, of knowing their values and of finding out what their pain means to them.

I was struck by the metaphors he used. He likened the state of persistent pain to a balloon bouncing on the underside of a branch and continuing to hit the branch time after time. 'If you have the same stimulus you travel in the same direction, but it only takes a small breath of wind to change that direction and free the balloon'. He brought our focus back on to our amazing nervous system and how we can influence positive change in its very makeup by utilising positive psychology – the strengths and virtues that enable people and communities to thrive.

Call to action

John Loeser and Alex Cahana's paper calls for change. 'Financial incentives for all sectors of healthcare delivery systems must change so that they reinforce doing what is right for the patient. What is funded should be based upon long-term outcomes studies that are patient-centred'.[1] In terms of whether we choose to change or not, Ian Stevens told us, 'Stasis – a period or state of inactivity – is the opposite of change and flux and is incompatible with life'. We need to change to flourish, and this is true of the individual who suffers from persistent pain, the clinician and the system we find ourselves in.

We *can* learn from appropriate, successful business models and what better way to win an argument than to turn the opponent's rationale around. Success needs action, so we need to spread our message far and wide. Trish Groves, Deputy Editor of the *British Medical Journal* (*BMJ*), in her talk on *Social media in medicine: benign influence or just more spin?* focussed on how we can use social media as a tool to enable us to reach millions of people around the world. Let's take full advantage of it.

Beatrice Sofaer-Bennet told the story of a mother and child walking along a beach strewn with thousands of stranded starfish. The little boy throws one back into the sea and his mother says, 'There's no point. You can't save them all. There are too many to make a difference', to which the boy replies, 'Oh but I can make a difference to this one'.

If we all throw back a starfish, we might have an impact! I am reminded of Margaret Meed's words, 'Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has'.

Reference

1. Loeser JD and Cahana A. Pain medicine versus pain management: ethical dilemmas created by contemporary medicine and business. *Clin J Pain* 2013 29:311–6.