



THE BRITISH PAIN SOCIETY

Special Interest Group for Philosophy and Ethics

# The Tyranny of Diagnosis

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## Introduction

Peter Wemyss-Gorman

The title of this conference was taken from a paper by Charles Rosenberg in which he argues that 'diagnosis, prognosis, and treatment have been linked ever more tightly to specific, agreed-upon disease categories, and that the patient has been objectified as 'a structure of linked pathological concepts'. Doctors are obsessed by making the 'right diagnosis', using more and more technically sophisticated tools to this end and correcting the departures from perceived normality revealed by them. They over-investigate and over-treat their patients because they are too busy looking at organs and laboratory findings to listen to them.

Pain practitioners are accustomed to seeing many patients who have been referred either because previous consultations and investigations have failed to attach a diagnostic label to them, or because the label they have acquired has set them on a fixed but futile therapeutic pathway. We are not immune to the temptation, sometimes justified by experience, to perpetuate these processes when we think something may have been missed, or having placed a patient in the apparently appropriate diagnostic box we prescribe a course of intervention.

But the experience of illness is of more importance to most patients than any disease label. Diagnosis is clearly important for both doctor and patient, and for the latter, the lack of any convincing explanation for their pain can add immeasurably to their distress and perception of not being believed or listened to. Be that as it may we can try to overthrow the tyranny of diagnosis, not by abandoning it, but by recognizing that we need many levels of diagnosis to explain the experience of illness, from the biomedical through the psychological and social to the spiritual, all requiring attention to the patient's narrative, and that there are many windows into suffering.

In recent years we have tended to widen the remit of the Special Interest Group for Philosophy and Ethics (SIG) to encompass ethical issues only indirectly concerned with pain medicine and to look at these with the help of authorities from other fields. This year we heard (from a senior civil servant in the Department of Health) about the ethical problems of resource allocation, which we tend to view, sometimes resentfully, from our own narrow perspectives; and the ways in which our patients' problems are compounded by issues such as poverty and inequality, and their need for advice about social security and the benefits system.

# Preamble: The Tyranny of Diagnosis?

Jeremy Swayne

For this preamble I have reframed our theme as a question. It is not a new question. *The Healthcare Dilemma* from which the quotation here is taken, is a booklet that I read back in the mid-'70s. It had many wise and thought-provoking things to say about the direction of modern medicine then, which are even more pertinent today. And although it made no reference to it, it was roughly contemporary with Ivan Illich's *Medical Nemesis*, and shared some of its critical stance.

This is the question we are setting out to explore in this conference, and we may want to challenge, and will certainly want to examine, the tyrannical nature of diagnosis implied in the title of Charles Rosenberg's paper that we have adopted as our theme. So as we set out to do that, I will set the scene with a digest of the arguments that Rosenberg uses to justify that proposition. In the process of digestion I have used many of his own words. But where it helps to convey his ideas more economically I have used the right words, but as Eric Morecombe might have said, not necessarily in the right order. Sometimes I have paraphrased his words for the same reason if I think it may express his meaning, as best I understand it, more succinctly. I will briefly amplify his arguments by reference to other authors. And finally I will depict the many aspects of the therapeutic encounter that the word 'diagnosis' evokes in a mind map; a 'landscape of diagnosis'.

As I review what Rosenberg has to say, at each point the questions we have to ask are: Is he right? Is it true? If not, where has he got it wrong? How does my experience correspond with or contradict what he says? And in as much as he is right, what is to be done about it?

These quotations from Rosenberg's Paper exemplify his theme:

Diagnosis has always played a pivotal role in medical practice, but in the past two centuries, that role has been reconfigured and has become more central as medicine—like Western society in general—has become increasingly technical, specialised, and bureaucratised. Disease explanations and clinical practices have incorporated, paralleled, and, in some measure, constituted these larger structural changes.

This modern history of diagnosis is inextricably related to disease specificity, to the notion that disease can and should be thought of as entities existing outside the unique manifestations of illness in particular men and women. During the past century especially, diagnosis, prognosis, and treatment have been linked ever more tightly to specific, agreed-upon disease categories, in both concept and everyday practice.

Everywhere we see specific disease concepts being used to manage deviance, rationalise health policies, plan healthcare, and structure specialty relationships within the medical profession. And I have not even mentioned the countless instances in which clinical interventions and expectations have altered the trajectory of individual lives.

In other words, diagnosis has become the servant, the slave even, of the disease-based model of medicine.

He goes on to describe disease and its specific categories and entities in a variety of guises:

- as a social phenomenon
- as a 'narrative' - in terms of the natural history (or biopathography)
- as a necessary tool for managing and transcending the subjective, local and idiosyncratic, the incoherence and arbitrariness of human experience; the elusive relationship between the individual and the collective; thus facilitating the progress of scientific medicine
- as the basis of protocols and guidelines for clinical care, institutional decisions, and research
- as a justification for the dominance of the hospital in medical education
- as a convenient mechanistic language for accommodating difficult clinical problems
- as permitting an 'iatrogenesis of nosology' through the invention of protodiseases; often defined by surrogate measures such as cholesterol levels or bone density
- as a bureaucratic and administrative necessity
- as an excuse for ignoring the social determinants of illness and the suffering of the person
- as a smokescreen obscuring medicine's moral, technical and market identities.

In all these diverse roles played by disease in the theatre of healthcare, diagnosis is the actor-manager. It is, says Rosenberg, "a key to the repertoire of passwords that give access to the institutional software that manages contemporary medicine. It helps to make experience machine readable." It is what Christine Barry and Nicky Britten called the 'biomedical filter'.

Diagnosis makes disease entities into actors in complex and multidimensional negotiations that can configure and reconfigure the lives of real men and women. In the process, "the patient is necessarily objectified and recreated into a structure of linked pathological concepts and institutionalised social power."

Diagnosis labels, defines, and predicts, and in so doing helps constitute and legitimate both the reality it discerns, and the authority of the medical system to manage it. In doing so it provides culturally agreed meanings for individual experience and, by this means, replaces uncertainties – for better or worse – by a structured narrative.

Diagnosis, says Rosenberg, is an age-old ritual that holds both doctor and patient hostage. The protocols that determine so many aspects of practice are powerfully constraining, although physicians concede their frequent arbitrariness in particular clinical situations. Diagnosis requires that a continuing narrative is condensed into a discrete act taking place at a particular moment in time. Agreed-upon disease pictures, often configured by what can be measured and evaluated against statistical norms, are points on a spectrum that do no justice to the infinite variety of men and women that comprises the true spectrum. Rather each specific point on the spectrum could be likened to the observations of the blind man in the fable who is asked to describe an elephant by feeling its trunk.

Within this managerial context the practitioner's role is inevitably compromised and ambiguous. How does one ensure clinical flexibility and an appropriate measure of practitioner autonomy in such a system?

Having given this exhaustive account of the limitations of contemporary concepts of disease, the social phenomenon that they configure, and the way they constrain the diagnostic gaze of the physician; having implied, so to speak the extent to which these things prejudice the role of medicine in human healing; at the end of the paper he changes tack.

He has earlier noted that from the beginning of the 20<sup>th</sup> century - that is even in the early years of the ascendancy of scientific medicine - there was disquiet that this meant treating diseases and not people; a glorification of the specialist at the expense of the generalist, and a tendency to denigrate the physician's holistic and intuitive clinical skills. And he turns to the distinction between the disease and the illness; which he refers to as 'the incoherence and arbitrariness of human experience, that needs to be assimilated into the larger shared context of institutions, meanings and relationships in which we all exist as social beings'.

We are always the sum of our illness and our disease, and there is an inevitably elusive relationship between the individual experience of the one and the collective context of the other. Just as disease entities and the diagnostic imperatives they evoke can be fragmenting and alienating in terms of an individual's relationship to larger society, they can also be understood, Rosenberg suggests, in a social system sense, as holistic and integrative.

That may be true. But it is an uncomfortably totalitarian view of medicine's role. It smacks of Iona Heath's vision of clinicians and health services ushering people in increasing numbers across the border from the Kingdom of the well into the Kingdom of the sick; a forced migration driven by "detaching notions of disease from the experience of suffering, broadening the definitions of diseases, turning risk factors into diseases (Rosenberg's 'protodiseases'), and most potent of all, fear." Is that true? Is that what we are doing?

This tendency to broaden the definitions of disease and turn risk factors into diseases is challenged vehemently in London GP Michael Fitzpatrick's book *The Tyranny of Health*: "When health becomes the goal of human endeavour", he writes, "it acquires an oppressive influence over the life of the individual. If people's lives are ruled by measures they believe may help to prolong their existence, the quality of their lives is diminished." Is that really what is happening?

The 'iatrogenesis of nosology', through the invention of protodiseases, is illustrated nicely by an account of the misfortunes of Mr Hudson, a journalist that I came across in the *Daily Telegraph*:

Mr Hudson was, pretty healthy, except for moderately high cholesterol, but he became a patient when that moderately high cholesterol was detected by routine screening. He had acquired a diagnosis. He did not have a disease exactly – or did he? But after a time he developed symptoms; he became ill.

He did not associate this with the treatment of his hypercholesterolaemia at first, but his memory was increasingly impaired, and he also developed poor circulation in his fingers and toes. Because he did not attribute the symptoms to the treatment he considered other explanations – some kind of incipient dementia for the memory loss, perhaps; the repetitive strain of his furious two-finger typing for the poor circulation in his fingers.

The memory loss and its association with dementia caused what sounds from his account like a sense of dread – “a gripping sensation around the heart.” It was an unhappy time for both him and his wife who said “I thought that this was how life was going to be for the next 30 years.” Not only did he have specific and distressing symptoms, but they were both evidently ill with anxiety.

He also became unusually reclusive for fear of making a fool of himself in public. His symptoms interfered with his golf and his tennis, and his use of words, the tools of his trade. He became a sick man, in the sense that his illness compromised his ability to be himself and take his usual place in the world.

He was also suffering. He was distressed in a variety of ways. He was embarrassed, fearful; even at times, reading between the lines, humiliated. He suffered loss of integrity, in the sense of being a less integrated person; and of meaning, in the sense of following his vocation and enjoying his relationships. Technically he also had a disease in that his condition involved pathological, though ultimately reversible, changes in the brain and his extremities due to the known but poorly understood effects of some statins in some people.

This story has a happy ending because the symptoms resolved when he eventually discovered their possible association with the drug, and stopped taking it. And I found his story instructive because of what it teaches us:

- Of the nature of illness: a subjective state in which we experience symptoms which disturb the normal equilibrium of our life, causing discomfort or inconvenience.
- Of the concept of disease: observable disorder of body tissues or functions.
- Of sickness: a state in which illness or disease interfere with our normal social functions and relationships.
- Of suffering: distress compounded of physical and/or emotional symptoms with loss of our sense of meaning and integrity as a person.
- And, particularly in the context of this conference, of the part played by diagnosis in establishing the patient state, or role, regardless of the presence or absence of underlying disease.

One reason, says Howard Spiro, why doctors over treat and over study (by which I take him to mean ‘over diagnose’), and do not always talk with or listen to, their patients, is because they are too busy looking at organs and laboratory findings. “Technology is overused,” says Spiro, “because doctors expect to find an answer to every problem if they only look hard enough with the right instruments”.



As James McCormick wrote: “Our patients deserve of us accurate diagnosis and appropriate treatment. But when accurate diagnosis is impossible and appropriate treatment unavailable we delude both them and ourselves by using diagnostic labels and prescribing specific treatments.”

Nevertheless, for all the dangers that attend the diagnostic imperatives of contemporary medicine, the art and science of diagnosis remain central to clinical practice and patient care. In his essay *‘Diagnosis is treatment’*, Howard Brody shows some sympathy for Rosenberg’s alleged holistic and integrative role for disease-focused diagnosis.

He points out that a virtue of diagnosis, involving as it must a human relationship between physician and patient, is “that it explains symptoms, encourages expressions of care, provides a mantle for distress that society will accept, and implies the possibility of gaining control over it”.

So diagnosis is an indispensable and multifaceted process at the heart of the therapeutic encounter. The implication of Rosenberg’s paper, and perhaps our task at this conference, is that we seek to redress the balance between its biomechanical, biosocial, and biopolitical dimensions and its role in promoting human healing.

In conclusion I have tried to represent this multifaceted endeavour in a mind map of the landscape of diagnosis.

# What is Diagnosis?

Paul Dieppe

When my colleagues ask me what I come to these gatherings for I tell them that it is my annual existential angst meeting! – but it is lovely to again be with a group of people who find medical practice confusing. I have always found it confusing and this issue of diagnosis is one of the most confusing aspects of it, and I am never quite sure what it is all about.

I'm going to talk about my angst with diagnosis as a rheumatologist because that's all I know. Jeremy has asked us: is diagnosis getting in our way? My answer is sometimes yes and sometimes no. I hate these dichotomies that we set up in medicine; the title of this meeting suggests the question; is it good or is it bad? Well, it's actually both.

So what then is diagnosis? I have come across various definitions; Wikipedia defines it as 'the process of determining which disease explains a person's symptoms and signs'. Another one I came across in a paper by Cournoyea and Kennedy states that "It is uncontroversial...that diagnosis means a medical, disease related explanation of symptoms" (!) What those definitions add up to, as Jeremy was saying, is that diagnosis is now being interpreted as being about a *single* disease within a *biomedical* framework to explain what are *considered* abnormal symptoms and signs. And this covers a lot of the evils and problems around this area.

But we ought perhaps to go back to what we are *for*, and I would posit that this is to help people to find out what is causing their sense of dis-ease, and help them find their own way to resolving those problems. This is quite different to finding a single biomedically related disease and may involve finding many different, complex and interacting predisposing factors. Dr H.W. Balme who was my mentor at Barts where I trained - a very irreverent Yorkshireman – had a number of Balmy [barmy?] sayings among which was "There are three principles to appropriate treatment in medicine: Diagnosis, Diagnosis and Diagnosis". When I got to know him a bit better I realised that he was saying something much more profound than I had supposed: that there were many *levels* of diagnosis, and always multiple issues around a patient's problem. Our problem is that most of us can only cope with one epistemological framework within which to find a *single* diagnosis; we are stuck in linear positivism: *this* causes *that* and through *that* pathway. This is completely bonkers within our current understanding of complexity theory; we are complex human beings living in complex society. But that is where we are and can only operate. We get into more trouble by invoking Occam's razor and saying you must look for single causes for everything before you start looking for multiple causes. I think that is horribly dangerous in medicine although it was taught a lot when I was a boy. I will argue, like Jeremy, that we need a more pluralistic approach.

## *Diagnostic scenarios*

This is a Pain Society, I was a rheumatologist, and rheumatology is all about musculoskeletal pain, so I am going to illustrate what I mean by discussing some

painful rheumatologic diseases. We are going to talk about knee pain and four familiar diagnostic scenarios. The first is a middle-aged, obese, hypertensive man. His knee is hot, red and swollen. The most likely diagnosis is gout, with septic arthritis as the most important alternative. You make the diagnosis by taking off some fluid, looking for uric acid crystals with a polarised light microscope, and culturing it. What is the best treatment for gout? – probably nothing at all, because as Hippocrates was well aware, an acute attack of gout usually goes away within a week, meaning that any treatment you offer (or none) is going to be successful. I usually explain it to my patients as being about kidneys and uric acid and crystals, and Hippocrates, who probably knew as much or more about gout than I do, explained it to his patients in terms of humoral theory and ‘excess’. His and my patients both got better and we both provided them with an explanation and *meaning*. This and reassurance that it would go away was all they really needed. So we both did good within completely different diagnostic paradigms. Hippocrates’ diagnosis was ‘syndrome-based’ and ours more aetiologically based, but both address the cause and neither of us is ‘wrong’. So the lesson to be learnt from this scenario is that there are diseases like gout which need to be diagnosed and differentiated from things like septic arthritis so we can treat them adequately. A lot of good medicine does involve accurate diagnosis within a biomedical framework, but it is important, in our diagnostic angst, that we don’t throw the baby out with the bathwater. Certain diagnosis is not, in my view, a tyranny, but it’s a bloody good thing to get it right.

Scenario 2 is of a woman in her 30’s who gave birth to her first child a few months ago, and who is feeling generally unwell with joint pains in her hands and feet as well as her knee. She finds it difficult to get out of bed in the morning because of stiffness. Many of her joints are tender and a little swollen. The diagnosis is almost certainly rheumatoid arthritis (RA). It doesn’t seem to have existed in Hippocrates’ time and we now think it is a discrete disease that we can diagnose and understand. We diagnose it with blood tests and stick people under big machines. The treatment is a highly contested area, dominated by industry and lots of nasty drugs, some such as monoclonals which are very expensive, and all dangerous. The cheaper ones are probably as good as the expensive ones (and the industry wants us to use the latter) but the important point is that whatever we do some of our patients will respond and others won’t. And within biomedicine we can’t understand that. One possible explanation is that it’s not really a homogenous ‘disease’, and there is evidence from other healthcare systems that that is the case.

Jan van der Greef from the Netherlands has been exploring this and has looked at the approach of Chinese medicine to polyarthritis. They would diagnose this lady with RA but then they would go further and diagnose it as being either hot or cold according to other symptoms and clinical findings. ‘Hot or cold’ means something different from what we understand within biomedicine and is to do with the balance of your body and the totality of your person. Jan has found that if you combine these systems you probably get on better in terms of individualising treatment. ‘Hot or cold’ does not link or correlate with the subtyping that we do with serology, but probably improves the ability to treat appropriately in an individualised way, in other words the ‘hot’ group may respond to a different kind of intervention than the ‘cold’ group. I say probably as the numbers Jan has treated are not very big yet; but it kind of makes sense to me. It is an example of something which is getting quite big in the literature just now: a systems approach combining Chinese and Western Medicine to make a more sophisticated diagnosis, taking us out of the purely biomedical paradigm. The lesson here is one that Jeremy alluded to earlier: that many of the ‘diseases’ that we

diagnose are not discrete entities; rather they just provide a convenient way of classifying our patients until we can understand things (and people) better. I think it's exciting that we might be able to combine systems and ways of thinking to help us to have a more sophisticated approach to things like polyarthritis, which, for better or worse, are more like gout in terms of the helpfulness of understanding the disease process than they are in my next two scenarios which are much more problematic.

Scenario 3 is a 69-year-old man who used to be very athletic in his youth, who is very overweight but otherwise fit. On examination you find crepitus in his knee. It's actually me, and according to diagnostic medicine I have osteoarthritis (OA). So we use X-rays to make an anatomical diagnosis. Mine show a lot of narrowing of the medial joint space with some osteophytes and even a bit of chondrocalcinosis, which would be classified as Grade 3 osteoarthritis. It's pretty symmetrical in both knees. So what is the treatment for this?...well, Lord alone knows. The treatment has nothing to do with the diagnosis as we have nothing that affects the changes in my X-rays, and even if we did there is no certainty that it would make any difference, so is there any point in diagnosing it at all? It gets more interesting as one knee hurts sometimes and the other one doesn't bother me and they are both the same on X-ray, and there is a very poor correlation between X-ray changes and pain. So we are diagnosing a pathology which doesn't actually relate to the symptoms. (Do you know when I started to talk about my knee pain my knee started hurting!) So how do I know how they relate? I have no idea and I'm supposed to be an expert in osteoarthritis. My orthopaedic colleague has offered to put a new one in. I haven't let him do that yet. So what are the advantages in having a diagnosis for my knee pain? Well, first of all it legitimises my being able to say "sorry guys – I really can't come for a long walk with you this afternoon". And of course it does open the door to some caring pathways like having a nice young physiotherapist treating my knee. But it does have some serious disadvantages. I may have pain for different treatable reasons. Osteoarthritis within our culture is considered to be chronic, progressive and untreatable. That's nonsense but I might choose to believe that. If I weren't a rheumatologist who specialised in OA I probably would choose to believe that and that would depress me. And I might avoid walking in case I might make myself worse and wouldn't be able to come next year. And I probably wouldn't come next year because I'd been suckered into believing that. I don't know the answer to that.

*It surely depends on whether your pain pathways have been activated and nerves have been sensitised?*

*I can bear that out from experience. I had no problem with my knee until I was suddenly smitten with excruciating pain which turned out to be due to spontaneous rupture of a medial meniscus, and X-rays showed quite severe OA – I forget what grade. The acute pain didn't last long but I continued to get pain on walking. Arthroscopic removal of the meniscus made no difference to the pain which got progressively worse until it was cured by a joint replacement. I obviously didn't develop OA overnight, and there is evidence of OA in the other knee which is painless. The only explanation I can think of involves central excitation. But if this so how was it cured by the operation? – it did take a long time to settle completely.*

*Perhaps it was to do with how your mother reacted to her pain?*

I have to say I rather prefer that explanation!!

*My understanding is that most people end up with arthritis at some point. I had no problem until I fell over the dog and ruptured a meniscus and the X-rays showed that I had grade 4 arthritis. I was fine after an arthroscopy and some physio but when I went for my follow-up the surgeon said that I would be back one day and would need a replacement. I replied that I would rather avoid that. His comment which I have never forgotten was "I'm not saying you are overweight, but every pound you lose is six pounds off your knees and losing weight is the best single thing you can do. He was spot on; I went away and lost a stone and a half and it made all the difference, and I can take part in long distance walking holidays.*

Osteoarthritis is difficult in people like me and Chris but there is a group of people whose joints fall dramatically to pieces and are cured; one of the miracles of modern biomedicine. We are doing about 100,000 joint replacements in the UK now and at least 80% of them are helpful. So modern biomedicine is making a big impact on something in the mix here. Where is it in the mix and what is going on with the rest of us? How we deal with it diagnostically is frankly beyond me – I don't know and I'm supposed to be an opinion leader in osteoarthritis.

*Would you like to say a little about the work you did with Michael Doherty and context and demonstrating that the effect size was greater than non-interventional ...*

That was about placebo in OA: you can only assess placebo if you have a no-treatment control group in the study; otherwise you don't know if it is just regression to the mean - treatment vs dummy treatment vs no treatment. You don't often see that but there are enough studies to show what the real effect of sham treatment is, and it turns out that it is rather bigger than tablets or physiotherapy or anything else with the exception of joint replacement. So doing nothing is the most effective thing to do provided you do it in a way that maximises the placebo effect. You are much more likely to be able to do this in clinical practice than in a clinical trial situation from which our data is derived, and in the real world placebo is fantastically effective for conditions like this. Suggestion may be involved but I think it's more to do with one human being interacting with another. I have had healing for my own knee joint which in a sense is one of the most powerful forms of positive interaction between two human beings. And it's worked pretty well. I recently went to spend a day with a homeopathic practitioner who treats knee pain, and I was fascinated by his approach to diagnosis which was not: knee pain ... old person ... osteoarthritis, but: knee pain? ... and? ... what else is happening in your life - and the whole totality of the person; and detecting a sort of pattern from the whole of this thing and prescribing and then prescribing according to the pattern recognition within the individual. He told me that it was very unlikely that two individuals with OA of the knee coming through his hands would ever get the same remedy; they would get an individualised remedy that was right for them determined by the constellation and pattern of their symptoms. I think that is fascinating and who are we to say it is wrong?

*Are you talking about the therapeutic effect of what's in the bottle or of the consultation?*

Well, that may be the case, but I think it's somewhat arrogant of us to say that it can't possibly work because of the dilution, and it doesn't accord with our understanding of the physics of the universe now. Quantum physics has changed everything in our lifetime, but hasn't much reached the consciousness of the medical profession.

Ted Kaptchuck from Boston has done an open study of placebo on irritable bowel syndrome of placebo against nothing and told the participants that they were getting a tablet with no active ingredient and people got a lot better.

*Basil Finer wrote a paper back in the sixties about 'good contact' with pain patients.*

*We're still on the biomedical model even with homeopathy. You come to me with your problem and I make a diagnosis as an expert, and we still have this relationship and you go away with something which may be conducive to change ...*

I totally accept that.

*The nature of this kind of consultation is more like a partnership. One of the things that patients sometimes have difficulty with is that they don't find the kind of biomedical explanation of paternalistic care they are expecting and have to learn a different kind of explanation, and that they are required to have a different role in the process.*

*The placebo effect works better if the person expects you to be an expert and there is a belief that you will help them – and people rely on this 90% of the time.*

*The only thing I can give someone is my time. I give very few prescriptions and the focus of my consultation is about patients managing themselves and not looking for answers. I have some colleagues come and sit with me because they want to know what to do about people in pain.*

*One of the things that is implicit here but no-one is mentioning is the fear and anxiety of the patient and a lot of the consultation is about allaying this. I often ask them what is it that you're frightened of? – and a lot of it is putting their minds at rest about what is causing their pain.*

*The human species is deeply imbued with symbols. I don't think any other species actually use objects, sounds and visual images as a symbolic representation of something else. The whole of language is like this. To augment the human contact with a token of some sort that they can hold in their hand – or swallow into their body – is a symbol of that interaction, that connection.*

*When they come and see you and you're the expert and you make the decision and give them a little bit of green paper and make funny signs and your mark on it and they take it to another expert in a place with lots of stuff and they put things in a little box with your name on it ... prescribing is a huge placebo - a piece of theatre.*

*Isn't it the truth of the matter that every therapeutic encounter is a black box and we don't know what's inside it?*

*As a clinician you can be most effective if you can help a patient find their own key to their own way of getting better. What I have learnt is that patients are actually holding this key but they don't know what it is or what to do with it. If you can guide them through a longer consultation they can find something within themselves to be resilient. It's not something negative – get on with your pain - but positive as in they acknowledge their pain but are able to get on with their lives. My angst comes when I*

*see your X-ray with a grade of OA and that makes life very difficult because you may be going away with a diagnosis of an illness you don't have.*

There are other ways of thinking about the world of OA such as the Chinese or Aruvedic approaches that involve detection of an imbalance of energy or fundamental factors within the body, and correction of this, and after an eight week course you don't have it any more. I think that's brilliant.

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

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

*...a slight deviation from normal ...*

How do we make the diagnosis? By exclusion? This is where the biomedical model becomes really stupid. We are trying to apply the gout paradigm to this patient, and she expects us to do that because of the culture we are in. She is convinced she has lupus and demands tests to exclude it. When these come back negative she says that she had just read that cytomegalovirus can cause her symptoms and wants tests for that. You've all seen this situation and it's difficult to get out of if you aren't careful to nip it in the bud. But of course what this person is doing is searching for the meaning and legitimisation which our biomedical system can't give her. And we can't give it to her by chasing a diagnosis.

*Isn't that rather a patronising judgement? What she's mainly looking for is a good night's sleep.*

A point very well taken.

Of course you can *never* completely exclude the possibility of an organic disease. Diagnosis is about probability and we've got all this stuff about ROC curves<sup>1</sup> and things which statisticians bombard us with, but they don't really help us at all, because this isn't a scientific dilemma, it's an ethical one. The search for a biomedical diagnosis as a way of finding meaning can be counterproductive and get in the way of understanding the patient.

Some of the words we use are frankly ridiculous, such as 'Chronic Pain as a Disease' How can a symptom become a disease? What could you say to patient who asks "why is my knee pain and my pain all over a disease?" 'Medically Unexplained Symptoms??' '... why can't we just say we don't know? What makes us so arrogant to pretend that we might still be able to help?

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<sup>1</sup> Receiver Operating Characteristic curves. See [www.anaesthetist.com/mnm/stats/roc/Findex.htm](http://www.anaesthetist.com/mnm/stats/roc/Findex.htm)

*Saying we don't know isn't the same as saying we can't help, is it?*

If we are stuck in a very biomedical paradigm it might.

*[partly inaudible] I've never yet seen a patient referred by a rheumatologist without a diagnosis... I can say I don't know what's wrong with you but I can help you....*

I don't know the answer to this but are we as doctors, imbued as we are with the biomedical concept, the right people to help such fellow human beings?

*We are in conjunction with other people in a multidisciplinary service...*

*... including a priest?*

*These guys are so convinced that there is something serious the matter that they demand that another system (gastro-intestinal etc.) be investigated – a good rule is not to look at more than three systems before you say sorry, this isn't going to help and perhaps we should be looking at other things in your life?*

*But they react negatively to the suggestion that they should see a psychologist.*

I think the knitting group or the walk in the park are nearer to the right approach rather than the psychologists.

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

This is what my mentor's approach that there is more than one level of diagnosis comes in. It may be to do with their mother or circumstances at home; or in many cases sexual abuse in childhood.

*Isn't it part of our role to stop this medical bandwagon? ...*

*... but they will look for another opinion...*

*...where else is there to go? ...*

... that's a very good question: the priest and the community at large was the way out but we have lost that in our culture, so for most people there isn't anywhere else to go.

The situation is great for industry and great for the people who are in control of health and healthcare at the moment because it suits them perfectly, and we are helping the great evil of industry control and commercialisation of medicine to succeed. Biomedicine and research are in control of companies with a vested interest in the maintenance of disease and in turning symptoms into diseases whenever possible.



## *The matrix*

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

Helping people like my patient in my 4<sup>th</sup> scenario requires us to abandon our biomedical, diagnostic paradigm, and if we are to be any help it has to be at the level of working with them as another distressed human, just like ourselves.

[brief break in recording]

*...Google ... and then it turns out she has got cancer! ...*

*And we've all had this experience of missing a diagnosis and it haunts you ...*

*...yes, and it engenders terrible guilt. I remember one vividly – a metastatic prostate cancer. And that drives us to: better do the tests, the scan ...*

*How many patients tell you when they first come in: I've got a disc prolapse ...*

*The latest thing is postural tachycardia syndrome – all these young girls with various pain conditions all get diagnosed with postural tachycardia syndrome.*

The best one in my specialty was repetitive strain injury, which has largely gone away now. It was arm pain from using computers which everybody gets sometimes but the Australian government decided to make it something claimable under workers compensation. There was a huge epidemic and when the payment was withdrawn the disease went away. The interesting thing for me was that absolutely everyone I saw during the epidemic was absolutely genuine and had it. They were not making it up; it was real. That's fascinating. But I hardly ever see it now – there's no money in it.

*We're also in it for the money ...*

Yes, and of course industry just loves all this stuff.

*I'm interested in your knee X-rays; if you do an MRI on someone's back it doesn't often correlate with their pain. Do X-ray changes in your knee consistent with your pain prove that that is the cause?*

No.

*We don't X-ray people who are not in pain so we don't know what their knees are like.*

*We've known that for years but the culture doesn't know that. Why has it taken so long for the culture to change? ...why do people believe that arthritis is something that is going to get worse and worse. I always think careless talk costs lives.*

*I had an interesting case of a guy who had had pain in his knee for about eight years. When it started he went to an orthopaedic surgeon who said: "I'll scope it, and if it's too bad I'll do nothing, but if it's a bit bad I'll do something". (But didn't say what he would do if it was OK.) When he was discharged the nurse told him they didn't do anything. So this guy spent eight years hobbling about on a perfectly normal knee! His knee looked OK to me so I looked up his files and read the operating notes that found nothing wrong with his knee to him and he skipped out of the surgery! That was a nocebo ...*

Our recent work on placebo suggests that placebo is not the issue, it's nocebo. We mostly do harm most of the time. Nocebo is much more harmful than placebo – about five times. That's deeply scary.

Anne Widdecombe tells the story about her mother who went to a healing service because she had pain in her hip and it went away. Years later she had pain in the other hip and went to an orthopod. He X-rayed her and told her 'this hip looks OK but the other hip looks terrible – I'd better operate on that'!

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

William House

## *Window 1*

Who am I? A lot of my talk will end up being about who I am, and I hope you will begin to understand why as the talk unfolds. I was a GP for 35 years, 27 of those in one practice in Keynsham, which is soon going to relocate into the site of the now closed Cadbury's chocolate factory! As time went on, I guess like many medics, I grew more and more frustrated when I asked myself what am I doing. What have I been doing sitting here seeing how many patients? 100,000? If you are going to spend that much time doing something, even if you are a relatively non-reflective person, you can't help wondering what you are doing. So I came to the rather depressing conclusion that we were propping up a system that was not only bankrupt but was actually generating illness in at least equal degree to the extent that we were actually curing anything. And I wasn't prepared to go on being depressed.

As we have already heard, one of the manifestations of this sick society is this junk category of illnesses. I wrote this before I heard Paul say the same this morning: much of MUPS and chronic pain is medicalised to no effect. My response has evolved over the years. I got involved in research into this as best I could as a GP with very little available time and because what I was doing was rather unusual, very little money. I joined the British Holistic Medical Association, and having been a trustee for 10 years I am now the Chair. I am tasked with modernising, or rather shifting the organisation so that it addresses what I have just been talking about. Along with millions of the general population the BHMA was drawn into a focus on Complementary and Alternative Medicine (CAM). I have no problem with CAM and indeed practiced homeopathy to a small degree; I go to see an osteopath, and we had a CAM suite in our surgery, but I want the BHMA to address the root problems that I am going to talk about and Paul already has.

The other thing I have done more recently is to move into society. While most of my career was spent inside houses (home visits are fantastic – they are not very time-efficient, but my, are they efficient in terms of understanding people) but now I'm out in the street among the dustbins. What I do now involves the Keynsham Action Network. It is an experimental organisation that aims to find a way of shifting the social norms of a pretty typical middle-class computer town in a way that generates health.

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

## *Window 2: Jenny*

A long time ago I was on call (we provided 24/7 out of hours care) and was called at about 11 o'clock at night by an anxious mum who said that her 7-year old daughter had a high temperature, and seemed quite ill. I went out to see her and found that she was very hot and listless but quite lucid and I couldn't find anything on examination. So I gave my usual advice and went home. I'm going to leave you hanging there for the moment.

How many of you have heard of Preventing Overdiagnosis? ... relatively few. This was a big international conference at Oxford in 2014. It was the second in a series, the first having been held in Dartmouth Connecticut which was such a success that the decision was made to hold another. I put up an abstract for a workshop some time earlier and was surprised and a bit scared – this was an international conference with some 400 delegates – to receive an invitation to hold it. It was sold out. The title was: if we are diagnosing too much what are the alternatives? Much of what I have to say is a development of what happened at that workshop. We asked participants to come with stories about real patients for whom diagnosis was not terribly helpful. We divided them into 10 groups of about 4 or 5 to share their stories and asked them to try to work out why diagnosis was not helpful and then what might help. It was very interesting in lots of ways, and I was struck most by the *lack* of ideas - the frustration that they didn't know what else to do. They were GP's and consultants from all over the world. Bits of what I am going to say emerged from that workshop and a lot more work that I have put in, thinking and reading, have become integrated.

Now, I made you wait for the rest of the story about Jenny, as we will call her. At 6 o'clock the next morning I got a call from the mother to say she'd got the spots I had told her about, and these were of course those of meningococcal infection. I was there in my pyjamas in about 5 minutes and she was in hospital within 10 minutes of that. In those days it wasn't thought the right thing to give children penicillin right away at home, although this changed a long time ago. I probably only saw about 8 or 9 cases of meningococcal septicaemia in my career, and most of them were pretty vivid in my memory, but I didn't realise that the receptionist in the local children's ' centre where I am still on the advisory board was that mother. She reminded me one day that I came to see her daughter who went to hospital and was very quickly treated, but developed meningitis from which after a long time she got better. Not long – perhaps about two years - afterwards she had a grand mal fit and turned out to have epilepsy. Maybe she would have got this anyway. "She was never very good at taking tablets, but we made sure she did and she was OK. When she left school, however, things started going wrong for her; started drugs and stopped taking her tablets, and was found dead in her room at 27". I didn't know how to respond other than thanking her for telling me. She told me this story in a completely calm way. There was no sense of blame attached to me. But I asked myself: although there was no evidence of whatever, if by some sixth sense I had identified that that child was developing meningococcal septicaemia ... Anyway, I was left profoundly moved by that little conversation, and thought about it a great deal. And a fair bit of what I've got to say is informed by that.

### *Window 3: Labels*

Maria Bello is an American lesbian icon. She is one of those charismatic women who appear a lot on social media and TV. She wears her lesbian label writ large and talks a lot about labels. One of her memorable quotes is “Figure out which labels disempower you and which labels shine with the light of the beauty of who you are or are meant to be.” Jenny had a label “I am an epileptic”. Whether that had any impact on what subsequently happened I don’t know but it made me think a lot about labels.

Sometimes when I’m trying to work out who I am and what my role is in the world, I find a piece of the jigsaw that looks as if it’s going to be useful and fit the picture somewhere in the middle so I put it there. In 2006 as part of my attempt to cope with the awful direction that I thought healthcare was going I became a GP commissioner in the Labour government’s edition of what are now called Clinical Commissioning Groups, and was then called Practice-based Commissioning. And I thought, right! – now I can make changes in the Health Service ... ever naïve! (I’m not sure if you can be worldly wise *and* enthusiastic but I’m certainly an enthusiast.) At that time the Primary Care Trust didn’t want Practice-based Commissioning because we were poaching on their territory, and made it as hard as they possibly could for us to do anything.

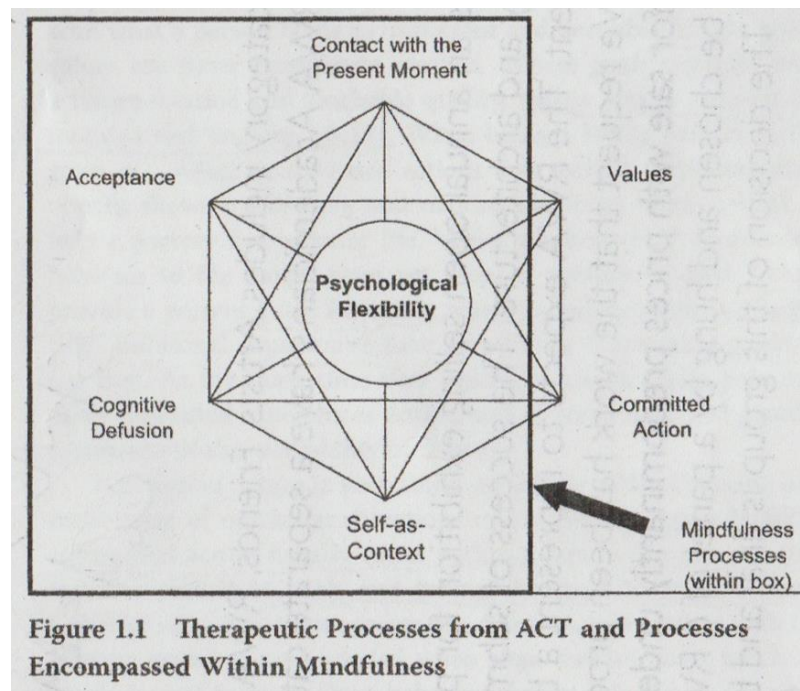
Right at the beginning, someone suggested to the Chair of the executive (which consisted of about seven doctors, one physio and one nurse) that he should ‘do Belbin’. Belbin invented the Team Role Inventory based on Jungian personality types, and they gave us a questionnaire to fill in. The next week we got our results and found out who we were. I was a PLANT, in other words I was individualistic, serious-minded and unorthodox. And I thought – bloody hell, that is me! (My wife says I am too serious and need to loosen up – but I’ve got to change the world, I say!) But there is more to it than that. You may also have genius, imagination, intellect and knowledge; ... and/ or: be up in the clouds, and be impatient with and disregard practical details and protocols. In business, the former are seen as ‘positive’ qualities and the latter as ‘allowable weaknesses’. They are all true except genius! – and you have to remember that while many geniuses are PLANT, most PLANTS are not geniuses. So I was always trouble, but I didn’t know of any other way of saying things and was completely incapable of being diplomatic. So I had a label, and that label really empowered me. I knew that I was a troublemaker, and that people wouldn’t listen to me. But I knew that there were other troublemakers around and this made me feel less alone. Through my life I have often felt very alone because I couldn’t understand why other people didn’t see the world as I did. Then recently a friend said: ‘I know what you are! You are a ‘tempered radical’. Tempered radicals were described by Meyerson and Scully in their 1995 paper *Tempered Radicalism and the politics of ambivalence and change* as “individuals who identify with and are committed to their organisation and also to a cause, community or ideology that is fundamentally different from, and possibly with odds with, the dominant culture of their organisation. Their radicalism stimulates them to challenge the status quo. Their temperedness reflects the way they have been toughened by challenges, angered by what they see as injustices or ineffectiveness, and inclined to seek moderation with members closer to the centre of organisational values and orientations.” So I suppose I am a radical but tempered because I didn’t actually rock the boat to the point of capsizing it; I would always stop short of causing serious trouble. In the end, if people didn’t listen, I gave them the benefit of my ideas and if

nothing changed I would get on with my day job. The Meyerson and Scully paper was actually mostly about the role of women in the business world but could just as well be about medicine and the strategies people come up with. My strategy was just to knuckle down and get on with it. So this was another label to add to my collection.

#### *Window 4: Psychological inflexibility*

ACT – acceptance and commitment therapy, developed by psychologists from elements of CBT, mindfulness and other aspects of Buddhist practice – is fascinating. I was involved in a research project run by Lance McCracken in the pain unit in Bath, and I was the GP on the steering committee. It took me ages to find out what it was about until Lance sent me a chapter he had written on the subject and my reaction was – yes, this is big stuff. This is relevant to what I have been talking about because it's about people having fixed ideas; fixed responses: "I am a pain patient", "I am an epileptic", "I am a PLANT". That becomes so fixed that anything in the world around you that doesn't correspond to that you discount. The research project I was involved in was a pilot study undertaking ACT with primary care patients – not the really hard nuts to crack as the people in the inpatients unit in the Royal National Hospital for Rheumatic Diseases in Bath, but people with less intransigent problems. These were dealt with in a group having a six week course of ACT. It seems to me that it has much wider applicability across the spectrum of suffering in society, because it challenges fixed ideas. Now that I am working out in the street by the dustbins I find that fixed ideas are rife about all sorts of things. People have views that become part of their identity.

There is an amazing book by David Bohm who is a quantum physicist and philosopher. This is a collection of essays called 'On Dialogue'. In it he describes the fundamentals of ACT using much more accessible language.



Acceptance is accepting something that you hear or think and not rejecting it, but 'suspending' or 'parking' it. 'Cognitive diffusion' means trying to distinguish between the content of thought and the process of thought, and in particular between thoughts and evaluation. ("I am feeling hopeless" is thought and "I am hopeless" is an evaluation.) 'Self as context' has to do with distinguishing thoughts from beliefs. 'Values' is a higher level thing that you might aspire to, but doesn't drive your everyday actions; you can look back at your actions and ask if they accord with your values, but in this context the encouragement is to incorporate your values into your decision-making. Committed action means not walking away when it gets hard. Psychological inflexibility is an inability to change and adapt. Everybody can change, but some people find it very hard. There are also links to what Paul was saying about legitimization. A fixed viewing package of yourself, whether it is part of a label that you carry or just a view that you express when opportunities arise, can legitimate behaviour. For instance I might legitimate my outspokenness by saying I can't help it, I'm a PLANT, and you'll have to make allowances for me.

### *Window 5: Creative Art*

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

I am not talking about not medicine with art, but medicine as art; not poems in the waiting room or dancing for post-natal depression or even bibliotherapy but the process of medicine understood as art.

*[Slide of William age 3 standing in front of an easel with a paintbrush pretending to paint his father's painting.]* I grew up in an intensely artistic household. My mother sang, my father painted and my sister played the piano. I did science and took my toys apart and put them together again. About four or five years ago, at a school reunion, I met my first girlfriend for the first time for 50 years. After the event we walked along the river and sat on a bench. She said to me: "do you know what the one thing is that I took from our relationship? – it was that you introduced me to high art". She reminded me that I had taken her to Covent Garden and to art galleries in France (I have no recollection of that but she said it was me!!).

"It is much more important to know what sort of a patient has a disease than what sort of disease a patient has." My own variant of Sir William Osler's famous saying is: "It is much more important to know what sort of physician has medical knowledge than what sort of medical knowledge a physician has." This is why I have been talking about myself; I don't actually feel comfortable talking about myself but this is a very good reason for it.

Let's turn to 2003. When Tony Blair came to power in 1997 he didn't do anything about the NHS at first and then he made big changes. He carried on some of the changes made under Margaret Thatcher and carried on by John Major to make the NHS more like an industry and more commodified. At that time I was struggling with the stupidity of it all, and I turned again to research as a sort of fall-back place where at least I could feel I was trying to make changes. I devised a series of projects which started off with what is written in patient notes. It involved putting a novelist, Pat Ferguson, into GP surgeries and asking her to write a vignette about every patient, and sharing these with the doctor who saw the patient. In one she wrote: "*Doctor: So*

you're artistic". She couldn't agree: too clear, too simple and much too like praise, for her to accept that it might fit any of the chaos she knew to be inside her. The doctor just recorded the blood pressure." This is creative art. When I showed selected vignettes to focus groups of doctors the effect was extraordinary. There was a sort of grief reaction from some of them: the sudden realization that they had completely missed the issue. This is kind of the kernel of what I have been talking about: that it is possible to understand someone's suffering with a new pair of eyes - the eyes of a novelist. The GP's were defeated at the prospect of having to try to emulate what Pat Ferguson was doing. I don't think sending them on a writing course would do it, but it might be an opening for them.

*Presumably your personality type will tend to drive you towards a specialty in medicine; I was thinking about Jung's personality types and the colours attached to them – you are presumably a green, very friendly and empathetic. Surgeons are red and fiery.*

When I went for a house job in Salisbury (I wanted to get away from London and teaching hospitals) my first interview was with a surgeon who asked "what do you want to do ultimately in your career?" So after a long pause I mumbled that I didn't want to do surgery and he said: "mmm .... you look like a physician." !

*I think this business about labels is hugely important. But I want to put to you that we can have several different labels for ourselves at the same time even if they are contradictory. In addition to how we label ourselves it's which label we choose to allow into the room at a particular time. When we are with another person (I really don't like the word patient) which label we present is an issue and the problem is that we do need a biomedical part of ourselves in the room but we also need a different part at the same time.*

I think that that was the first thing I did in the situation of the girl with meningitis. There is a tyranny – a horror – about meningitis which haunts GP's ...

*Can we change labels? We talk about listening ... is that a label or are we still scientific doctors underneath?*

I think in a sense we do have to be two different people: the scientist at one level and the rounded individual at another and kind of slip between those roles. They are different and segueing between them is tough.

*One of the phrases you used was; we share a cipher or an object ... [which] can be reductionist ... Labels to me mean a number of different things. When I'm sorting out things at home, do I put all the screwdrivers in the screwdriver box or do I keep one for the electrical box because it is different, and that gets me conflicted! There was a discussion at the last BPS Annual Scientific Meeting, or it may have been the Canadian one, where there was a scientific dissection of coding: how patients code their perceptions, ideas, concerns and expectations and present them to us, and how we receive and decode that and reflect it back, maybe with another language or maybe the patient's own language; and the scope for understanding or misunderstanding, empathy or disinterest, within that.*

All a complete mixture: the patient draws a response out - the relationship moulds ...



*One thing I learnt from Peter Maguire many years ago was that I didn't have to be as self-aware as you were implying about whether I'm behaving as a doctor of a human being; but actually what is going through my head or emotions about the appropriate response, and being genuine about that.*

To some extent it's spontaneous and you think about it afterwards: did I say the right thing? ... should I have been standing with my arms folded? ...

*I'm dredging up from memory something I read a long time ago on cognitive styles: I think the author's name was Steingruber. He was distinguishing between three sorts of cognitive styles. One was purely fragmentary, in other words reacting to things without any sort of overarching theory. There are people who have one overarching unified theory of everything – for some theologians everything is traceable as a sort of final corollary from five things that they really believe – it's internally very coherent. There are others who have three or four organising principles that they somehow very naturally tend to flip between, and each one pretty substantial kind of stuff. They're not exactly inconsistent but [not commensurable with each other? – inaudible].*

I suppose that is psychological flexibility.

*Looking at the slide [about the novelist and her vignettes] from a nursing perspective: nurses are equally constrained by artificial frameworks. For example, on our acute wards we have this way of assessing patients' pain (the nought to ten score) which is a nonsense. ... and an inadequate way of identifying patients who may have a problem. One thing I am always trying to encourage staff to do, having identified a problem, is to explore it further. The other thing is to do with labels. We have a second scale for people with dementia who can no longer communicate. As soon as they find someone who can't seem to manage a 0-10 pain scale and seems a little demented they immediately spring to the other scale which gives you another number when they could give you a perfectly adequate narrative account of their pain: 'It makes me feel scared when I stand up' - that sort of thing. But nurses are so tied to this rigid framework of pain scales that they fail to be creative about something that might be more appropriate and effective for that patient. It's as if they have been denied the individual professional permission to use something outside the framework.*

That is a fantastic example of what the psychologists advocating ACT are talking about. They say that CBT doesn't always work so well with pain (and with other problems that are characterised by psychological inflexibility) because context is ignored. ACT indeed used to be called contextual CBT. The reaction someone has is a combination of permission and context, and if the context is all about numbers and scales then it's quite hard for people to move into an area which is less clear – a bit uncertain and vague. What an ACT therapist would do is to create a very permissive context where people can just save enough to move out of their comfort zone. But you have to feel safe in that context which is very hard when the outside world thinks you can't.

*Do you think we can compartmentalise like airline pilots? We are talking about this free and easy interaction we have with our patients. If you've just had a major row with your wife you think you can put this on one side, but does it affect your interaction and capacity for active listening?*

Ian McGilchrist wrote about right brain/left brain in *The Master and his Emissary*. Whatever you may think about it from a neurophysiological aspect, as a metaphor it is hugely powerful. The left brain is said to be analytic and compartmentalising and fits very well with biomedicine. The right brain is more concerned with patterns, is able to hold a whole lot of ideas simultaneously and is creative, but it doesn't do compartments at all. You can only fully function if both are really active and working. One of the things that creative art does is to give the right brain exercise.

Rita Charon is a physician and literary scholar who was one of the founders of the Narrative Medicine movement: understanding illness as a narrative. It doesn't just mean that you put time into it; it's much deeper than that and is about evolving a relationship. I was spellbound by a lecture I heard her give in 2004, from which I captured the quote: "When we see things in the world, we rescue them from formlessness by giving them form." This is what the creative artist is doing: the artist in me knows that there is something in my mind that I can't quite get or formulate into explanatory language, but I know it is there. I recalled her lecture and this quotation (with its resonance from the book of Genesis) in an article I wrote for the Journal of Holistic Healthcare, which arose from the Preventing Overdiagnosis workshop I referred to earlier. I wrote: "Then she drew on French philosopher, Paul Ricoeur's interpretation of the Aristotelian concept of *mimesis*. This involves a three-fold process expressed by Ricoeur as *attention*: the process of taking notice, looking and listening (including history and examination) you go through when assessing a patient; *representation* (such as a diagnosis): you process what you see in your mind in visible and/or audible form; and *affiliation*: sharing the representation with others." This is a creative and imaginative process still pursued by most artists and with obvious resemblance to the medical consultation.

Less obvious is its resemblance to science, still less biomedical science, but science can be regarded as a creative act. Aristotle said that an artist's copy of nature could be true, and Plato disagreed: a conflict that resonates to this day. I'm with Aristotle. Faced with the European Enlightenment belief that the scientist's interpretation is considered truer than the artist's, taking Plato's position in which philosophy, the forerunner of science, is truer than art, medicine has fallen in with the science camp. But it is now trying to fall out to some extent, and to build a bridge between the two.

Has anyone read the book *The Case for Working with your Hands – or why office work is bad for us and fixing things is good* by Matthew Crawford. Absolutely stunning! The author did a degree in philosophy and ended up as a motorbike mechanic. Two quotes from it: "There may be something to be said for having gifted students learn a trade, if only in the summer, so that their egos will be repeatedly crushed before they go on to run the country." "To be capable of sustaining our interest, a job has to have room for progress in excellence". (My wife and both my children are artists. Art to me is about materiality – stuff. My wife says when she is painting it's about the paint on the surface: the way it moves, grips or slides.) This really resonated with me. I had spent my GP life developing a way of practising that became progressively detached from the mainstream – but it worked – my surgeries were always full with low use of hospital resources, high satisfaction and no complaints. Maybe I had at last found my way of being the creative artist that I was born to be? I realised, partly through that book, that this is art, and mending motorcycles is art. It's not the mechanics; it's somehow the relationship of the material.

## *Epilogue: forgiveness*

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

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

*You learned the end of the meningococcal story after quite a long time. Would it have changed the way you work if you had known it earlier?*

If you make a mistake it's almost inevitable that afterwards you are cautious, and it may affect your judgment adversely. There is a fine line ... you have to somehow set your judgment so you are not too influenced ... it's not easy.

*The sitcom "Dr House", which is all about finding a medical diagnosis which can be fixed whatever else has been going on is a cultural expression of what people think good doctors are about. So perhaps it ought to be banned?*

And finally!:

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

## **Animal Farm: The meaning of being a ‘Lay Patient’**

*The value of diagnosis and effects on Patients and Healthcare Professionals.*

*We’re all patients, aren’t we?*

Antony Chuter

What does having a diagnosis – or not having one - mean to a patient? What does it mean to me now and what did it mean in the past?

### *My Story*

I’m going to tell you all about my life because it interacts with my experience with clinicians, and every interaction is with a whole person. I was born in 1971 into a normal middle class family. At the age of five my previously happy life began to fall apart when my mother had a breakdown. After that doctors labelled her as a ‘neurotic mother’. Any time she took us to see them it seemed like “there, there, dear” and she came away feeling she hadn’t been heard. Then when I was about seven my mother’s father started to sexually abuse me and my sister. Because of the power imbalance of an adult neither of us told anyone. But kids seem to pick up on this sort of thing and I started to get bullied. There was no question of what was going on but when I was sent to a child psychiatrist they didn’t get out of me what was going on, nor did they didn’t sense what it was. But the teachers picked up on stuff as I went from a very sociable child to one who went and sat in the corner at break time and didn’t interact with other children. I was moved from one school to another. I was also isolated from adults, especially clinicians, and very scared of men. This led up to a number of difficult teenage years. I was raped on a beach at age 13.

I would stick something into my ears to make them sore, go to the doctor and given antibiotics and signed off from school so I could get a few days’ respite from bullying. My attendance was dreadful – I was hardly ever there. But still nobody asked the question: why? The teachers have told me since that they knew something was going on but didn’t know what. It got to the stage when I was being beaten up every day at school; every walk between classes involved little kicks and name-calling. One day after been beaten up my jaw started to click. I went to the doctor and they asked “does you jaw dislocate?” So at the age of 15 I became very skilled at faking a dislocated jaw; every time I did this the school nurse would take me to A&E and I would have the rest of the day off school. I had my jaw wired which wasn’t pleasant but meant I would be safe for a while. Then eventually I was told I needed an operation which I really didn’t want but couldn’t tell my parents, even when I was waiting to go to theatre for an operation I knew I didn’t need, what was really the problem. Shortly after this I was again beaten, taken to A&E where I saw a maxillofacial surgeon who tore me to pieces for wasting everyone’s time, money and resources.

And still there was no diagnosis.

Around this time I left school and went to catering college where in the heat of the kitchen I started having blackouts. Dad, having medical insurance through IBM whom he worked for, got me seen by a private specialist who recognised that I had

Marfan's syndrome. But he didn't tell me; he wrote to my doctor saying this young man has Marfan's but we won't tell him as it's a distressing diagnosis to give anyone, and we'll just keep an eye on him. That letter was lost in the notes.

When I left catering college I followed my Dad's footsteps into IT, and while I was at college in Chichester I met Nick, my first love and my first taste of happiness in life. We went mountain climbing, sailing (preferably in winds above F7) and life was one big party. And then: renal colic. I didn't know what it was; I just knew I was passing white powder in my urine and frequent attacks of colic – sometimes twice a week. It was messing up my work. My GP's just gave me pethidine which was great for the renal colic but bad for the rest of my life. I just entered a black hole. During the first year I lost my job, my relationship with Nick as he couldn't cope with the change in me from climbing mountains to lying on the sofa taking pethidine, and I lost my home.

And I really wanted a diagnosis. I wanted to know what was going on. I had a jumble of symptoms and contradictory positive and negative tests. Every time a test was negative I felt I wasn't being believed. I got really angry with my clinicians; they hadn't given me a magic pill to take away my pain and give me my old life back. And I became depressed. I was eating one meal every other day and was skin and bone. I went out once a week to the supermarket at 3 o'clock in the morning because I couldn't cope with being around people; there was something about being in pain with consequent anxiety and depression which made me feel very vulnerable in crowds. I grew my hair long because I couldn't face having it cut. I felt suicidal. People would say: "there's other people worse than you - cheer up" – but my life had disintegrated. And there were the well-meaning suggestions – have you tried this ...or that ...? Did they think there was anything I hadn't tried! Lots of lay people will come out with this stuff when they don't know what to say; they can't think of what it is like to be in pain day and day out. I was completely hopeless and never thought life would change.

I bounced around different clinics and saw urologists, nephrologists and other specialists but I still don't have a name for my condition even today.

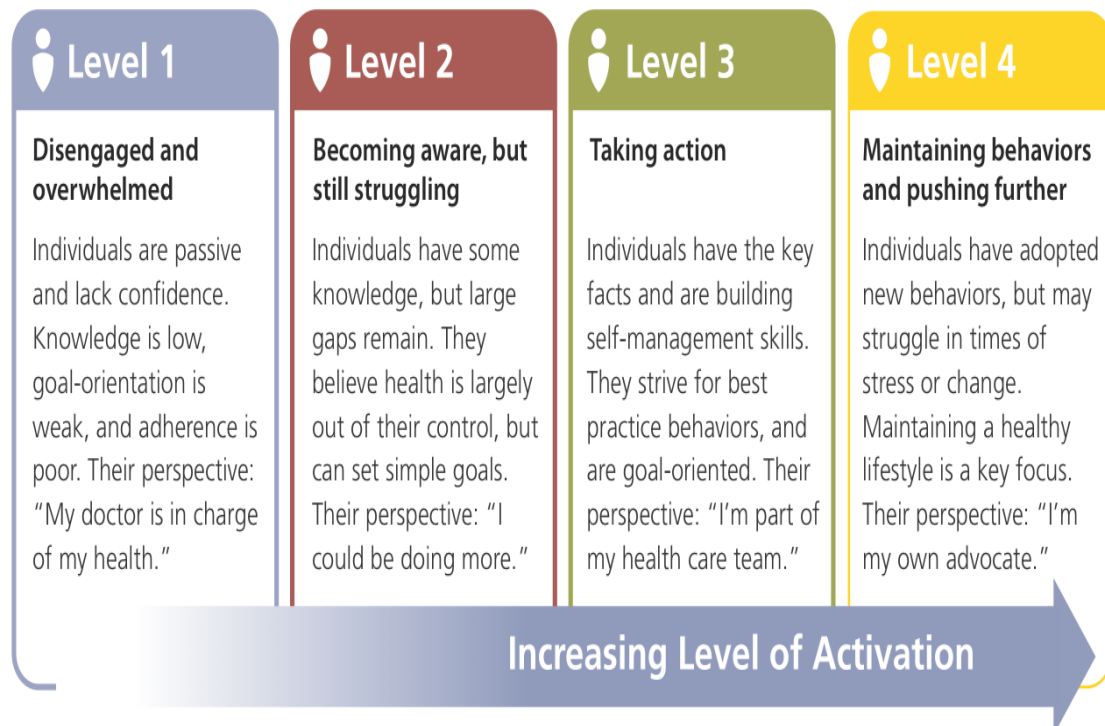
I joined the Samaritans. I don't know who was helping whom most but it did give me a bit of my life back as I felt useful again for the first time in a number of years: for a few hours a week I could give something back, and somehow listening to other people's problems sometimes put mine into perspective – and sometimes it didn't.

Eventually I was sent to a pain clinic. The most useful thing that was said to me there (by an OT) was "no-one can say you're not in pain – you know you are", as I was very hooked up on being believed. I didn't find the pain consultant very helpful. He enrolled me in the Pain Management Programme which didn't work for me: I felt it was a group of professionals telling me how to live without living my life with me - there was no empathy. The consultant decided to do some sort of procedure involving a long needle - I still don't know what it was – and when I was in recovery he came in and asked: "are you in pain?" When I replied that I was he said: "well, it didn't work then" – and walked away. In other words YOU HAVE FAILED. I was in tears and I remember the nurses consoling me.

## *The expert patient*

A few years went by and I found a new GP who was the first to say “I don’t know”. He showed that he was human to me. He got me into psychotherapy, and I started to sort my head out about my past and my childhood. Although the therapist wasn’t pain trained he was also very good at helping me to come to terms with living with pain that wasn’t going to go away. I found the Expert Patient Programme and became a volunteer, and then they gave me a job three days a week when I never thought I would work again. Unfortunately I became redundant from that, but whilst I was doing it I became involved in my local strategic health authority and set up my first patient group. I also got involved with the Royal College of General Practitioners in setting up a patient group and before I knew it I was elected chair and ended up counselling 70 GP’s and telling them how it was.

So my confidence went up, and I became an activated patient. Some of you may know about this: there are different levels, and the aim is for patients to go from being passive and inactive to active within their own care.



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So in 2005 I was still in pain but had a new perspective on it. But then I developed a heart arrhythmia, and when the cardiologist’s secretary went through my notes she found the letter about my Marfan’s that had been lost all those years ago, and the cardiologist suggested my condition ought to be treated. I was then referred to another specialist who said that the original diagnosis was wrong! So I went from not having, or not knowing about, a diagnosis buried away for 20 years to having a diagnosis and then not having a diagnosis! And I’m now told I have osteoporosis as a result of my kidney condition. So the search goes on.

So does diagnosis mean something different to patients and health professionals? For me, being on a care pathway is either heaven or hell. For the patient, having a diagnosis can be reassuring, but it can cause anxiety about the future path of a condition. It can make symptoms less worrying, and put them into perspective – or more, depending on the condition. I believe that for the health professional (and you may correct me on this) diagnosis provides a certainty about treatment and also a check list of potential disease progression. It's a bit like a word search: the words are there somewhere, and some are more obvious than others, and perhaps for the health professional there is a satisfaction in having solved a problem. But something can be lost; in solving the problem you can lose something from finding the right treatment for the person. In the best case the diagnosis will help the relationship between the doctor and the patient and in shared decision making, but in the worst it can create a very rigid care plan where the doctor dare not stray from the guidelines and the patient feels under-heard.

So my buzzwords today are:

Listen: Research shows that GP's will interrupt a patient before they are 30 seconds into their story, but other research suggests most patient stories barely last 30 seconds if they are allowed to tell it without interruption. It's a bit longer in secondary care but basically the lesson is: listen, let the patient flow.

Believe: I didn't feel believed in at so many points along the way.

Diagnose: it's sometimes useful, but ask: is it really important in this situation?

Treat: we can have a debate about overtreatment, but treat with respect; treatment must involve care and keeping engaged with the patient to reinforce listening and belief.

Remember that there are 8,765 hours in a year. Even someone with a long-term health condition may only spend three or four hours a year in the company of health professionals and the other 8,761 hours dealing with their symptoms and not with a diagnosis.

*We're all patients, aren't we?*

All animals are equal but some are more equal than others.  
(Animal Farm)

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

Albert van Durer is a psychologist in California who has theories of how people and groups learn and how behaviour changes. He showed a video of some adults beating up a clown to some kindergarten children who were then sent out to play. They found Bobo the clown in their play area, and they hit him and shouted YEE HA! So the modelled their behaviour in this way, and this is the basis of van Durer's theory of learning by modelling.

Once something is learned it changes our behaviour. Take the motor trade. I imagine most of you drive a car, and at some point will have bought and sold a car; you've been to a second hand car dealer, you've felt a little disempowered and wonder whether you've paid a fair price or been ripped off. There's always that niggling feeling that they know more about cars than you do. If you were to do some market research on the motor trade would you want anybody involved in it to take part or would you think they were biased? Let's look at Sainsbury's. They do a lot of market research and collect data on us. Can you imagine them wanting a market research company to poll a member of their staff? The thing they are all avoiding is bias. So anyone who has had clinical training or who has ever worked in even a minor role in a clinical establishment has had their behaviour changed and has a different outlook on life. The view of the public is that they have insider knowledge.

What I do now in my day job is to get involved in research projects and recruiting lay people. My definition of lay patient is someone who has not received any clinical training of any kind and/or has never worked in a profession allied to medicine.

I believe that people fall into four main categories:

1. Health Care Professionals or Public with experience of a long term health condition and or a life limiting or life changing health condition.

Many lay patients talk about the effect a long term condition or a life limiting or life changing health condition has on a Health Care professional - it can change Health Care Professionals into more sensitive and empathic individuals. It can add a level of humbleness to them and the care they give - in short it makes them more human. It can be a curse too being a Health Care Professional who has developed a long term condition or a life limiting or life changing condition - insider knowledge can be uncomfortable as well as comforting. Understanding how the system works and knowing people can also be a double edged sword. Their knowledge mixed with their work and their own health experiences can mean that in groups of lay people everyone will look on them as experts on both sides of the fence. Alas their training and experience created a bias which is unacceptable to the 'green' lay patients/public members.

2. Lay Patients or Public members with experience of a long term health condition and or a life limiting or life changing health condition.
3. These patients usually become self managing - if they get support then they can become 'activated patients' and learn to self manage many aspects of their symptoms to improve their quality of life and do some of the things they want to do. This is a growing group of people and the NHS and society needs them to be self managing. It is good for everyone. They make good lay reps but can be stuck in their area of experience - this can be good in service redesign but it needs to be balanced. They can be less helpful in public health research as they carry bias towards their condition being more important than others. They may be misinformed by information on the internet which add to confusion, misunderstandings and worry, anxiety and frustration. They can be great at running things like Expert Patient Programme 'self management' courses.



Health Care Professionals or Public who work in Healthcare but are not medically trained.

Someone who is medically trained and or works in a profession allied to medicine - i.e. they have been on the other side of a desk in some way from a patient or have treated or been involved in a patient's treatment. This group may be a patient on an occasional basis or even have had small operations and treatments which have been time limited. Their experience of healthcare is very biased by their training and their work with patients and the public. They probably think that they know how to get the best out of the system. While they may not be experts on the whole system they have much more insight into how things work both from a system perspective and also from a disease perspective. They have contacts who will help and advise them if they need advice. This advice would not normally be shared with the public.

#### 4. 'Green' Lay Patients or Public.

These may have used health services on an occasional basis or even had small operations and treatments which have been time limited. Most of the population fit into this category and their voice is usually underrepresented in healthcare research and service re-design. Their experience of healthcare is very limited and some would say that they are uninformed about how the system works and how to get the best out of the system. They may be misinformed by information on the internet which add to confusion, misunderstandings and worry, anxiety and frustration. They are a desirable group when looking at health screening service redesign and also for getting Public Health messages out to the population. They are also a desirable group for involving in Healthcare Research teams but there needs to be a balance of them with the lay patients who are living with a long term condition or life limiting or life changing condition.

### *Discussion*

*I've been meaning to get a patient to talk to this group for years but it was worth waiting for that sometimes moving presentation. It so accurately mirrored and complemented what Paul and William were saying this morning about the attitudes some people have. I don't know how select we are in this group in thinking that we have better attitudes than other doctors ...*

One of the things I have come across is that the health service trains you how to deal with the health service, so when you first come into it as a patient you are untrained in getting the best out of it. You haven't learned to get the best out of appointments so you come away feeling you have missed so much. It takes time to really get organised around dealing with health professionals. It's like any walk of life: different healthcare professionals have different personalities ... the first time you see them you're sussing each other out and the next time you go and see them you've got a better idea of how to get the best out of the few minutes you've got with them. My experience was indicative of what it was like for children in the 70's and 80's when abuse and bullying happened and how schools, doctors and everybody responded ... especially if you came from a nice white middle class family. There was no counselling when things came to light. One of the weird things was after I had the jaw operation I was sure the doctors would tell my parents that I didn't need it, but they

didn't. I was gobsmacked as I was sure I was going to be rumbled. I only told my parents about it a few years ago.

*Was it only when you joined the psychotherapy group that you were enabled to talk about the abuse?*

Yes, I joined it the year my grandfather died; I hadn't told anyone about him till I was 26 or 27.

*Do you think that having had to keep so much hidden made it more difficult for you to make yourself believable in other contexts?*

Because I felt that there was something in my notes somewhere saying "this teenager faked this so don't believe a word that he says" and that all doctors who had access to my notes would find this and go pfff... and yet I suddenly developed this pain. In some ways in my early years I thought ... I faked it before and now I wouldn't be believed.

*Can I ask you about the Marfan's diagnosis? What you said is very interesting in relation to this morning's discussion. But you didn't really tell us how you responded when you were told you didn't have Marfan's.*

I wasn't told I had it – all I was told was "your aorta looks fine and we think your blackouts are due to postural hypotension so don't stand up too quickly" and I was taught to squeeze my legs ...

*... but then you went to a doctor who told you you didn't have it ...*

... as a teenager I moved about and went from one doctor to another and the letter was lost ...

*... what I am getting at was whether it would have been helpful or not to you to have a label?*

Interesting ... I actually think not because at that time a Marfan's diagnosis was pretty bleak – I was going to end up having heart valve surgery and a split aorta and all those things. It would have helped me to understand why I was so tall and gangly but on the whole it would have brought far more concern and worry. So in a way the doctor saying "don't tell him" ... looking back that was quite an outrageous thing to do. I was sent by a GP in Milton Keynes to the cardiac department for a check-up (having presumably found the letter) where they said "you haven't been for a check-up last year – don't you care about your heart?" and I replied that nobody had told me there was anything wrong with it.

*Part of my work is in a chronic paediatric pain clinic. Your presentation has helped me to understand that a bit more. We pool all our resources as a team as we believe that if chronic pain in children is not recognised they become adults in chronic pain.*

*In your experience could all these things have been stopped in childhood and what could have been done?*

If I wind back to my mum's breakdown – I suppose if the family had had more support then someone may have picked up on my grandfather's abuse of me and my sister. Nowadays I suppose children would have had some sort of counselling. And the same with the bullying which is treated so differently in schools now. Today the aftercare from the incident on the beach would have been phenomenal. But then I was interviewed by male policeman who looked like the guy who raped me in front of my parents, so I didn't give them any details and the next day I was sent to school. The attitude was just move on – if you don't talk about it you will forget about it. I don't even know if the school were told. There are so many things that would be done differently now. There were many things affected my later relationship with doctors who were in there with parents and all adults who had let me down when I was a child. I had to look out for myself which I did very well – I'm a survivor.

*Did you have to testify in court?*

My parents decided I shouldn't go to court as they didn't want me to have that experience and my attacker was charged with gross indecency (which at that time was the same charge as would have been used for two adult gay men having consensual sex in public) and given a suspended sentence.

*What about your sister - you said she was also abused? ...*

My sister is a complete train wreck. She has never accepted ... I have recommended that she go to counselling many times. In her twenties she had abdominal pain and they opened her up and didn't find anything. In her thirties she had children and got divorced because she can't do relationships. She's now nearly 50 and for the last three years she has had vertigo and migraines which I don't doubt but the extent of how much it affects her means that my parents who are approaching their 80's have to look after my twin teenage nephews because my sister can't manage. She spends most of her day in bed and has an 'attack' every time she gets up.

*Do your parents know what happened to your sister? Have you ever been able to discuss it?*

I told my mother some time after my grandfather died. Her first words were – Oh, it was the drugs he was on. I really suspect ... she worshipped the ground he walked on.., I wanted to talk to my dad about it ... but ... when my sister was pregnant my mum told her if I told my dad he would leave her. Then my sister told my brother who had known nothing about it ... and eventually I told my dad as I didn't want to play the secrets game anymore.

*Could you say something about the Patient Liaison Committee? Is it helping to educate us?*

When I took over the PLC it had four or five members and hadn't had a Chair for a while. It had lost its way a bit. It's rather difficult to come into a group when you haven't been one of their peers and suddenly you're their Chair and I felt very uncomfortable doing that. (I'd just finished my term of office with the RCGP where I had been elected by my peers). I took the first year or 18 months getting to know everyone and to understand what they were all doing. But now I've been there three years I can say "right, we're doing this or that ...". We have set up an online patient reference group, and within days of setting it up we had 400 members. People join by

filling in a form online which goes to a website called Mailchimp which is a newsletter generator, so we can use it to send out newsletters to members of the group as well as questionnaires. I wanted to set it up because the PLC now has six members representing all the people in pain in the UK and I didn't think that was enough, and I wanted a larger group that the PLC, the BPS and the SIG's could use to send out questionnaires. We know that about 80% of our members are women; we have basic demographics of age and locations and know that they are spread all over the country and are of lots of different ages. It's working very well and what we need now is stuff to send them and I have a very energetic new member of the PLC who has taken this over.

We have our annual seminar later this year at the College of Anaesthetists. Sir Michael Bond will be giving a lecture and it will be a mixed seminar for patients and professionals. This is the Year of Neuropathic Pain so we have Austin Leach talking about this.

*That's tremendous in terms of your vision. Working with patient support groups locally I find to be a double-edged sword. We set up a group in the gym to help people get into this and we found that after a few months half of them said I don't want to do this anymore, I just want to do my own thing, and they kept moving through, but there was another hard core who said we are the pain group and this is our identity and just got stuck there – so do you get involved or not?*

*My second question is: you're talking to clinicians, and clinicians are people who come in contact with people in pain, and I think we have some insight. But the people who manage and shape our services are business managers who often have had no patient contact, no patient experience nor any health background, and yet have a huge impact on any shape of service. I would suggest that that is a target audience that maybe you should be aiming at.*

I have a dual role in that I am also chair of Pain UK. When I left the RCGP I wasn't going to do any of this patient group work for royal colleges anymore. I don't believe in people staying involved for ever, and that you should move on and let someone else have a go. There are lay reps around who have been advising Primary Care Trusts - they usually talk about car-parking – which is a big issue for some people – but they get lost and caught with an axe to grind. Unfortunately those same people sometimes create a disservice to the public because they talk to the commissioners about things they think are important but the commissioners really need to be listening to people with experience like mine. It's quite sad: when I first got involved with expert patient programmes my local PCT would invite me to clinical and service redesign meetings. There were people there who would say they had been doing this for ten or twenty years; they'd bang on the table and shout and really turn people off. I think I got on well there as (a) Samaritans taught me how to listen, and to listen to what was behind what people were saying and (b) expert patient programmes taught me how to present to a group of people. Those two skills stood me in good stead for presenting the patients' perspective. When we set up the patient group at the SHA (Strategic Health Authority) unfortunately I didn't have a hand in selecting the people as I would have stood at bus stops and train stations ... but people in the SHA did it the easy way: we'll contact the people we know. And so they got the same table bangers and every time the Director joined us he would be pilloried and shouted at – and never came back. So there needs to be a change in the way public involvement is done to get 'green' people involved. The BPS does try and engage with decision

makers. The PLC is probably not funded enough to do that at present but we were involved in the care pathways which did try to show the commissioners the way to commission pain better.

## **The diagnosis: shades of grey**

*Healing the disease or the diseased?*

Suan Khoo

I was a dentist to begin with, and then in the 80s I went to pursue my speciality of oral medicine in the UK. When I trained at the Eastman Joanna Zakrewska (the trigeminal lady) was there. I returned to Malaysia but came back and spent two years in Leeds doing oral pathology and medicine, but I did my PhD later.

I think I am in a privileged situation whereby I do something, oral pathology, very objectively: I look down a microscope and it is yes or no with no shades of grey, and at the same time I see patients in the clinic, many with lumps and bumps which is again very objective, but a large part of what I deal with is orofacial pain. I spend a lot of time talking with patients; in my morning orofacial pain clinic I spend about three or four hours only seeing three patients.

*Temporomandibular joint disorders*

This is a very non-homogenous group including myofascial pain, arthrogenic pain from a true joint disorder such as disc displacement, or from degenerative osteoarthritis, as well as neuropathic pain such as trigeminal neuralgia, or secondary to interventions such as extractions or root canal treatment, and people suffering from what is known as burning mouth syndrome. The latter occurs principally in perimenopausal women; it is thought to be psychogenic and is very controversial. We also see a few neurovascular disorders such as facial migraine which we don't treat but diagnose and refer.

I did my PhD in biopsychosocial aspects of temporomandibular disorders. Quite a lot of the patients do have depressive or anxiety disorders together with TMD, which makes it complicated when you treat them. I always tell the GPs or the students that it is a thing you cannot deal with quickly because by the time the patients reach me they have acquired many layers that I have to uncover.

Incidentally, and influencing my approach today, I am also a sufferer myself. I have temporomandibular joint disorder.

We tell students and trainees that the first priority is to make to the diagnosis and make sure they aren't missing anything, and decide if they want to treat or refer. There are a lot of things they need to compartmentalise. But if we're not careful we may end up by just putting people in compartments, thinking we've got it right and dishing out the prescriptions. It's only when they keep coming back that you start thinking that you probably don't have a cure or even an appropriate treatment for them, and will have to spend time with them. Over the last 26 years seeing these patients day after day, I have discovered that nothing beats spending time with them right from the beginning. Time is a very expensive commodity but there is no other way. We tell the trainees that they have first to exclude pathology, (including cancer which can present as neuropathic pain) but then assess people psychologically and go into their family and social history and so on. But they still take the cold attitude:

'we've taken the history and excluded pathology so it's got to be psychological'. We have tried to tell them you need to have a *feel* and this is something they cannot grasp; they dismiss it as something philosophical or spiritual and something they will do only if they have time. One said that talking to me is like meeting the Buddha! At first I thought that was a compliment but then I thought maybe not! A few of them can really understand and develop some insight but others seem to be thinking 'oh, there she goes again ...'.

I tell my students that 90% of the patients come because of pain and anxiety is usually only a secondary issue. It is difficult to get Asian patients to talk about their pain. Asians tend to present themselves a little differently from Westerners. They are less verbal and expressive. They come and they want something done. They will tell you where the pain is but will talk *about* the pain only if you ask them. But times are changing. For the last ten years I have worked in a private hospital and the patients that I see now are a little different from the ones I saw in the public hospital in the city. They are more affluent and more like Europeans. They verbalise and express themselves but the flip side is that they spend a lot of time ruminating about their pain compared with those in the public unit, who are more stoic and just get on with it.

Dental pain is very common, but this is not so much my concern; mine is a referral clinic and they don't often come to me as dental pain is usually acute and dentists can see and treat the cause. Many of the patients I see also have chronic pain elsewhere, although in Asian society we don't hear much about fibromyalgia or chronic fatigue syndrome or MUPS and things like that. The patients don't know about them so when they come to my clinic they cannot legitimise their problem with a name. I do not entertain the idea much and I believe that this may avoid setting up a vicious cycle.

I have suffered from TMD myself for more than 30 years. At about the time I left high school and started dental school pain I developed pain in my jaw and my face. One of my lecturers treated it at the beginning with diazepam which they said was a muscle relaxant. It gave me some relief but I wanted more and more. When I got married I asked my husband (a urologist) to bring me diazepam and he would bring fewer and fewer. I realised, having become familiar with the literature, that I was dependent on it and this was something I had brought upon myself. Although I learnt to identify all the stressors and where they were coming from I couldn't do without it. So for the last 20 years I have hardly used anything at all. I had splints, I tried everything. But I was never desperate; I'm not in pain every day and most of my life is fine. Pain has become a warning signal to me that 'there I go again....'! This is what I tell my patients and they can absolutely relate to me. I tell them: "you know what? I have had this for thirty years..." and it does help me a lot in managing them. I have been through the usual stressors of getting a career and bringing up a family and can relate to most of the problems my patients have, at least those of women between 20 and 45. But I have learnt not to intrude. At the beginning I thought I was doing them a favour by giving them a year of appointments and if they wanted to pour things out to me it would be great. But then I realised that they might not want to see me again because they are very embarrassed because they have told me so much, but I say the moment you walk out I really cannot remember. So nowadays I tell them that it could be this or this ... only you know. But the more I don't want to know, the more they want to tell me and very often they break down. Maybe what I have said triggers something. They know that I'm just trying to help. So they unload everything on me.

So what is new in the management of TMD in the last ten years? We now have Dworkin's dual axis classification according to which Axis I refers to physical characteristics and Axis II to psychological factors. Previously the approach was very biomedical, trying to find out what was wrong with the patient's muscles or joints and trying to fix it. Occlusal rehabilitation [correction of bite abnormality by dentistry or jaw surgery] is irreversible and we don't advocate it any more. I don't even believe TMD is much to do with the dental apparatus but is very psychological. But there is a danger in trying to educate trainees about this and not doing it well so that they will just go out and tell the patients: "you know what, it's stress". Don't we all have stress? It is the most overstated diagnosis. So when I say to the patients or the students that I'm not about to tell them that it is 'all stress' they love me for that. But stress needn't be anything major; you don't have to be depressive or have financial problems or face losing your job; it may just be something persistently bugging you that you push aside which comes up again and again. It happens to me. And if you have a personality which is a bit more sensitive you may take on a bit more and that is a stressor. I try to explain these sorts of psychological stressors to patients and I believe that helping them to catalogue these minute things helps them a lot. It takes a lot of time and I can only see three patients in a morning but I really don't mind doing it.

That said, I still have to assess the physical disabilities of the jaw: what the patient can and can't do, movements, joint sounds etc., from which I can get an Axis I diagnosis and classify them as suffering from a muscle disorder, a disc displacement or a joint condition. This is a new approach; ten or fifteen years ago it was all lumped together simply as TMD disorder, but over the years we have realised that each one is different. Assessment of pain is no longer on a simple zero to ten VAS; we use an assessment of functional limitation due to pain.

As regards psychological distress, we aren't trying to diagnose depression or anxiety, but rather getting a feel that something is going on. And that is good enough. We may want to refer them but most of the patients I see don't want to see a psychiatrist, mainly because they think I think they are cuckoo, even if I say it's a psychologist, not a psychiatrist. But about 2% of the patients I see are suicidal, and those I have to refer. When they get a little better they want to come back to my clinic and over the years I have begun to realise that maybe it is the time I spend with them that everybody wants.

It remains for us to assess their psychosocial functioning and things they can and can't do. All these things are given scores and take a lot of time, and I now use a simple questionnaire which is quite worthwhile going through with my patients.

I do find the kind of descriptive diagnosis that Dworkin's Axes I and II provides more useful than a label. For instance patients like me may have myofascial pain with limited jaw opening. I may have some somatisation and I may not be able to do certain things and a pain score of 3 or 4. This may mean something to the clinician and help the patient to understand a little more.

Although I have begun to use and to teach a biopsychosocial model of pain, I don't actually say this to the patients, but rather something on the lines of "when I was examining you ... and trying to find out what you can and can't do ... I got the impression that when you feel the pain you avoid doing certain things...". I try to show trainees how to use the biopsychosocial model to see that the ways in which a



patients manifests and appraises their pain is individual and different from any other patient. As society is becoming more affluent I am seeing more people with verbal diarrhoea: "I cannot do this and this and my daughter-in-law is fed up with me and I can't get up in the morning and ... etc. etc." In Asia we aren't so used to listening to patients and if you have a very busy clinic that is regarded as wasting time. A lot of GP's don't want to see chronic pain patients. One reason why I chose TMD for my PhD was that everybody wants to do cancer research and so did I, but there just isn't enough research material to share. So I decided to do something that nobody else wanted to. I have grown to like it as I think I can get through to the patients if I spend time with them.

### *Neuropathic pain*

I see a group of patients with burning or shooting pain which can be trigeminal neuralgia but is very often related to trauma. Sometimes they volunteer the information and sometimes you have to dig it out. Some have had implants. The damage is done and the brain pathways have changed and very often the management is only supportive. Occasionally I can pick up from the cone beam CT that there has been damage to the alveolar nerve either from local injections – always a danger when you take out a wisdom tooth or place an implant - and sometimes the CT shows that the canal is breached proving trauma. This is avoidable and the question of litigation arises. What should I tell the patient? Should they sue? A familiar scenario is a 50 year old woman with a dull continuous pain which may be mild or severe. You can't always identify an event. We know that we are not dealing with TMD or trigeminal neuralgia which you can diagnose objectively and treat. This group of patients is difficult to treat. This is a growing problem as people are more trained in physical interventions. Patients come with a mouthful of root canal treatments which may not have been done properly. There are already plastic changes in the brain and once again treatment is mainly supportive.

Another big group of patients, usually women, tell you that their whole mouth is on fire. This kind of expression is something we have learned from the West and is not Asian at all. We learn words such as lancinating and pricking from textbooks and try to place them in Asian society, but this is difficult. They are English words to start with – of course I understand them, but if I use them to patients they have to pause and sort of translate them into something they can understand. Students ask them to rate their symptoms on a scale of zero to ten but this introduces them to a new concept of numbers which may puzzle them. It's not totally useless and although I caution students about it I do sometimes use it. But does a score of 8 mean the same to me as it does to you? It's not Asian versus Western – it's the difficulty of getting into numbers words and symbols that you are familiar with but may mean little, or something different, to us. Not all mouth pain is burning mouth syndrome and I may still have to eliminate infection or lichen planus etc.

### *Illness, suffering and culture*

In Asia when you are ill you are really ill. To the simple lay person it means being sick in bed, perhaps in the public hospital, and not able to do much. In the West it may mean I am ill but I try to carry on. In Asia they may carry on but they don't think about suffering – it is part and parcel of life. They may still have to work. They may be stoic and not express themselves much. But our society is changing. So when you talk

about suffering, for Asians this means really, really suffering. I probably suffer like a Westerner: I can't stand pain – my tolerance is very low. I often wonder what my last days would be like if I were to suffer from cancer.

Illness is one of many possible forms in which suffering can appear and take shape in any culture. Suffering induces an individual to try to understand and do something about what is happening, by seeking the help of a doctor to establish it as the result of disease. The IASP does not differentiate pain from suffering, and equates emotional experience with suffering.

How do we read people? Just because a person doesn't verbalise does she not have pain? People from our different ethnic groups in Malaysia react in different ways. We have migrants from India and China (I'm third generation Chinese but I have never been to China). The Indians tend to be seen as having a low pain threshold. When we go to the dental clinic in the public hospital we often find Indian people shouting in pain. This used to be attributed to their low pain threshold but we have begun to realise that this is because they verbalise and are very expressive about pain. Maybe shouting makes them feel better? When Asians are trying to express their suffering in terms of their illnesses there is a lot of collaboration between the clinician and the patient. They are looking for legitimisation of their illness, perhaps more so because they have read about it. Doctors in Asia are probably put on a higher pedestal than the rest of the community, and people don't like to question the doctor even though they may disagree with him. There is a certain amount of faith there. So when people are trying to legitimise their illness there is a lot that the doctor has to do to bring that out. The problem then arises when the doctor cannot pinpoint what is wrong and they don't have a diagnosis to legitimise their problems and their suffering.

### *Buddhism, mindfulness and meditation*

I come from a Buddhist background, (and am en route from Malaysia to the USA where I go for a Buddhist retreat every year.) I have been brought up thinking about questions about me, the I and the ego, such as who is experiencing pain? What is the *me* that is suffering? When relieving pain of the other who is "the other"? When pain is "relieved", who finds relief? These are very philosophical concepts to bring into a scientific culture but Western society has begun to embrace Buddhism.

When I ruminate too much about my pain I sometimes try to detach myself from it through my practice of mindfulness, which stems from Buddhism. Clinicians need to learn about this but when I hear my students say to patients: 'you just have to be mindful' I wonder what on earth does that mean to the patient?! I'm not a trained psychologist but I try to use my own experience to help them, for instance by asking them if they do anything other than going to work and encouraging them to think of activities which will distract them from their pain. I also try to introduce them to mindfulness and meditation. I tend not to use these words as Asian society is steeped in religion which is somewhat dogmatic and most people are not very open-minded. So I tell people: "You just have to sit in a quiet corner and concentrate on your breathing". I tell them I find this very helpful because I do it myself, at stressful moments like giving a presentation. Mostly their problems are with daily small stressors rather than big things like debt or divorce. I only ask them to do this for three minutes a day. If they find this too difficult I say OK just one minute, because

one minute is an awfully long time to watch only your breath. But if they can do this they can begin to detach themselves from their pain and ruminating about it.

I like to tell my patients about a study involving functional MRI. Patients with rheumatoid arthritis were divided into two groups. One underwent six weeks of meditation training and the other just conventional treatment. In the first group the region of the brain associated with pain perception didn't light up: they still had the pain but the brain wasn't processing it. I tell them that they can achieve some control over that bit of their brain through pleasant distraction, meditation or praying.

My patients have taught me a lot. Culture has gone beyond race. In their search for healing and relief which may involve identifying symptoms that confirm the presence of disease, patients are engaged in a continuous search for new doctors and new information, looking for something to give them some hope of the possibility of healing. Trainees tend to learn everything in black and white, and like labels such as psychogenic pain, but I have been trying to get them to look behind the patient's actions at the reasons for them and what they are searching for. Some students may swing too far and respond with empathic distress and tears to a patient's story, so I try to bring them back to the middle and recognise that this is not necessarily good for the patient, and you have to be professional, otherwise you are adding to their problems...! I encourage them to look at themselves and what is going on in their own minds and examine their own actions. For instance, I say to the male students that when they see an attractive young woman they are happy to spend the hour taking their history but when the next one is a scruffy old man...! Over the years I have seen thousands of patients, and I worry that they can become just the next number. I have to ask myself: am I becoming more reluctant to share my own experience with patients?

So having asked the questions, whether or not they have fully understood the patient's answers, doctors have to make clinical decisions such as is the patient's problem relevant to somatic medicine or should he or she be referred to a psychiatric clinic or to a psychologist? Is the present clinic the one that should be responsible for the patient? Is the patient eligible for continued contact and treatment at the present clinic (e.g. for physiotherapy)? Should the patient be on sick leave?

I work with the pain clinic in another hospital where there is a psychologist, an attending psychiatrist, a physiotherapist and an interventional anaesthetist. They do very well with these patients. But I am concerned that some clinicians are being more inclined to take the short cut of resorting to intervention.

### *Listening*

The patient's narrative gives us the context which is going to affect his compliance. I tell the students we don't listen just because it's a good PR thing. In the private hospital the students come from an affluent section of society. They are courteous and good at socialising but do they really want to know about the patient? I sometimes find them spending the time waiting for X-rays either leaving the patient sitting there or indulging in small talk instead of using it to educate him about his pain and helping him to understand more about himself. I say: "they aren't telling you the story about all their family problems etc. simply because there is no-one else to download it on but because they are looking for understanding."

The physician-healer creates a safe environment for patients to reveal their stories by encouraging storytelling. Clinicians must bely intentions to heal and suspend personal views and values so they can enter the patient's world without bias.

What the sick man wants most from people, "is not love but an appreciative critical grasp of his situation, what is known now in the literature of illness as 'empathetic witnessing'.

(Broyard, *Intoxicated by my illness*, 1992)

Helping patients to make this connection allows them to better own their illnesses, by ascribing meaning to them, and to move through the processes of devastation to reflection and on to a new narrative that increases the ability to respond to the changes wrought by the illness. I have to keep reminding myself to listen properly. Sometimes we listen just enough to make the diagnosis, trying to filter out the significant symptoms. But we have to remember that this is set in the background of this unique patient. Can you function as a clinician without being totally immersed in a patient's situation? Possibly, but people do want the clinician to feel what they are feeling. I believe that there are different levels of where you want to draw the line. Some people are much better than others at this.

...I listen not only for the content of his narrative but for its form – its temporal course, its images, its associated subplots, its silences, where he chooses to begin in telling of himself, how he sequences symptoms with other life events. After a few minutes he stops talking and begins to weep, I ask him why he cries. He said "No one has ever let me do this before".

(Rita Charon)

We are so keen to get down quickly to when-why-exacerbating features and so on that we are continually interrupting the patient. And because he has come to see a dentist he only tells you about dental things – not about the pain in his shoulder or low back, or if he is depressed. So instead of plaguing him with pesky questions we should be listening attentively and analytically as if he were a character in a play giving a soliloquy. I'm not good at multitasking and I can't write listen and talk at the same time, although a lot of clinicians do. But if you can totally listen to them and are one with them they like it that way. Sometimes when they are given a diagnosis the patient becomes very emotional. The question often is what that diagnosis means to them.

My own experience of not being listened to or believed was instructive. I developed ectopics of which I was subjectively aware; I don't think the cardiologist believed me – at least the signal I was getting was that I was imagining it - but put me on a Holter [ambulatory ECG] for a week which showed that my perception was right (to my relief!). I also wanted him to look at the record between eight and nine at night when I do my meditation to see if the ectopics were less frequent, and whether it might help me to be doing more meditation but he kind of cut me off – he was like: don't worry about it ...OK, OK ... I didn't feel he was taking me seriously, perhaps because he is a friend of my husband. (But I take me seriously!) I only wanted him to take the time to listen to me. I elected not to see him again.

### *Objectivity and shades of grey*

We use tools such as the Brief Pain Inventory and Beck's Depression Inventory in both research and in clinical practice to try to be as objective as possible but I am not sure that something like the 'faces' [emoticons expressing severity of pain] in the Universal Pain Assessment Tool is very helpful in our culture. Nothing beats actually getting down to the patient. We use tools such as the Brief Pain Inventory and Beck's Depression Inventory in both research and in clinical practice to try to be as objective as possible but I am not sure that something like the 'faces' [emoticons expressing severity of pain] in the Universal Pain Assessment Tool is very helpful in our culture. Nothing beats actually getting down to the patient.

Assessment and treatment of diseases and disorders are more or less universally accepted but it is the cultural context that presents shades of grey.

Our people are a little bashful and not very forthright with their opinions; in Asia, especially Korea, Japan and China, the ideas of harmony and balance of Yin and Yang, and striving for the least disruption possible, are prevalent. We try not to draw attention to our problems. (But I do! – perhaps because I spend a lot of time here and in the USA.) My parents are in pain and are not happy about it but don't talk about it.

Technology is becoming a problem. Patients want it – in Asia they want to see that you are *doing* things. They want dental procedures. If you say they don't need an MRI they think you aren't doing enough for them. A follow up appointment may only last a few minutes because essentially they come to be discharged, but some should really be getting much more time at this stage. An ethical problem with this arises in my hospital where if patients are used for teaching they don't have to pay, but if I don't have a student with me when they come for follow-up they do. I spent 26 years in the public hospital so it is very difficult for me to have to start valuing my time.

### *Success stories*

I always think whatever happens to me in my life is going to be useful someday. It is important for the patient to share success stories and I think I can do it authentically; I can say "you know what? I have pain just like yours but over the ten years I have had it I don't need anything because I am very mindful of what is stressing me up and I can just stop and examine why a situation or person is winding me up, or why I am hung up about something, and it helps me to come to terms with it."

### *Diagnosis and suffering*

Whether or not the diagnosis is apparent we are often tempted either to endorse someone's suffering or to alleviate their anxiety by giving them a minimal diagnosis. We are reluctant to mention death. This goes against the objectivity of my oral pathology training, and again involves compartmentalisation. I tell them "I don't really know but I don't think it is this, this or this and definitely not cancer but let's monitor you..." But this may not do the patient justice.

To receive a diagnosis that places one's suffering in a medical context can be both a confirmation and a disappointment for the patient. It does at least give them access to some treatments. But if these fail, then what? The patient possibly acknowledges with gratitude the diagnosis she has received from the doctor but this does not account for the fact that she never recovers. Diagnosis has elicited recognition from the medical establishment for her ailments and part, but not all, of her suffering. The remainder remains to be dealt with: she still has to live with it.

The information you give depends on what the patient wants to know and why she wants to know it. We deal with so many shades of grey. We sometimes don't know who is playing the bigger role: the clinician or the patient. If you are dictated to by what the patient wants all the time, we who are supposed to be medically trained have no choice but to collaborate.

So are we treating the disease or the diseased? Maybe both; we have to treat the disease, I may have to cut out a lump or bump, that's easy. But when you look at the mouth and can see no signs at all and the patient asks where the pain is coming from it is much more difficult and intangible.

Medical recognition of suffering involves acknowledging (and even sharing?) patients' feelings of helplessness: when we do not have a diagnosis or know what we are treating and at best are relieving only part of their distress the patient needs to be aware that we do not know – but confident that we will continue supporting them.

The diagnosis of suffering is uniquely dependent upon the clinician's subjective experience, making physician-healers "strange instruments".  
(Cassell EJ, *Diagnosing suffering: a perspective*, 1999)

We need to be instruments for assessing and appreciating suffering, be it by direct questioning or intuition. We need to recognise that someone may look happy, cool and fashionable, perhaps goes clubbing every night, and still be suffering.

The word suffering is deeply ingrained in Buddhism. We talk about the suffering of suffering which is the pain you get when you cut yourself, and the suffering of change we don't like such as when a normally cool room gets uncomfortably hot. Then there is all pervasive suffering which goes on from the day you are born.

The change from expert-doer to servant-accompanier requires that physicians attend to how they *are* with patients as much as what they *do* for them".

(Adler HM, *The history of the present illness as treatment: who's listening, and why does it matter?*, 1997)

This involves what has been called 'emphatic connection'. Clinicians must draw on themselves to explore the meaning patients append to their illness experience, to guide healing and to act as 'morale catalysts'.

The most powerful therapeutic tool you'll ever have is your own personality.  
(David Sackett)

Advances in medical technology infuse a hope that medicine is able to alleviate troubles, pain and suffering. In order to gain these benefits, patients as well as medical professionals, must interpret somatic or psychological suffering and disturbances in terms of medical diagnoses. The diagnosis becomes an emblem for hope while at the same time turning suffering into something medically and socially legitimate. Are we there to bring hope through diagnosis?

Pain is inevitable. Suffering is optional.

### *Discussion*

*You have reiterated a lot of what we have talked about in previous meetings about the importance of active listening. One of the most frequent criticisms I have heard about GP's is that they gaze at their computers and don't look at the patient.*

... It used to be pen and paper ...

... I don't write anything...

... I don't either because I don't have the ability.

*In 1980 one of the first pieces of research on empathetic sharing: sharing self, was done by a health visitor called Sue Dalton, a Canadian health visitor – about the way in which we have traditionally been taught professionally to keep boundaries, but now are beginning to learn to share a bit of self. I have found it useful in my counselling practice. 'I know where you are coming from'. The idea of 'being at one' with a patient brings us back to what Basil Finer said about making good contacts. It's extremely important for both patient and those of us looking after them.*

I agree with you totally. But you have to be careful as well. There are also stories I could tell you where the boundaries were crossed, maybe because people picked up the signals wrongly. There was one young man whose mother was about the same age as me; the son of a colleague of mine who had died in a tragic accident. After this he developed OCD and pain and was referred to me. Perhaps I listened to him more attentively because I knew his parents. Then he wanted my phone number and to phone me up ... I wondered how to deal with that in a gentle way. I had to be so careful but I did feel that I loved him as a person who was helpless and needed love, whatever that means. It didn't cross my mind about having a relationship. This was about six months after his father's death. He was a Malay. In our country there is a Muslim law that if a father dies the oldest son has to shoulder responsibility for the family. But he was only 20, and with his OCD he was spending all his time washing and in the shower and that sort of thing and couldn't do that. I wanted to tell him that I was with him and one with him. Maybe he picked that up as pure and fresh; he was confused about what I was offering and wanted to see me more. I told him he could come to the clinic any time, but my nurse said Dr Khoo is very busy but you can contact me... I felt sad at this point that he had to be rejected, but wondered how to let him down gently. I don't want to be his crutch. That is a potential problem if you are trying to be one with someone.

*Thank you for that insight into working with someone from a different culture. When I worked in Israel we saw people from many different countries; Germans would say I*

*have pain hier und hier und hier ...; Moroccans that their pain is like a stone round my neck ...*

*There are many Iranian patients who find it difficult to express their pain. I deal with a lot of Middle Eastern refugees who are full of anxiety and fear. They have seen lots of colleagues. I asked one lady (through her interpreter) what was her fear – I was sure there was something underlying their problem. It turned out that she was waiting to be paralysed – she was sure that her back pain was going to result in this. Once I had allayed this fear she was a different person.*

*I am very interested in your thoughts about pain scores. My feeling is that they can be useful but they can be like a Richter scale: every time you go up a rung in the ladder it's ten times worse. I don't think pain scales are described to patients in a way that they can use them properly. I also feel that it is a deficiency of 1 to 10 pain scores that they don't take anxiety into consideration. Stress and anxiety directly affect health and how you experience pain. My question is: is there a pain score that takes these into account?*

Characteristic pain intensity is one part of the Axis 1 and 2 classification of TMD that I talked about. That is a composite of three: your worst pain, your average pain and your functional limitation by pain.

*I hate VAS scores with a line on paper – all you need is mild, moderate and severe.*

Words are better than numbers – numbers are a new concept to most people.



# **The tyranny of the hidden waiting list: bureaucratic management of referrals and unmet patient needs**

Frances Beswick

I need to share with you the things that are eroding my energy for my work and the conflict of values that we keep hearing about in this meeting – between the managerial and the patient sides of things. But I wanted to talk, instead of about the patients we are seeing, about the patients we are not seeing and who are experiencing ‘The undulations of hope and despair’. (One of the chapter headings of my son’s PhD thesis, quoting the physicist Ernest Brown.)

But first a word about my background. I trained in pain in Seattle with John Bonica and John Loeser and then I did ten years in Gloucester with John Miller who was replaced by Paul Hardy.

I’ve always been interested in that tension between looking after the individual well giving them a Rolls Royce service and looking after the population, and maintaining the balance between the two. One of the suggested ways of dealing with bigger numbers and not having waiting lists is to just run groups, with no individual assessment. We are always trying to reconcile the demand from service managers with the needs of the patient in front of you, or the despairing patient in front of the GP desperate to come to the pain clinic.

The political background we are working with in New Zealand has involved copying bits of the things that haven’t worked in Britain Australia and America. We have been given the triple aim ‘to improve Quality, Equity and Best Value from the Resources’. We have to think about the whole picture all the time.

Last November our secretary had a strange phone call. A patient said “I’ve been told to see my GP but I can’t afford it”. (In NZ people pay to see their GP; there are some subsidies but basically they are private contractors). It eventually turned out that round about October a manager realised that there were a whole lot of patients who wouldn’t be seen within the recommended time-frame of four months, so they had to be returned to their GP - in other words dumped. There was no record of the number sent back. The GP’s were sent letters saying “please reassess if they still need to be seen in the pain clinic. We will give you \$45 to see them.” So they started to trickle back as people realised they could see their GP for free; in the meantime more new people had been added to the waiting list, so we’re now seeing people after eight months. So that wasn’t very helpful.

Like here, these ideas were brought up to ensure that the process of getting care is fair and consistent. But it was designed for surgery - for acute care – and never for long-term care, outpatients and pain clinics. When we spoke to the Minister of Health about it he said that lots of people are getting better care so it’s tough luck that these people aren’t. The approach was supposed to ‘reduce the barriers to access’.

How can you deal with the experience of chronic pain with the alterations of hope and despair and the guilt and all these things with a priority list? How can you put it

into numbers? We are supposed to give patients a 'Clinical Score' from 1 to 5 based on measures of pain, disability and ability to work etc. which will be used (by management) to give them a Priority Ranking for surgery (for which it may be appropriate but clearly is not for an outpatient pain service.) We are being told we shouldn't worry about our patients' social problems etc. so we can 'mitigate risk' and use scoring tools to 'facilitate access'.

Strategies we are exhorted to use include:

- Communication (a good word!)
- Integrated care pathways
- Improving the ratio between specialist and follow-up appointments (meaning we should aim see a patient once, cure them and send them away. I've never worked like that, apart from the occasional patient.)
- 'Whole system thinking'. (I think that probably came from the NHS.)
- Support the GP's (that at least is good)
- Pop-up clinics (for people that don't need the whole thing)
- Specialists in the community (what you call GPs with a Special Interest or 'Gipsies')
- Non-contact first specialist appointment: the specialist writes an investigation and care plan for the GP without seeing the patient. This apparently works for neurologists, but despite its not saving any money in the long run our managers want us to introduce it into the pain clinic.
- Collaboration, evaluation etc. – none of which actually happen
- Alternative providers, including our nurses (that's good)

All this is supposed to lead to better job satisfaction. It is presented with a 'can do' attitude so if it doesn't work it's the clinician's fault. It has been described as the imposition of spurious rationality into an irrational process.

We do need some rationing but although society needs numbers patients need care; they are not integers. This is the push button mentality: we give them a score such as the priority scores we have for when they are allowed to come and see us, but we can only measure their functional capacity, we can't measure their experience.

Pain bloggers say the trouble with doctors is that they don't know how to deal with disability and blame them for treatment failures. Some find it hard to accept patients as experts, and some don't communicate well.

### *Waiting lists*

If waiting lists do have a purpose, is it deterrence, delay or deflection? I think it's exclusion. I get the feeling that our patients don't matter because pain isn't a life-threatening disease. It's not glamorous – we don't have an Angelina Jolie publicising us. When you see the amount of money that has gone into chronic pain compared with palliative care we seem to be falling behind. Who decides what is important about whether or not patient should be seen soonest?

Habituation is a wonderful term; when managers start to use words like empathy, communication, competency and relationships frequently they sort of morph into trigger words stripped of their real meaning

*Help me please!*

I'm asking for help – how do I manage myself? I get so tired with feeling that managers' actions are unethical. How do I come to terms with that without getting angry and being rude to them? How can I manage patients more efficiently so I can see more? How can I teach GPs so they don't say things like 'you'll end up in a wheelchair'.

*Discussion*

As part of their endeavour to get to grips with MRSA infections on the wards our local hospital changed from using numbers to patients' names: Mr Smith 78 years, with a brief summary of his story - a picture of a real person. That change halved the number of infections in the hospital

*As a GP you have all sorts of reasons why you should refer. One would be that you don't know enough about a specific pain problem. Another is a patient who has joined your list with an extremely complex pain history and you are simply not able to look after them alone; or you run into trouble with one of your patients that you have been managing to a degree but now need expert help with. A lot of referrals are in anticipation of success and a management plan, but they may be so the hospital doctor can be the bad guy who says 'no, they can't have more morphine' because the GP has to maintain a relationship with the patient. And of course some GPs haven't got the inclination, resources or the time to deal with complex patients and that's going to become more of a problem.*

So we need to find a way to simplify. It's a good idea to see them earlier but we can't do that if we have a long waiting list.

*We have a priority system which may be unfair. If they are dying with cancer we see them sooner, or things causing pain which we know may result in long-term problems like CRPS ... I'm never sure if this is ethically valid or not.*

*But the thing you have illustrated is something I'm always banging on about: the fault line between managerialism and professionalism and how we cross that fault line. The NHS is in big trouble if we can't somehow close the gap.*

*There is an interesting development in England with GPs being the commissioners and hospitals providing services. My own experience locally is that the CCG's aren't getting great value for money. I don't know if this is because the hospitals are more expensive than the tariff is willing to pay for. As patients we are told that the CCG will commission enough capacity for the area. The Hub is supposed to solve all problems but if you mention the subject to clinicians ... !*

*When I tried to get a cardiology appointment after Christmas I was told that 'the list is being rebuilt'. After two months I started the process of a complaint, not just to the*

*hospital and the Hub, but I copied in the CE of the CCG and the NHS England Commissioning Board. There was no way that any patient who doesn't know about these structures could have done that. The CCG CE said 'we know about this and we're dealing with it' and so did the Hub and miraculously I got an appointment. But that seems unfair to me that a member of the sharp-elbowed middle classes could force their way in, and you have to be so tenacious as a patient to get an appointment. It seems that there isn't enough capacity in secondary care and the Hub is there to filter things and slow them down. Some people may be in the position to say to hell with it – we'll go privately even if it means we won't have a holiday, but many people don't have that option.*

*I understand your pain but I think you should stop beating yourself up about this. It seems as if what you are trying to do is to get it right for the patients who can get to you, which is surely our job as frontline clinicians. What you are battling against is the system that, frankly, you can't change and it's bigger than you are. William [House]'s answer was to get out of GP and try to change the whole system. But that is a special person and I don't think most of us either can or should do that because the system is part of the culture. I think our responsibility is to do the best for the patients we do see and not beat ourselves up about a system we may not like but we aren't in a position to change. Maybe that's defeatist but my philosophy is that if we behave to high ethical and moral standards and try to be exemplars of what good care might be, that will filter through in other ways.*

*When I was training and I was complaining that we didn't have enough beds one of my consultants said: "remember you are the bus driver and your responsibility is to drive the bus safely. You're not responsible for the bus service and how long it is before the next bus comes along". And there was something about that that really helped me. But one of our problems dealing with chronic pain in the NHS is that although palliative care in the community is superb we are dealing with palliative care of non-terminal patients. If we look at what they are doing in Sheffield we see that they are doing tremendous things in primary care. In County Durham where I work we are seeing the top of a huge pyramid, about 2% of the people in pain, and the other 98% may be getting nothing or over- or under-doses of opiates. What we are trying to do is to say that there are different kinds of pain: you should refer neuropathic pain early because we can do something about that; musculoskeletal pain we can work on with the physios and spinal surgeons. But chronic widespread pain shouldn't be coming into a medicalised service and we need to develop something completely new and different for that involving social prescribing and support. This is a different world that we need to create and trying to adopt this pattern involves eating too big a cake but if we all take small bites we can eat it quite well.*

That's very helpful and what we have tried to do for years but it's ended up now that we can only see post-herpetic neuralgia and CRPS and nothing else and there's nowhere else for people to go.

*What happens to all the people in pain that haven't got a diagnosis?*

Your priority score doesn't depend on a diagnosis; it depends on their coping mechanisms. At least that's what we try to do; of course you can't put that in a tick-box but that is the aim. And the people with neuropathic pain with whom you might be able to succeed if you see them early enough.

*The way your story came across to me was that what you were describing an ethically scandalous managerial system. Is that how you feel about it? ...*

Yes.

*So you have the alternative of adopting Paul's recipe [to do the best you can for the patients who do get to see you and stop beating yourself about the others as there is nothing you can do about the system] or, depending on your passions, to right a serious ethical wrong you've got to do a sort of Erin Brockowich: What do you actually want to achieve? Do you want to blow the whole thing apart so it can be put together again better, or follow Paul's recommendation?*

... little ideas ... Stephanie Davies groups

In England it's hard with seven-minute appointments, in New Zealand it's hard because you have to pay. You can do a little bit of tweaking here and there ... but it has got worse. The Professor in Christchurch, a so called tertiary referral centre, can only accept 13% of referrals.

*I tried desperately to change things and failed miserably so now I just keep my head down and deal with the patient in front of me. It's clearly not going to change. The NHS is so mammoth it is unchangeable.*

*I think the issue is that individuals on their own can't change things but maybe as a group we could. I used to tilt against the pharmaceutical industry's control of rheumatology and all I succeeded in doing was to get thrown out of all professional societies. But as a group ...? Maybe that is what this group is for.*

*How can patients be mobilised?*

*When the White Paper for the Health Bill came before the RCGP when I was Chair of the patient group I was told at a dinner: "you guys are going to be the most important people in the room". Patients are going to be everything in the new health service and everything is going to be patient led. In some ways it has happened but you have to be part of a large group for a large condition like Diabetes Care, which is a force to be reckoned with. So is Cancer Care. Cancer charities can do almost anything when it comes to fund-raising, and are hugely disproportionately funded. But although 8000 women die every year from cancer, 30,000 people die from sepsis. The public are good at cancer awareness but don't have much awareness of pain – and they don't want to because it's too difficult to think about. It's a bit like child abuse that no-one wanted to talk about a few years ago and now it's OK and everyone is coming out of the woodwork. But it took some very high profile cases, and pain is just not seen in that light. I think palliative care of the living is a wonderful concept, but there are 14 million people in the UK living with chronic pain and in a city the size of Sheffield that's 29,000 people in pain but only a thousand get to see the pain service.*

*Most of our work is about lowered expectations because if expectations are low people won't be disappointed.*

*One can't set oneself up against a mammoth organisation but we can tilt at it. If we use the media and get stories into the Daily Mail ("I was suffering because I couldn't*

*get to the pain clinic”) or the internet, whether it is right or not giving a patient the number of their local MP or someone at the BBC – to empower them to go out and pursue the matter. But we within the system are pretty hamstrung.*

*Wearing my Pain UK hat I do get invited to comment on media things on BBC Five Live, BBC West Midlands and BBC Merseyside and every time I have done that the phones have gone berserk with people saying ‘that’s my story’. I talk about losing my job, my home and my relationship and all hope; bouncing around from clinic to clinic trying to get diagnosed and the pain never getting sorted and people just relate to that. You’re right – we do need much more of that.*

*Is it then a question of pointing them in the right direction?*

*Unfortunately with the media you’re kind of stuck with their agendas; sometimes they allow me to plug Pain UK from which they can get information about their nearest pain clinic and the like ...*

*... but they do like a good story!*

*Pain needs to be remodelled as a disease in its own right. Perhaps we need to change its name to give it more cachet and so the message can be clearer.*

*If you were to list all the effects pain has on someone’s life and give it a Latin name it would have much more effect.*

*The trouble with calling it a disease is that it suggests a medical treatment. We should all quit doing pain and imagine it as a mostly non-medical process.*

*Someone suggested we should have suffering clinics!*

*I have been suggesting that we should never say someone is suffering with pain we should always say they are living with pain – at work, at home, when they get up, when they go to bed, every day of their lives. The problem with the word suffering is that it invites a sense of victimness – ‘he’s suffering with pain, he’s suffering with cancer, he’s suffering with diabetes’ - we wouldn’t use the word suffering with some conditions, we’d say living with – not victims of.*

*What about ‘fighting’?*

*That’s OK.*

*[murmured dissent in audience]*

*There are people out there living with pain who never seek help. They are coping with it and dealing with it. It’s the people that can’t deal with it that are the problem.*

*There are also people who aren’t dealing with it but can’t get the medical help they need.*

*Suffering is a state ...*

# Is our model biopsychosocial or just biopsychological?

## *The social determinants of pain and the place of social security advice*

Matthew Jay

Someone said earlier in the meeting that they felt like an imposter here. I have to admit to feeling like an imposter at all pain meetings. I am neither a healthcare professional nor a patient so I come to pain somewhat from the 'outside looking in'. I'm a social security lawyer by background and came to pain more recently when I joined the pain team at Great Ormond Street Hospital (GOSH). My interests are therefore very much on the social side of health and in particular how social conditions such as poverty and inequality influence health.

This talk is really about the biopsychosocial (BPS) model of pain, with which I'm sure we're all familiar. I will try to put the social determinants of health into a pain context and examine issues of social security. So we'll look at the BPS model, I'll go over the social determinants of pain and look at one particular possible causal mechanism and we'll consider the social impacts of pain. I'll then suggest a model which draws all this together and puts social security advice, which has been shown to be beneficial in other health contexts, into place. I stress at this stage that this is mostly quite hypothetical. I am here really to talk to you, as people involved clinically in the pain world, and to find out what you think.

And just one final preambular paragraph to give you an idea of the setting in which I work. Our patients in the pain clinic - a highly specialised children's pain service - are all young people with intractable chronic pain. As in adults, this is defined broadly as pain which persists for or recurs over three months and which has adverse functional and quality of life impacts. Our patients often have had pain for much longer than this, sometimes years, and will have tried a range of treatments in the community before being referred to us. Naturally, we adopt a multidisciplinary, BPS approach to the management of pain in children. Our clients in the Bureau<sup>2</sup> are all families of patients at GOSH (not just the pain service), mostly referred to us by the hospital social workers. We'll see a typical example soon and I'll show you the kinds of issues we advise on.

## *The biopsychosocial model, pain and chronic stress*

The BPS model is very well known in the pain community. It posits that pain (and health generally) is comprised of not just the biological, but the psychological and social as well. We of course have to consider the physical manifestations of illness and health processes - we have to think about pain intensity, its locations, any neuropathology and so on - but we must not neglect the psycho- and the social. As regards the social factors in particular, we can divide them into the three levels: the micro, mezzo and macro. Micro level factors include immediate peer and family relationships, the mezzo level factors, work and school, and the macro level factors,

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<sup>2</sup> Following a brand modernisation exercise, Citizens Advice Bureaux are now known as local Citizens Advice. The 'local' is used to distinguish the national umbrella organisation, the National Association of Citizens Advice Bureaux, colloquially referred to as Citizens Advice.

which are what I am interested in, are issues such as poverty, inequality, discrimination and social security.

These macro level factors tend to receive relatively scant regard in the pain literature and this is perhaps quite strange given the wealth of literature on the social determinants of health in other contexts. Figure 1 shows a simple example of what social epidemiologists look at. It uses data from the English Index of Multiple Deprivation and shows clearly that the more income deprived a neighbourhood is, the worse is the health of its inhabitants. There are two things about this I want to emphasise. First, it is a gradient. Everyone in England lives somewhere along the x axis. In other words, nobody is exempt from having their health determined as a function of their social status. Secondly, you can take nearly any measure of social status and plot it on the x axis, and take nearly any measure of health and plot it on the y axis and you will see the same or a similar gradient.

The same is true of pain. Increased pain prevalence, persistence and/or severity has been associated with a range of measures of social status, including: less education; less income; being unemployed; lower social class; lower work grade; living in areas of low social capital and trust; and living in deprived areas. There is also a life-course perspective to this in that it has been shown that childhood deprivation predicts chronic pain in adulthood.

What could be causing this? There are a number of possible mechanisms at play; I will focus on one which seems to be a particularly promising avenue. That is the effect of chronic stress caused by social adversity (unemployment, poverty, lack of control, etc.). Acute stress of course is a protective mechanism behind the flight or fight response. The problem is allostasis: the way in which the body changes its 'normal level' to respond to chronic stressors. It is well known that the products of chronic stress have widespread ill-effects on the body and dysfunction in key stress pathways has been linked to chronic pain states. It is thought that chronic stress can disrupt various systems which, either in the presence of an acute injury or spontaneously, can contribute to the aetiology of chronic pain. And because these social stressors are distributed according to a gradient (by definition, poorer people have more of them), chronic pain follows the same gradient.

At the same time, we know that chronic pain has enormous social impacts. Chronic pain causes people to lose schooling or work; to make adjustments at home or elsewhere; to change occupations; to incur out of pocket expenses; and to withdraw from social activities. I do not want to get into the reverse causation argument (that poor people are unhealthy because their ill health came first) but it must be acknowledged that in some cases, pain can lead to social adversity. This may be especially true of those already suffering from adverse social conditions who do not have, for example, any savings to support them in illness.

Bringing this all together, we have Figure 2. This shows, in very simplistic form, the hypothetical pathways from social adversity to chronic pain along with a possible feedback loop for those who face further difficulties when in pain. Social security advice has been shown to have relevant positive health outcomes, as we shall see, and may therefore act to alleviate sources of stress and the impacts of pain.



## *Social security advice*

Before considering how advice might help people with pain, it is worth looking at exactly what social security work entails.

When I use the phrase 'social security advice' I am referring to what many call 'welfare rights advice'. I very deliberately use the former to emphasise the fact that it is a right we all have and not something charitable afforded only to 'the needy'. By necessity, social security advice services are free or act on legal aid and all advice services are independent, impartial and confidential. There are a large number of such services, the most noticeable of which is Citizens Advice but other organisations such as law centres, specialist charities and solicitors and barristers can provide social security advice.

Their mode of delivery is also varied. Some are walk-in or appointment only, some advise by telephone or e-mail and there are websites you can go to. Some services, again like Citizens Advice, offer a mix of these. They may be situated on the high streets, like most Citizens Advice Bureaux, or exist in health settings. There are services in GP surgeries, hospitals and mental health clinics. Some services serve everyone in their area whereas others only a particular client group. A GP service will only see clients registered at that GP; a hospital service, only clients at that hospital, like us. Or even more specialist, only clients with a particular condition. Macmillan and advice services for cancer patients are an example of this.

The actual issues we deal with ('enquiries') are also numerous. The core of my advice work is the rights of European migrants but an advice service will usually deal generally with benefits and tax credits; housing and homelessness; landlord and tenant; employment rights and unemployment; immigration; debt; relationship breakdown; and so on and so on. Let me show you a typical case. This is a real case from our bureau, though the names of course have been changed. Again, I stress I am not clinically trained - we rely in the first instance on the families to tell us in their words what has brought them to GOSH so the medical terminology I use here may not be entirely accurate.

David and his wife, Julia, live with their son, Sam. They are all British nationals. Sam is an otherwise fit and well 16 year old young man in his final GCSE year and he regularly played football. He was thinking about his A-level options as he wanted to go to uni to study accounting and go into business like his dad. Mum and dad ran a corner shop. Dad has had a long-term heart condition which renders him easily fatigued. He has had this for about 15 years. The family live in a mortgaged, small, first-floor flat with no lift access.

One day after dinner, Sam collapsed on the floor and had some kind of seizure. This was the first time this had ever happened. He was rushed to A&E and later transferred to GOSH. He had had a brain haemorrhage and was in GOSH for weeks. Once he was discharged, he continued to need on-going, intensive physiotherapy rehabilitation to regain his strength, especially on his left side, though after a while there were no neurological abnormalities. He continues to attend GOSH for regular follow-up and will likely have long-term care needs. At the

moment, he mobilises using a wheelchair though it is hoped he will not need to in future.

Because of their son's sudden illness, David and Julia were no longer able to maintain the business. They spent most of their time at GOSH so they wound up the company and ceased trading. After the sale of their assets, they had no debts other than their mortgage. David and Julia attended the bureau for advice. They have no savings and no income (other than dad's Disability Living Allowance and the family's Tax Credits). Their housing is also unsuitable: the stairs are becoming unmanageable for dad and they are not sure how they will cope.

Over the course of an initial one-hour interview, a few follow up interviews and a couple of telephone calls, our advice was as follows. The family were relatively light with follow up and there was very little casework involved.

Income maximisation:

- Income Support or Employment & Support Allowance – could claim either
- Personal Independence Payment for Sam – but too early to tell whether eligible
- Carer's Allowance
- Checked dad's Disability Living Allowance was correct – it probably was

Prevention of overpayments:

- Inform HMRC that work has stopped so that Working Tax Credits will stop – people often do not realise that they must notify certain changes, they continue to receive a benefit and eventually are asked to pay it back

Housing:

- Advised on options for public sector housing and private renting

Other:

- Disabled Person's Parking Permit (Blue Badge)
- London Congestion Charge exemption
- Explored adaptations but unlikely will be possible on current home

What was particularly heartening was that over the course of our time with dad, his health and demeanour visibly improved. One of the most rewarding parts of social security work is in helping people regain control over their lives when so much has gone wrong.

The health aspects to social security advice are central to what I am talking about today. Advice has been linked with a range of positive health outcomes including less stress, anxiety and depression, better self-perceived quality of life and wellbeing and improved health behaviours such as reduced smoking. People with chronic pain may need benefits and other forms of social security, whether related to pain or not. However, social adversity and social security may be particularly pertinent for chronic pain patients because of what I spoke about earlier. Social adversity, e.g., debt, lack of income, causes stress which may contribute to the aetiology of pain and its social gradient. Removing this source of stress and giving control back to families may have a positive impact on pain outcomes as well as reducing health inequalities.

## *Secondary gain*

Just one more thing before I draw to a close. 'Secondary gain' (I hate this term) has been accused of causing problems when it comes to chronic health conditions. It usually refers to external benefits obtained from having some illness or being disabled. It can be either financial or non-financial but in this context I take it to refer to financial rewards, such as benefits. There is a related concept of tertiary gain, which refers to benefits which accrue to a third party. These gains may be seen as problematic because there is some literature on an association between benefits/compensation and poor outcome or higher prevalence of pain; there are concerns about fabricated or induced illness; and there are concerns about fraudulent or conscious malingering. If these concerns are borne out, then helping people to access benefits may lead to iatrogenic illness and disability. Stressors follow a social gradient, chronic pain follows the same gradient. Social security advice may act to alleviate sources of social stress and give control back to disadvantaged individuals and their families.

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## *Discussion*

*We treat dying patients in palliative care units and hospices where you have access to financial advice as well as pain therapy, psychology and spiritual advice. We say that chronic pain management is palliative care of the living and treat chronic pain patients who have all these needs but we only give them what is often ineffective medical treatment and we often ignore all these other aspects. Maybe – this is a call*

*to arms – we should start thinking about how we should incorporate these other aspects.*

*I was lucky in that I had a job that carried on paying me full pay for six months and half pay for six months after I was forced to stop work, and an insurance policy that paid my mortgage in that time so in the first year I was slightly better off than I would have been working. But when I had to transition to benefits it was like entering a completely different world. The system is completely stacked against people. There was no support ... it was a constant battle ...*

*I see many patients caught in this system. How do you advise me how to direct them to get help?*

The place to start would be the Citizens Advice website, or their local Citizens Advice Bureau. CME's are individual charities up and down the country and are all different – where are you based? ...

*....Leicester...*

*...I don't know what it's like in Leicester. Although I am based at GOS I do some general work with Citizens Advice...You need to have time to spend with people... If they present with pain ... they should be able to begin ...*

*Pain UK is an umbrella charity with 29 member charities all about conditions that involve pain, and I am its chairman. Our remit is to encourage best practice; one thing we do is to facilitate public access to our website where they can find outlines of the key areas where the CME and the CAB can help.*

*When people are having their sickness benefits questioned they go through an enormous amount of stress. Their pain and depression get worse, they get panic attacks and the whole clinical situation deteriorates. If someone has been off sick for any reason they only have a 5% chance of ever returning to work - almost never – and the pressure is “get a job” ... it's not going to happen. There are no jobs and they are not employable...*

*... it's got to be the right kind of work.*

*We're talking about sticking plaster. If you go back to 1994 when the original CSAG (Clinical Standards Advisory Group) report on management of back pain came out, it had an economic evaluation which said it would be cost neutral to implement. But it never happened. In the late 90's (or more recently) we had a disability adviser come into our clinic ... but it never got off the ground ...*

*It was somewhat limited in that because he was a disability adviser that's what he was authorised to talk about and some more general advice about benefits would have been more helpful ... but it meant that some of our patients could get help from one place and didn't have to go from here to there – for the job centre for one thing and disability advice for something else. For patients who fell into that category it was incredibly helpful but we got to the point where we didn't have enough patients to make it worthwhile for him to keep coming to the hospital. If we could have had more generic advice it might have been more helpful. We do have an OT who is very good at dealing with housing problems but ...*

*It needs to be recognised on high that instead of putting things on one side we need to have a proper strategy built into the system ...*

*A number of years ago somebody came to talk about benefits and up until then we had quite good outcomes from our PMP. However this person said "if any of you can walk more than 50 metres whether you are fit for work or not" ... after that nobody could walk more than 50 metres!*

*Regarding the well-known statistic that only 5% of the people who have been off work for some time will ever work again, I think part of the problem is that when you have been off work for a long time life has crumbled around you. That's a common experience for people who go on benefits. Let's be really clear: living on benefits is not fun; you can survive, you can exist on benefits, but you don't live on them. You have to gradually rebuild people's confidence. Just telling them to 'go get a job' is like asking them to jump over the Grand Canyon; they're just not going to do it, and they get into a defeatist cycle of trying and failing. Things like voluntary work and adult education - there are all sorts of baby steps that people need to take towards going back to work. That's just not acknowledged by the government. People need to be rebuilt bit by bit and that may take a year or two or more before they are ready even to take a part-time job and that may be all they are able to do to contribute to society.*

*[partly audible] Nine out of 36 patients [referred from the job centre with pain related problems in Leicester went back to work after a pain management programme ...*

*Way back in the early ninety's there was a study comparing different factors determining the outcome of chronic pain management and the one positive one that came way above all the others was getting back to work. Paul Watson did a lot of work on this. The only time I submitted a poster at the ASM was about a little survey I did of my own patients who had benefitted enough to want to return to work and the difficulties they had experienced in getting re-employed. A typical remark was "if they find out why you haven't been working for the last couple of years they don't even bother to send you an application form". I actually got a prize for that poster, although it wasn't professionally presented research like most of the others in the section, I think because the adjudicators recognised the importance of the subject matter. That was a long time ago but we don't seem to have moved on ...*

*I see this sort of problem at least once a day in my practice - the frustration is there ... We have these sick notes which make me laugh... Take somebody working in the meat factory round the corner: all they do all day is taking turkeys out of a crate and putting them on hooks. Each turkey weighs about 20 kg; they're not trained so they get a stiff back or shoulder and have to stop working and nobody wants them back unless they can do their job. These people who are on the bottom of the employment scale are abused; they are not worth anything as they are completely replaceable. So if I tell them that they should report for work on Monday they immediately say - and have taught me in no uncertain terms - that unless I can do that job again I shouldn't turn up'.*

*The other problem is that struggling with this is increasing their stress and you then find you haven't anywhere else for them to go. They want to work because they need the money but they can't. It's very rare to see people who really want to mangle - barely one or two a year - and they can see that I am unsympathetic and don't come again! But somewhere down the line they may get a lawyer or someone ... But*

*thankfully these are very rare. But there is an ingrained prejudice that it may be encouraging this sort of thing to give people access into the system. There is a difference between chronic and acute illness in this context. It is very rare to see malingering in someone who has just run into a wall ... maybe they have private insurance ... but that's usually as far as it goes. But with chronic conditions people are frustrated because they haven't got the access, and some of these people malingering because they only wish to get help. So I can see their dilemma, and I think that part of this problem is created by the system.*

*You have to be careful what you wish for. We [in New Zealand] have the Accident Compensation scheme. It sounds wonderful: a person gets injured at work and he gets benefits and gets looked after. But there are caveats all along: you have to do their back to work programme but they get it all back to front: they do the programme and then when it fails they go from one doctor to another and everybody says something different. It's imposed on them and not their choice. They are supposedly supported and supposed to go from light duties and build up slowly on the hours, but if they haven't managed this within a certain time the employers' lawyers get involved ... it's just a total mess. And when they fail in that system they come to us.*

*I see a lot of patients in East Anglia who come from the meat or chicken factories (it's enough to make you a vegetarian just talking to them!). The Brits won't work in these factories so they are mainly migrants: Portuguese, Estonians, Russians, etc. They injure themselves at work and now of course they are in the benefit system. And who doesn't like migrants in the benefit system? The whole thing has acquired a complexity because we are not addressing it at a high enough level – people aren't getting to grips with it.*

*What we need is a centre where people get their pain management, they get help to get the right benefits – everything co-ordinated ...*

*... a proper, truly multidisciplinary service...*

*If you are an employer looking at someone's CV and they have a ten year gap where they haven't worked and you've got 30 people in the line wanting the job what would you do? I know in my practice with three doctors and eight staff we can't really afford to have someone on a long-term sick. A company like Bernard Matthews has slack in the system but the small partnership ... and then somebody else wants maternity leave, so the rest of the staff are all buzzing around doing extra time so ... The only person I heard of who had a twenty year gap in his CV and got a top job was George W. Bush!*

*Does anyone know if there are any pain services in the country with social workers on the team? I understand that there are social workers active within IASP. Our discussion has convinced me that they should be an essential part of any pain service.*

*It strikes me that what Matthew is talking about belongs to that hierarchy of diagnosis that we were talking about yesterday and this is clearly another level that needs to be within our routine diagnostic spectrum.*

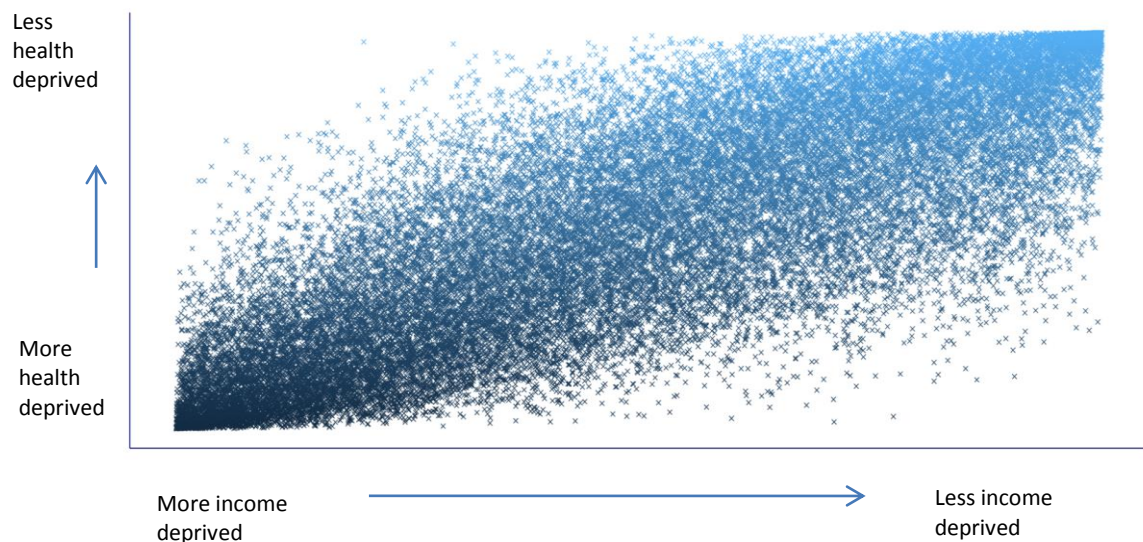


Figure 1.

A scatterplot showing the association between area-level deprivation and health. Each cross represents one neighbourhood of England (technically, lower-layer super output areas, LSOAs). The income deprivation scale (x axis) is derived from indicators such as the proportion of individuals per area receiving certain means-tested benefits. The health scale (y axis) is made up from indicators such as years of potential life lost and A&E admissions. More information can be found at:

Source: Index of Multiple Deprivation 2010

<https://www.gov.uk/government/statistics/english-indices-of-deprivation-2010>.

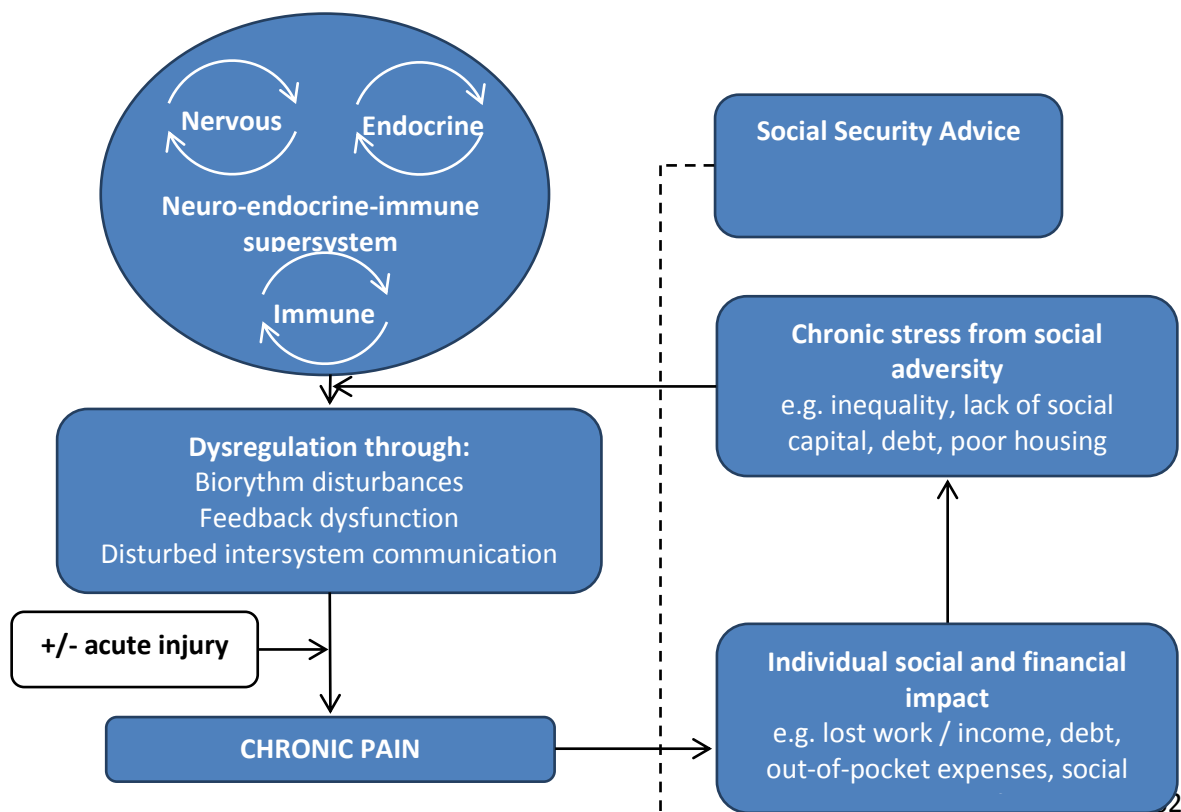


Figure 2.

A hypothetical model explaining the aetiology of the social gradient in pain. Social stressors are thought to disrupt the body's homeostasis maintaining mechanisms which can lead to chronic pain. Because chronic stressors follow a social gradient, chronic pain follows the same gradient. Social security advice may act to alleviate sources of social stress and give control back to disadvantaged individuals and their families.



## The Virtuous Patient

*Boundaries and impact in the chronic pain setting*

David Laird

I would like to share something of my story with you, and the conflict between it's being both a linear story and a chaotic one. This may reflect some of our patients' narratives in the way that things flow from one to another, or their episodic nature where it is almost like two – or many – fragmentary episodes which seem to have little relevance to each other.

I would also like to acknowledge that I stand on the shoulders of those who have gone before me: my grandmothers, both with back pain and one with trigeminal neuralgia as well, but who continued to be a very active and caring. One of them obsessed about her health and the other almost ignored it. Different patterns. I can think of consultants and other doctors who impacted on and challenged me. I can think of books which greatly influenced me. I also think of a patient who was on my ward when I was a house officer, who had oral cancer. He was dying; we had no specific treatments for him and he was in pain. I tried to organise some treatment for his pain and his mouth ulcers but this was an uphill task. He died six weeks later.

That episode was a major part of my motivation to develop an interest in pain. I felt that surely more could be done. So we learn from things that haven't gone well. It's not the events that change things but our response to those events. I think of another patient with back pain whom I saw in the clinic about four years ago, sent by her GP because he was tired of alternating Tramadol and Dihydrocodeine. I started talking with her. She had no social contact, she went out to the shops about once a week to get her groceries (this had become twice a week as she couldn't carry two bags) but apart from that she stayed in the house, watched TV, went to bed. No family who made any contact. That really upset me - here was a human being who had all the potential for enjoying life, for creating, who was virtually a prisoner in her own home.

I have been learning, especially recently, that we are not in neutral emotionally, cognitively or even medically. That patient we saw last week with a similar condition will impact on us for the next one with the same. I have been through a cycle familiar to many of you of overwork, pressure and burn-out. I had four months off work with depression, I have been on antidepressants and off them because of side effects; I have experienced relapse but struggling and holding on, trying to hide things and continuing to work. That has given me more insight into my patients but I've got to be careful of that: who am I treating when I talk to the person in the chair next to me – is it me giving advice to myself (which I then fail to take) about regular exercise and sleep hygiene and so on.

### *Virtue*

So I would like to explore the concept of the virtuous patient. I know about three years ago you explored the theme of the virtuous doctor and eudaemonia and so on. I was sparked by the Department of Anthropology at Durham University who were doing a study which involved interviewing a number of us using their grounded method. What I took out of that is that there is virtue, and I don't just mean in the

sense of good. How often do we use that word when what we actually mean is *effective*; we almost put a moral connotation to it. We think this consultation is ineffective at the moment because we are going in circles, but it may be much more useful than it appears.

I want to explore, at one level, the straightforward behaviours and consequences inherent in the doctor/patient relationship. Because of course if you are with the patient there is more than one person in the room. Is the professionalism you bring reflected – it certainly can be impacted and altered – by the other person *and their response to you*?

So what are the consequences? And is it the consequences which determine effectiveness? This is a virtuous patient for whom I will go further. Or is it because of a surgical mishap, or a failed treatment that we have given, and we are thinking we must try harder? Or do they remind us of our son or our mother and are we thinking I would want more for them? I would also like you to think at the next level about who they are as a human being. But that's much more difficult to infer.

[The audience were invited at this point to spend a minute or two compiling a mental list of patients with attributes that endear them to us and make us want to go that bit further – and somehow warm us or connect with us. Then we were asked to break up into two's and threes to share this. The process was then repeated for a list of patients that evoke negative feelings; that we find more challenging and difficult.]

[short break in recording]

... and also explore how you as professionals, with your experience - and there is a lot of expertise in this room – deal with this and have any tips like normalising (“I feel that way too”) ... you like people to wash their feet before they come! ...

### *A useful model?*

I would like to share a model with you which I found useful as a scientist and anaesthetist who twiddled knobs (and maybe as my wife says should have spent at least another week at school!) This came out of some workshops I did with Peter Maguire many years ago. The author was Nira Kfir who has recently published a book on cancer with Maurice Slevin. She was a bereavement psychologist in Israel at the time of the Yom Kippur war, and had had to deal with a lot of angry bereaved parents of dead adults and injured soldiers. She had recruited a number of post-graduate mental health workers. She gave them a simple model and said: “the people you are seeing are in crisis. It is a new situation for them; they feel alone and hopeless. Information is useful, but not ‘ – here is the Macmillan book on back cancer, go find the over whelming variety of stuff on Google ...’. It’s about drip-feeding them, about working with the patient’s words, at the level of their ideas and understanding.” Some of the patients we have identified will put ‘minimal pain 9, maximal 10, average 5’ – which illustrates that they have no understanding of numerical rating scores. Information has to be drip-fed and misinformation corrected: the ‘crumbling spine’, ‘wear and tear’ (“you want me to go to the physio for *more* wear and tear?”!).

How do we deal with our patients' sense of being alone? The only thing I can give as a human being is my time: that active listening, that seeking to empathically understand where and why they are, and saying "I may not be able to relieve your pain but can we help you to cope?". There was a study in Liverpool showing that House Officers who asked people who had attempted suicide: "who cares for you? Who do you share your thoughts and feelings with?" helped them to identify somebody they could relate to after they had left hospital. This reduced re-attendance for suicide dramatically. Being with that person. We talked earlier about the Sherpa; the servant accompanier. So we need to sit on our knowledge and waive our defences.

We can address hopelessness by generating a plan with the person so they go out with something; not necessarily a prescription or an appointment for the waiting list but a plan: it might be a plan about their sleep, or just changing the way they take some medication. It may be just a start. It may be a wider plan but it is *their* plan as opposed to what you think is best for them. It has to be shared for them to take that on board. Sometimes we may get a bit frustrated; we see the answer – why don't they just *do* it – but that's our answer. And there are many things that we may not know about going on.

So: being with the person as opposed to doing things to them, and generating a plan with them - this is what I have found really helpful, and try to apply it to the patient who tries to entice me almost to collude. We have to bring them on board – we do use a bit of grooming and flattery sometimes – even with the person who exasperates me. And for me the first thing to recognise is why I am feeling this way as I am not very good at identifying my own failings.

## *Discussion*

*Regarding loneliness: I don't want to encourage dependency on the health care service and people are always looking for some sort of support.*

The person who is in with you has felt very alone. When you are actively listening, how many times do people tell you that you are the first person who has listened? We give them 40-45 minute appointments; how do we use that time? Do we let them tell their story? Do we reflect back to them, showing that we have heard what they have said? People that feel they are not heard are angry and raise their voices. And then we can ask who they share their thoughts and feelings with? Why have you held it back from your partner? – your friends? Maybe there are spiritual issues. I sometimes say to people: this sounds more than a medical issue; you have described grief and loss, and these go right to the core of you as a person. Have you anyone you can trust – a minister or a priest perhaps – you can turn to? Why wait until the next crisis like a death or bereavement. I don't want to be about: I want to be your friend and your supporter. Sometimes we do have to jump into the water and bring someone to the shore, but sometimes we jump into the water and discover that our role is to hold them there until someone else can take them, or to swim with them and show them how.

But does just one intervention make a difference? I think it's a number of iterative processes.

*In Liverpool there is a charity alongside the pain clinic called Smile, and they will make you a cup of tea and chat to you in the waiting room and also act as an ongoing support group. One of the things that I have picked up from other pain patients is that when you come away from a pain clinic or a pain management course you just fall off a cliff. How do create a system which provides ongoing support? Patient groups like Smile could be one way.*

*Another thing you touched on reminded me that I have never heard of a pain clinic that ties up with a sleep clinic, because it is so integral... One of the things that I did independently was to attend a sleep clinic because I also had sleep apnoea and this totally changed how I perceived and experienced pain.*

I think patient support groups can be a double-edged sword. I have experience of their becoming quite political with strong characters seeing them as their fiefdom and they can become symptom maintenance groups. One of our pain management groups spontaneously generated a Facebook page for themselves and have kept that going. We run a seven week programme with a six-month follow-up. I have worked with a local College of Further Education and encouraged graduates from our programme to go into further education. But I think that more integration with normality like work is almost better than a support group. And it's also about families, because if that person starts changing and becomes more able how ...

*I went to our local cancer charity for a day and one thing that struck me was that you were welcomed into a family: a cup of tea and some food, and there was always someone there who was interested in you. I couldn't help comparing this with the pain clinic where they used to have a lovely receptionist, and whatever her workload she would still give the people coming through the door a lovely big smile. She was replaced by a big blue screen with YES in green and NO in red. And as they came through the door the first thing they saw was the word NO. My point is that by having people come into a friendly environment ... and think a little about things like - is this desk a barrier or low and welcoming? ... and a smiling greeting ... I used to have patients given an outcome sheet which said please take this ticket to the appointments desk and earn yourself a smile on the way out. And if only they could have had a waiting area where the chairs weren't in rows and you could be served a cup of tea by a person rather than a machine in the corner ... I think this sort of thing is so important...*

That aspect of patient experience is going up the agenda. The story is told about the British Rail Consultancy who employed a firm to give them advice as to how to improve in their early days. They organised a meeting with the Chief Executive of BR and a few others. They were ushered into a small dingy room and a receptionist came in about 15 minutes later and said: "he'll be another ten minutes. I brought you some sandwiches" and produced some dry ones that had been made the day before, and some lukewarm tea. And the chap eventually came in and said "Well, I hope you have experienced some of your own medicine – that's what you give ...."! Maybe we need to be doing that.

*In the last four months my trust has been in the process of removing the receptionists. Every patient gets a letter with a bar code and when they present this I get a message on my computer saying the patient has arrived. We too had a lovely receptionist ... and every patient is complaining that there is no one ...*

# Some Ethical Dilemmas in Public Health: how can we value life and health fairly?

Peter Bennett

I am part of a small analytical team in the Department of Health that looks at interventions in public health. My day-to-day stuff is primarily to do with cost effectiveness of things done at a population level so I never encounter the problems 'of the patient in front of me'. However what does concern me is the allocation of resources: money and other stuff – the £200bn or so that goes into the health budget - and whether this is being used as effectively as possible. I head a team of research analysts, economists and statisticians and a lot of what I have to say is about health economics. I have to declare that I am not nor have I been a member of the economists' profession; nevertheless working alongside them I have come to respect them more than I expected to.

## *The Challenges*

So how are we to use all this money to best effect? The sorts of decisions that I would like to think our team has some influence on in practice are things like purchase of vaccines, vaccination programmes, preparedness for emergencies – anything from pandemic flu downwards - and other things to do with infective disease including hospital associated infections. Then there is all the lifestyle stuff: all the things that are fun like smoking, drinking, sex, drugs and rock and roll; what is there to do about them as central government and what is it worth trying to do. I am going to talk about costs and the only costs that matter in this game are opportunity costs. It's not actually the pounds that matter but what else you could have done with those pounds if you hadn't spent it on this. So what we end up with is a lot of decisions that do effect life and death at a population level, and which rest on ethical considerations. They may be dressed up as technical ones but are at heart a matter of ethics, and if we get it wrong, we do so in a way that skews the whole system. It's not like getting it wrong with an individual patient; it's a question of getting it wrong systematically so that the whole thing doesn't work as well as it could have done.

If there is a tyranny here, it's a tyranny of classification: not individual diagnoses, but the way we classify people and the things they may or may not suffer from, including what were referred to earlier as protodiseases, and shared risk factors, for example those shared by the obese as a group.

## *The ethical dilemmas*

I would like to give you a taster of what we do and the ethical judgements that underpin that. It is a world that will probably be mysterious and distasteful to some of you because it is a world of measurement and quantification, including quantifying the unquantifiable, but it has to be. By the time I have finished it may be no less distasteful but I hope it may be slightly less mysterious. You may all have some acquaintance with the wonderful concept of a QALY (Quality adjusted life year). I want to achieve three things: first a glimpse into the world of the QALY and its underlying ethics; secondly to share the ethical decisions that underpin using that

particular metric or anything like it to prioritise resources; and thirdly I want to share a couple of ethical dilemmas with you which I am currently working on. The two specific dilemmas I will come to at the end are firstly how to value the avoidance of harm - that's an old chestnut: is harm to be valued differently from failure to do good, and if so on what ethical basis, and to pose the question: how much more. The second is how to value lives that are already disadvantaged in some way. Do you value the life of someone who is disabled, in a wheelchair and in chronic pain as highly as someone who is not, and what do you mean by 'highly' in that context. There are some really difficult dilemmas around that.

The one thing I am not going to talk about is uncertainty about the effectiveness of things. A lot of what we do, leaving aside cost for the moment, is assessing the evidence from RCT's etc. as to whether something works or not, and there are huge questions around how much good in terms of improvement of health something is actually going to do. That's a different talk. It's the other bit of the equation I'm interested in: suppose you know how much good something is going to do versus how much good some other way of using the same resources is going to do.

How do you try to value peoples' health and wellbeing? To go back a step, the most fundamental question is how do you value a life? That's something philosophers have long grappled with but on the whole haven't been putting a pound sign on the answer. But economists have - I suggest because you have to. If anyone disagrees with this I shall ask what do you do instead. The way it used to be done in the dark ages up to the 1980's was to say if someone dies in an accident, for instance, you have to look at what their salary would have been if they had lived to a normal retirement age. So things were based on that sort of economics: that somebody's worth would be measured by market value and how much they could have earned. So, for example, if you were looking at improvements to transport safety (which is where a lot of this work originated) and how you value reduction of road fatalities, that was all based on markets and salaries, and you had to know a lot about the individual. It had lots of pernicious consequences for any of us who were concerned with fairness in any sense. It was entirely dependent on how much the lawyer in any particular case could make. Someone who could have gone on to be a brain surgeon or a pain researcher who would either have earned an awful lot; or if you want to generalise the argument, would have done a tremendous amount of good in the world which is so much poorer a place because they died, whereas poor old Joe Soap who didn't earn very much or do anything remarkable - how much was he worth? You had to be very careful not to assign people who are past retirement age a negative value, but all they do is draw a pension... All pretty pernicious.

The breakthrough came by economists and political scientists saying 'if you actually want to find out what it's worth paying for a reduction in risk you should actually ask the people whose lives are going to be put at risk. It should be their collective judgement. And that is where the modern concept of willingness to pay came in. You ask the population: suppose you have a safety measure which could reduce your risk of death by, let's say, one in a million, how much would you be prepared to pay to reduce this risk; given a veil of ignorance because you don't know who is the one person in a million of the population who is going to be killed but it *could be you*. And the radical egalitarian bit is that you then take the average. We say that what we are interested in here is society's average willingness to pay, and whether we take that value as a society and say we don't care who it is, be he brain surgeon or dustman, we value all those lives, in this sense, equally. That's quite a radical

departure. The answer used to be about a million, so if you asked a million of the population about a one in a million reduction in risk they used to be prepared to pay about a pound for it on average – the rich more for more and the poor less for less. It's now gone up; it's now about two and a bit million. For example the people that do cost benefit analysis for transport schemes value reduction in road deaths by two and a bit million each.

### *Quality of Life*

But obviously what we are interested in, though, is not just life but quality of life. So what you then try to investigate at the population level is peoples' willingness to pay for a Quality Adjusted Life Year. We want to know what peoples' trade-offs would be between a life in 'perfect' health (or as good as you could imagine it to be) and various other health states. There are various ways in which you can describe the other health states and the way it is done at the moment is a wonderful thing called EQ-5D which is a five-dimensional state of health survey instrument. I guess they are reasonable common-sense dimensions. They are:

- Mobility: the extent to which you can get about versus, in the worst case, being bed-bound
- Self-care: can you actually look after yourself
- Usual activities: whatever these may be, whether work, sport or leisure – the extent to which you can do whatever you normally want to do
- Pain and discomfort
- Anxiety and depression

I haven't time to go through the details but there are things called standard gambles with risks of death and time trade-offs (how much time you would be prepared to spend in one state as compared with another) and you get the collective view of how much people will value those states as better or worse along those five dimensions; (there is a substantial cottage industry engaged in trying to elicit those kinds of judgements from the population) and you end up with a QALY. And what that gives you in the magical world of economics is a common currency. So if you want to measure how much good you are doing with an immunisation programme or something to cut down on smoking, or introducing a new drug, (and NICE uses the same method) you can work out how many QALY's you are gaining and how much it is costing. In a perfectly rational world, on this model at least, what you would do is to order all the things you could do in terms of cost per QALY, and then you tick them all off from the top and go down to the bottom until you run out of money (in terms of the health budget until you run out of £200bn.) So you would have done as much good as it was possible to do given the resources at your disposal.

That all sounds very nice, but what are the problems and dilemmas that it involves? Firstly, it's obviously crude; it's population based and it doesn't take any account of individual variability. So even taking for example survival versus absence of pain – we would all like to survive longer and all prefer not to be in pain – but Mrs Smith might actually be prepared to put up with a huge amount of pain because she wants to survive, perhaps to see her grandchildren grow up, whereas Mr Jones actually would be prepared to give up on life. So (as we all know) the trade-offs between individuals may be quite different, and all you can do at the population level is an accrued average - and none of us is average. The challenge there is if you don't do that, what else do you do? If you've got a patient in front of you, you may do

something different, but if you haven't, and all you have is a population in front of you, what else do you do?

There is an ethical controversy about ageism: the older we get, the fewer QALY'S we have to lose. I don't mind that – as someone of a comparatively advanced age, I think saving my life aged 20 would have been more worthwhile than saving it now. The alternative is the implication that the last 43 years of my life have been entirely worthless. More philosophically, what you are doing is asking people hypothetical questions rather than asking the people who are actually suffering the conditions. We are asking people to imagine what it would be like to go from, let's say, full mobility to wheelchair state rather than asking the people who are in that state how they value it as compared to full mobility. There is a nice saying (which is unattributed) that nothing in life is quite as important as you think it is while you are thinking about it. So do people imagine it being worse than it really is? Does it systematically run one way or the other? There is an alternative: there was a very interesting paper in the BMJ, *How does NICE value health*, by Paul Dolan. He is suggesting that instead of asking a hypothetical question you should assess value according to the judgement of the people who are in the state that you are trying to value, and that you should use subjective wellbeing. That is one alternative; it has problems: just to mention one, it doesn't necessarily give you answers that you would like around this room. Pain and discomfort get less weight than if you value it in advance, as it were. Why is that? It's almost certainly because people come to terms with and adapt to the state they are in. Now there's an ethical dilemma: should you value reduction of pain less because people are living with it, adapt to it, are resilient and self-managing it? Or is that somehow ethically perverse?

*You used four phrases that are not synonymous: living with it; self-managing; adapting; and resilient. Because people are not actively complaining about it doesn't actually mean to say that they are managing.*

It doesn't, but something is going on which if you ask people after the event they don't appear to rate it as bad as when you ask before the event. I don't know what is going on. And again that is taking an overall view – some individuals will say I thought I could manage this but I can't and it's absolutely terrible and I would rather be dead. But as a collective it seems that people self-report more positively than they think they would have done. All I am saying is the alternative of asking people in those health states how they feel about it produces a different answer which may be counterintuitive and even unwelcome. If you want people to pay a lot of attention to pain and discomfort you are apparently better off with the existing system.

The temptation here is to say, OK, you're asking someone who has had an experience – let's take pain as an example – to make a trade-off between relief and other goods; but if you ask someone who is currently suffering they will tell you it's a heck of a lot more complicated than that. But the research seems to show that that argument doesn't work. If anything people anticipating the suffering of pain seem to place a higher value on avoiding it than the people who actually are. It's extremely counterintuitive.

*If you read Seligman on how people adjust to disastrous events and to amazingly wonderful ones like losing a leg or winning the lottery, within a couple of years they have gravitated back to their average ...*



... Nothing is as good or as bad as you think it's going to be ...

*In my experience of people doing advanced directives most of those would think that they wouldn't want intervention at the end, but I have seen people who are now very disabled and those boundaries have moved and keep moving and they are prepared to put up with a dreadful quality of life ...*

... There is a philosophical point that it would be better to base these judgements on real experience rather than hypothetical experience. My only health warning is that won't necessarily give you the answers that you think.

*I am really interested in this as I did a piece of work with Professor Rachel Elliott, the Lord Trent Professor of Medicine in the University of Nottingham, to evaluate the new medicine service in community pharmacy and to work out its cost/value. She introduced me to Markov models<sup>3</sup> and we looked at four common conditions. I was always concerned about how blunt an instrument Markov is for measuring health states; you miss all the soft stuff about someone's life. If you go back to my story, someone could put a cost on all the benefits I received, how much the treasury lost in tax receipts by me not working, how much my use of the health service cost. That goes for anyone who isn't working or not working to their full potential. My problem with Markov is that it just looks at the health state and costs and it needs some softer qualitative research. That doesn't seem to happen. I came across this before when the expert patient programme was being evaluated for government funding when again they were looking at very blunt measures and not at the whole person and the people around them: carers and other family members. They weren't looking at the whole effect that somebody has on the local and national economy.*

This is sort of an ethical dilemma. We have gone from the dark ages of only valuing somebody according to their earnings to saying we are only going to count their intrinsic value to themselves, as it were. A QALY may be egalitarian but it is also a very individualistic measure. What about wider society and societal costs and benefits? There is a move within this whole area to say actually we should not just be looking at QALY'S but also at wider societal benefits and costs; not just at the direct health costs, which are in the model, but also costs in terms of time, caring, whether we are improving the health of somebody so they will need less care (that's in the model) but also whether they can contribute care to other members of the family...

*... Why does NICE put a maximum amount on that? - when they are reviewing a new treatment it's strange that they don't take other factors into account.*

There is a disagreement between NICE and the Department of Health about that and I'm actually on a group which is discussing this. There are two senses here: one is you can take the comparatively narrow view that what it is that you are about is maximizing health, given a constrained health budget. That tends to be NICE's view. Or you can take the view that ideally you should be doing a complete cost-benefit analysis including not just health but wellbeing and all the societal stuff. NICE, on the whole, doesn't like the societal stuff. The DOH, on the whole, tends to argue that we

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<sup>3</sup> In probability theory, a Markov model is a stochastic model used to model randomly changing systems where it is assumed that future states depend only on the present state and not on the sequence of events that preceded it. (*Wikipedia*)

should be including more of this. The challenge is doing this without going back to the dark ages of saying we are only going to value somebody according to how much good they can do for the economy.

*With the various campaigns about assisted suicide one of my concerns has been that older people will feel pressured to shuffle off and (a) leave an endowment for their children and (b) not rack up costs to the state or for themselves. Although at the moment assisted suicide is talked about only for people with terminal diagnoses in the last six months of life, my concern is that in our society and our culture in the UK it could very easily slip into "I'm just going to get out of everyone's way".*

*If it was a 20-year old doing that we would not accept it but with an 80-year-old we kind of go "it's your decision ....". QALY'S do come into it. It's a slippery slope. It is, although I have not yet seen anyone apply arguments about societal benefits to assisted suicide - but clearly you could. All it would do would be to formalise the sorts of thoughts that you have described ... I can imagine myself thinking at some time in the future: am I a burden? – am I contributing anything? This brings us into the classic question of how much you value autonomy. Personally I value it very strongly: if someone has a fixed and firm intention that they want to end their lives that should be their choice. But that has nothing to do with this.*

### *Valuing QALY's*

So how much is a QALY worth? The answer is you do a cost benefit analysis, leaving out the wider societal stuff for the moment, and it's quite a lot: about £60,000, which is more than most people earn. That is the value of a year of perfect health or two years of 50% health or whatever multiple you want to have. But can we afford it? – no, we can't. If you're looking at it in terms of cost-effectiveness within a limited budget, at what price can the NHS actually 'purchase' QALY's? This is where you get to the lower threshold which has until now been NICE's £20-30,000 per QALY for efficacy of new drugs. It's not necessarily a strict threshold but it is becoming increasingly like one and you need better and better arguments to go above it. And the latest research suggests it's lower than that, and eventually the NHS purchases QALY's at about £15,000 each. So if you approve a new vaccination programme, however wonderful it is, you really ought to be getting QALY's at £15,000 *and no more* because otherwise you may be displacing other stuff. You don't know exactly what it is you are displacing. If you don't implement something you know who the losers are; if you do implement it and you use up resources you know there is a loser somewhere in the system because you know the system is buying somewhere at about £15,000 a piece. You don't necessarily know who they are; they are hidden - that's a problem in itself.

So as a health administrator you ought not to be willing to pay more than about £15,000 per QALY if that is all you are interested in, all things being equal. But other things are never equal. There is some quite good evidence to suggest that if you want to follow society's preferences they will weight QALY's a bit more for more severe things and add more at the extreme suffering end. People will want you to weight things that happen to children higher; it will be higher anyway because they have more QALY's to use but over and above that. So things are never strictly equal.

## *Specific dilemmas*

I will leave you with a couple of specific dilemmas. Firstly, avoidance of harm. Something like a blood transfusion that carries an infection; you actually harm somebody, you don't just fail to do them good. How should you value that in cost per QALY terms? Let's suppose you can measure the amount of harm you have done in terms of health states – let's say you have infected them with AIDS or Hepatitis C or something horrible – and you know on average what the consequences of that will be. How much are you prepared to pay as a decision maker to avoid doing harm, and is it different from failure to do good? There is quite a lot of research on that. If you ask people if they are willing to accept values: how much would you be willing to accept in order to have this risk increased rather than how much would you pay to have it reduced, you get a very different answer. It's about seven times bigger. So when and under what circumstances should you use this much bigger willingness to accept value rather than just willingness to pay? In some instances, such as the infected blood example, the issue is relatively clear cut. But if you are just reconfiguring services, even though you are reconfiguring them very much for the better, there are always going to be some losers. And if you always value the losers as seven times as great as the gainers, you are not doing the best you can for the population as a whole. So under what circumstances do you make that differential? What are the limits of sheer bad luck versus somebody who has actually been harmed in some unacceptable way? That gets you into the concept of entitlement and suggests that safety is an entitlement but access to services is not. Why, how and where do you draw the line?

The second dilemma, which is causing us a lot of headache at the moment, concerns valuation of lives in poor health. So is a QALY the right measure or should lives count equally? Under Policy A you expect to save the lives of 100 people who would live on average another 40 years. So you are saving the lives of healthy young adults. With Policy B, which for the sake of argument costs exactly the same, you would expect to save the lives of 100 people who would live on average one year. On the whole, I would suspect, here we would have little difficulty in choosing Policy A; even if the people are young rather than elderly we wouldn't think it was ageist if we devoted resources to the people who are going to live 40 years rather than one. (I have deliberately chosen an extreme example.) A much more difficult one, though, is if we've not got two groups with a differential in longevity but in quality of life. Policy A would save the lives of 100 people who would on average live in fair health for another ten years. (Let's say 0.8 QALY's.) Under Policy B you would save the lives of 100 people who would on average live for another ten years in poor health (say 0.4 QALY's.) Do you reckon everybody's life is worth the same, or do you do it by QALY value? That gets you in to all sorts of equity and antidiscrimination issues that we are currently grappling with. Does choosing one of these above the other discriminate against the disabled? Someone in a wheelchair, for example? Suppose they were morbidly obese? I might seem very nice to say OK, we're not going to discriminate, we're not going to do the QALY calculation, we just want to save lives. But then you come to Policy C which is to improve the quality of life for 100 people from 0.4 to 0.8. If you believe A and B are the same in terms of their value, then C must be definition be worth nothing. We are currently grappling with the question of how you manage, in one sense, to count the lives of people regardless of their level of health or disability as equal in one sense without devaluing things that you could do to actually

improve their quality of life; and how do make those things add up: not only morally but somehow, in our world, arithmetically.

And with that little conundrum I will leave you.

# Fuzzy Edges

Willy Notcutt

I have been a warm-up act at a few conferences when it was clear that they wanted someone to liven things up before they got into the seriously heavy duty stuff which is usually pain physiology in the morning. Or you can have the graveyard slot after lunch, or you can come on after someone has given a 45 minute lecture on NSAIDs to resurrect people ... and then you can be the final speaker: are you going to be the star turn to keep people there till the last minute or are you just the filler while they all slip away? But you have the great risk and problem in our meetings as I have is that everything that could be said has already been said more eloquently over the previous two and a half days. So now I am the warm-down act, and will leave you with some ruminations.

I thought I would use a Tom Lehrer song:

Plagiarise, Plagiarise, let no-one else's work evade your eyes....

(but not the next line which is be sure to call it original research (!) as will be apparent from the next bit.)

So what about fuzzy edges? If we look at the coastline of Britain and measure it one way (round the sticky-out bits) it comes to approximately 2400 km but if you stick closely to the shoreline it measures some 3400 km. The more detail you include the more difficult and complex it is to measure. How on earth do we measure some of the things we are doing? In the Google Consultants Newsgroup, Nick Hacking was reflecting on his time as a clinical director and recommended avoiding absolute rules like the plague as unforeseen consequences lurk at every turn; to try to be as fuzzy and vague as possible; to tell management on the one hand what they want to hear and to give colleagues the reassurance that they should still do the right thing. He cited the example of Human Resources who wanted to identify breaks in all-day theatre lists so that anaesthetists could be guaranteed time when they could eat and relax. HR were equally keen that they should not be paid for these breaks! The reality is that if you tell an employee that he has to stop for 30 minutes, and that there is a 30 minute period in the day when he is "on his own time" you will get people who (not unreasonably) insist on stopping work for 30 minutes every day, even when the morning list has over-run. Have you ever tried to get a theatre team back to work in the afternoon, after a lunch break? So Hacking went back to them and said the sensible thing would be to grab a quick sandwich between cases or break for ten minutes.

## *Guidelines, rules and fuzzy edges*

So rather than having hard and fast rules wouldn't it be better to allow things to be a bit fuzzy, and allow the people who are paid for exercising judgement, common sense and expertise, to do so?

Back in the early 90's there were still the Sir Lancelot Spratt's amongst us, surgeons who encouraged their patients to regard them as gods and behaved like them, who were an absolute nightmare, and some of their outcomes not very good. Undoubtedly there were bad practices, detrimental to patient care, which lurked in amongst the positive aspects of unfettered clinical freedom and no-one should mourn their passing. But from then on, rules, paradigms, pathways, protocols and guidelines started to become more and more influential. The politicians wanted a health service which could be controlled, and to that end emasculate the doctors and nurses. And then we had the scandals of the Bristol heart surgeons [who concealed their poor results], the Alder Hey pathologist [who stored dead babies' organs without the parents' knowledge or consent] and the case of Harold Shipman. The nearest GP practice to Harold Shipman realised that there was a problem before anyone else and twice alerted the police and the coroner – but were ignored. Nevertheless, the case of Shipman, was seized upon, not as an example of murder, but as an example of how medical self-regulation was inadequate.

Now we are in a situation where everything must have clear, tight, rules; everything must be organised, everything open. Everything can be resolved with binary logic, 360 degree feedback, reflection, appraisal, revalidation, performance indicators etc. We are getting hidebound by rules which try to define every last bit that we do. I have stopped doing epidurals because it was decreed from on high that steroid epidurals should not be done without ultrasound or X-ray screening. I have done thousands in theatre, for obstetrics and pain over the last 30 years (with just one total spinal in my very early days), but the system is so rigid and makes no allowances for someone who is pretty experienced whose patients seemed pretty content with my efforts ... so I decided to stop doing them.

I have recently been reading (and re-reading as I have found some of it a struggle to understand) the book *How (not) to speak of God* by Peter Rollins. It is difficult but worth struggling with and trying to understand what he means by a/theism and a/theistic. When he talked about fundamentalism it occurred to me that we are encountering the fundamentalism of the rulebook that we are obliged to work with. Rollins quotes a story about the Buddha:

A disciple plucks up courage to point out to the Buddha that some of the things he taught were not in the scriptures.  
In response the Buddha replied "Then put them in".  
After an embarrassed silence the disciple spoke again.  
"May I be so bold, sir, to suggest that some of the things you teach actually contradict the scriptures?"  
To which the Buddha said without hesitation "Then I suggest you take them out".

Life is too short to be always following the rules but unfortunately we have been forced into this position.

Hacking went on to talk about assisted dying. He asked why we could not continue to preserve the sanctity of human life within our laws, without some remote and over-arching Court looking so closely at our treatments that we act to defend ourselves, rather than acting in our patients' best interests. There is an article in the latest BMJ about legal rulings on when and how to discuss 'not to resuscitate' decisions with

patients; what conversations are necessary, whether to ask for a second opinion etc.  
– trying to codify and tightly define every last bit of our practice.

Our duty of care is not just about finding a cure for the problems - we have heard the quote by Edward Trudeau but often attributed to Hippocrates “To Cure sometimes, To Relieve often, To Comfort always”. All doctors and nurses should understand the concept of palliation and supporting patients at the end of their life or caring for them when they have a chronic illness with no cure. It is not for the doctor to decide when the patient should die or whether they should live or die.

I think there is a danger in relying on legislation to usurp disinterested professional judgement that we might either deny relief to those who need it, or shorten life unnecessarily. Neither of these outcomes can be good. It is a very difficult area and this is why it should be left to doctors and patients. Fuzzy can be good.

### *Mathematics and fuzzy edges*

But we can define things to a certain extent. We see a coastline that is immediately recognised as such but the more we try to define it the more complicated it becomes. Some of you may have heard of the Mandelbrot set from mathematics. If you haven't, then click this URL: [https://en.wikipedia.org/wiki/File:Mandelbrot\\_sequence\\_new.gif](https://en.wikipedia.org/wiki/File:Mandelbrot_sequence_new.gif) . The pictures you will see are generated from the iterative application of variations of a simple formula:

$$Z_{n+1} = Z^2 + C$$

where C is a complex number including the square root of -1 – conventionally known by the symbol ‘i’. Complex numbers crop up all over maths and science even though they are a difficult concept to get our heads round. Of course this might just be fancy maths, but type “Barnsley Fern fractal” into Google Images then have a look at a Romanesco Broccoli! (or buy one!). It is identifiable as a type of cauliflower but look at the surface patterns.

Like the weather, the stock market and other chaotic systems, negligible changes in quantities, coupled with feedback, can produce both structure and unexpected chaotic effects.

As we dig into the narrative of chronic pain, layers of experiences and diagnosis are revealed, and patterns appear. Nothing though is black or white but all is shades of grey. Each stimulus triggers a further iteration within the system. The deeper we look in, the more we see.

Two or three weeks ago I developed some abnormality with my right eye which appeared first all as a big floater. It was a ring and it's still slightly a ring. The optician thinks it is a change in my vitreous humour involving syneresis (degeneration and part liquefaction of a gel). It looked like a similar pattern to the ones produced by applying the Mandelbrot sequence and I wondered whether there was a complex system at work here.

## *The tyranny of diagnosis and EBM*

A couple of stories: John Homi was the Professor of Anaesthetics at the University of the West Indies, and before that had been a GP in London. He had this schizophrenic patient who was convinced that the next door neighbour was sending electricity through the plumbing system so that every time she went to the toilet she was getting an electric shock. Having listened to the story he suggested that if she wore a pair of tennis shoes when she was on the toilet she would be all right. This worked wonderfully and she was coping well until one day he was called to her house and found the police there; she was throwing things over the garden wall at the neighbour whom she accused of shining rays into her living room and spying on her and so on. Homi went in and calmed her down with a sedative; then he went upstairs to use the toilet and got an electric shock!

A more recent one involved a patient of mine with MS, who I had known for some time, and quite severe and painful spasticity in her legs. I saw her last October; the GP had tried to treat it for a couple of months without success. I went to see her; her MS was obviously quite severe, and she mentioned that one of her legs was quite swollen. In the course of examining her I put a hand on her leg and this was the third time in my career that I have diagnosed a sarcoma of the thigh. So here again the tyranny of diagnosis led to the assumption that the cause of her pain must be what was written on the notes.

I also want to reflect on some research I have recently been involved in looking at cannabinoids, which illustrated the tyranny of evidence based medicine and statistics. The problem with statistics as it always has been is that of accurately evaluating them. If you are looking at the use of cannabinoids in multiple sclerosis you are dealing with a complex medicine which works in a multitude of ways, and a complex and infinitely variable disease with a narrative of complex symptoms. EBM and statistics will only look at one symptom and not the narrative. The outcome of this is when they look at the economics of this there are three papers and one report which suggest that it is effective, but NICE say it is not on their own evaluation. So we still have to adopt a fuzzy, pragmatic approach to try to discover if this is going to work. But the bean-counters are there looking at whichever paper they want to.

In his latest BMJ blog Richard Smith (the retired editor and a philosopher) asserts that the idea that the (sole) purpose of medicine is to diagnose, treat and cure is largely dead ([http://bit.ly/diagnose\\_dead](http://bit.ly/diagnose_dead)) (as we have been saying for the last two-and-a-half days). Where there are layers of diagnosis a narrative is often better than a label. "Because of the shift in epidemiology from patients with a single problem to those with multiple long-term conditions, treatment has become the province of patients rather than doctors ... [which has] sounded the death-knell for the usual standard medical paradigm of diagnose, treat and cure."



In 1984 a star in the constellation of Monocerotis exploded and the light illuminated the neighbouring dust clouds. I watched it expand over a few years on *Astronomy Picture of the Day* and it struck me as a good analogy for chronic pain which starts at a point but its growing complexity ripples outwards in time and space.



### *Discussion*

*I'm often reminded of the 'temperate rebel'. If you are using too much restraint the person that is caught in it will want to get out. As a clinician if you are using too much constraint or not being listened to you will do it your way which completely defeats the object. You then be alone because a good number of other colleagues do the same. That is a lot of what we experience with over-politicalisation of our environment.*

*This reminded me of the Rosenhan experiment. In the sixties the psychiatric hospitals in the US were full of people who had been there a very long time. Rosenhan joined volunteers presenting to psychiatrists claiming to have had auditory hallucinations. They were all given a diagnosis of schizophrenia and interned in psychiatric hospitals. They then had to prove that they were normal. This often proved difficult and some were not released for several weeks. They still were given the diagnosis of schizophrenia in remission and obliged to accept antipsychotic medication (which they flushed down the loo) even though it was acknowledged that this had been an experiment. That shook the psychiatric world in the USA and led to the discharge of thousands of people from hospitals because they thought they might be volunteers. This does illustrate the fuzzy edges of diagnosis.*

*Two of the patients I described yesterday fall into this category: one where I had to go out on a limb and take this seriously ill patient who refused to see anybody else and wanted me to take the risk on her behalf, and the other person with 'split personality' ...*

This is a problem of taking risk; in the past we have been prepared to take risks but the climate is getting so much worse ... Getting towards the end of a career you may be getting risk adverse ... there is this problem of the organisation trying to define everything we do ... the lawyers are in there ... and the justices deciding about CPR ...

*... we will no longer be able to practice as free professionals ...*

*... it's a worrisome thing: it affects the whole issue of interventional pain medicine.*

*[inaudible] ? new wave of doctors... dependent on guidelines finding themselves in difficult situations where there are no guidelines ...?*

*I heard of some studies with rodents where the experimenters found that if conditions in the lab were getting too hot or there were too many in the box they started*

*attacking and eating each other. I sometimes think it's like that in medicine: as the temperature goes up, rather than arguing for something completely different we end up biting each other. One of the questions I ask people who are keen for me to implement a pathway is "where does the path go?". Because with long-term conditions, unlike a diagnosis-treat-cure consultant episode, there is no defined end-point.*

*If you imagine diabetes as a pathway between primary and secondary care, a patient goes wherever they need to be given the state of their diabetes throughout their lives – it is a flexible system. It started out in the community with links to secondary care. I think that pain would fit the same model.*

*There are ethical considerations here which society should be paying attention to about how we as professionals should work in a rigidly hidebound world. An awful lot of our patients aren't typical and need untypical ways of treatment. How can you have fixed guidelines to treat them?*

*That's where Engel's work came from, isn't it? In 1977 Engel from Rochester NY published a paper on the biopsychosocial model partly as a reaction to the insurance companies who were trying to force people into biomedical boxes. When his residents went through a lot of them became internists along the East Coast of the USA. There were about two dozen of them who had been his research fellows and who wanted to propagate his teaching and developed an academy of medicine that took those notions on board. So some of these things have been and are being addressed.*

*He also published an essay on the subject and added the note that so much had already been said on the subject he was afraid that one more essay wasn't going to make any difference.*

*There is inertia in the system. Is it because society is less caring?*

*Does the medical profession collude in that inertia? There is a book by Derek Wootton called Bad Medicine: doctors doing harm since Hippocrates. He coined the term 'institutional inertia' to describe a lot of the problems and gave many examples of medicine's reluctance to take on innovative thinking.*

*We are innovative thinkers but it is management holding us back.*

*Is it management? Or are there some of our colleagues for whom management provides a convenient environment in which to operate?*

*That's a very good question. Some people do want rules and guidelines and they want them to be rigid because they feel safer that way.*