

Contents

Introduction <i>Peter Wemyss-Gorman</i>	3
Consent and deceit in pain medicine	
Moderator's Introduction <i>Paul Dieppe</i>	4
The humane lie: acceptable deceptions in the doctor-patient relationship <i>Daniel Sokol</i>	5
Consent: 'In modern law medical paternalism no longer rules' <i>Jayne Modolysnski</i>	16
The truth, the whole truth or anything but the truth? Mechanism, magic and meaning in (post-) modern medicine <i>Jeremy Swayne</i>	28
<hr/>	
Surprise – you get what you expect! What hypnosis teaches about the placebo/nocebo response <i>Michael Kell</i>	47
Images of Pain: Understanding pain related distress from the viewpoint of semiotics <i>Owen Hughes</i>	53
Painting over the Cracks: Creativity when art and medicine collide <i>Diana Brighthouse</i>	59
The Creative Arts in Palliative Care: The Art of Dying <i>Nigel Hartley</i>	64
Hope, Against the Odds <i>Christine Chisholm</i>	70
Positive Psychology <i>Wendy Callaghan</i>	76
Suffering in Silence? Persistent scar problems following Caesarian Section <i>Hubert van Griensven</i>	81
The loss of the Ethos of Care in the NHS <i>Michael Platt</i>	86
Why do we fail to relieve pain? <i>Willy Notcutt</i>	90

Contributors

Paul Dieppe: Professor of clinical education research, Peninsula Medical School, Plymouth, Devon.

Daniel Sokol: Lecturer in medical ethics and law, University of London

Jayne Molodynski: Medico-legal Adviser, Medical Protection Society, Manchester

Jeremy Swayne: GP, Scientist, Church of England Priest and Homeopath

Michael Kell: Director, Labyrinth Institute, Atlanta, Georgia, US

Owen Hughes: Consultant Psychologist, Brecon, Wales

Diana Brighouse: Retired Consultant in pain management and Psychotherapist

Nigel Hartley: Director of Supportive Care, St Christopher's Hospice, London

Christine Chisholm: Palliative Care Specialist Nurse, Romsey, Hampshire

Wendy Callaghan: Clinical Psychologist, Leeds

Hubert van Griensven: Consultant Physiotherapist, Southend, Essex

Michael Platt: Consultant in Pain Management, London

Willy Notcutt: Consultant in Pain Management and Anaesthesia, Great Yarmouth, Norfolk

Introduction

Trust has always been seen as an essential component of the doctor-patient relationship. Lack of honesty on the part of the doctor is a betrayal of that trust. Doctors must be totally honest and frank about possible problems when obtaining consent to treatment, and about the possibility of failure. The GMC insists on this, and we are warned that we depart from this standard at our peril.

This is the ideal, but is it always attainable? Is it even always desirable? Are there situations in which deceiving patients is in their best interests? Is, for instance the deliberate use of the placebo effect ever justified – bearing in mind that all treatments involve this to a greater or lesser degree, and their success is always at least partly dependent on its exploitation?

We spent the first day of the meeting struggling with these and related questions under the guidance of a lecturer in medical ethics, who argued for the acceptability of deception in certain situations, and a representative of the Medical Protection Society who warned us of its possible consequences, and of the increasingly rigid attitude of the GMC to departures from honesty in recent years.

In order to be sure of telling the truth one has to be sure what the truth is. This might seem simple enough in the context of modern scientific medicine, but we might be compelled on reflection to accept that the reductionist biomedical model is a very inadequate medium for arriving at truth in such a complex area as that of human suffering and healing. Our third speaker argued that homeopathy, which might seem to have no scientific rationale whatever but had demonstrable value in the relief of suffering in 'whole' people, suggested pursuit of a different path in the exploration of the elusive concept of truth.

The topics covered in the remainder of our time together were as usual diverse: three of the sessions were connected by the common thread of the need for imagery and art for both expressing and addressing suffering, but all reflected the need for something more than a biomedical approach to pain.

Peter Wemyss-Gorman
Secretary, Philosophy & Ethics Society Special Interest Group

Consent and deceit

Introduction

Paul Dieppe

This is really about truth – truth in the face of uncertainty. We don't ever really know what's going on in medicine and that's the key problem – we can't be certain about anything, so deceit and consent issues become paramount. The context for having these discussions now is the change from paternalistic medical practice to shared decision making.

When I qualified deceit was considered to be an essential part of medical practice. I remember my boss and mentor telling me it was a terrible mistake to tell anybody they had a serious illness because it was better for them not to know, and if challenged on this he would say that he once told a young chap that he had terminal cancer and he went out and shot himself and he never wanted this to happen again.

That was 40 years ago, things have changed and that would be considered no longer acceptable. In the time I have been practising medicine that change has occurred in a not very overt way. Consent has been much more overt: fully informed consent is assumed to be a *sine qua non* in research although there have been some interesting exceptions to that. This change has been largely driven by scandals such as the study in the States where black convicts were deliberately infected with syphilis.

Two professions have been at the forefront of the consent agenda: the *ethicists* who have been particularly concerned with the concept of respect for individual autonomy, and the *lawyers* with legislation to protect individuals from harm.

There has been a lot of discussion recently about whether it's all gone much too far: whether fully informed consent is ever possible or even whether it's a meaningful concept at all. There is a feeling that good medicine does still sometimes require deceit. Something that bothers me a lot is that the societal perspective, especially in the context of research, is in danger of being forgotten. We are so busy worrying about the individual we ignore the benefit to society that research may bring and there is a mismatch there. It is possible now with things like value of information theory to work out how much society will benefit from a piece of research but that never seems to be brought in to the perspective of ethics committees. The consent process is now so incredibly difficult to find one's way through that many clinical researchers in the UK are giving up and moving into other fields. I actually have to go to Australia to carry out the experiments I wanted to do on placebo which implies deceit. It's getting almost impossible to do research here – my last PhD student spent nearly 18 months out of his three year project getting ethics and other permissions and didn't have time left to complete the project.

Things like trust, hope and belief are important and you all know that they improve health outcomes; but I am worried that complete honesty in informed consent may undermine these, not just for patients but potentially for us doctors as well. I am concerned about this in the research context but I think this will sort itself out as there is plenty of academic discussion about it, and pressure groups, but the real worry is about routine care, where we are left a little rudderless.

The Humane Lie: Acceptable deceptions in the doctor-patient relationship

Daniel Sokol

‘There are some things like the preservation of life or the avoidance of profound suffering that are more important than telling the truth.’

The whole issue of deceit in medicine is actually very broad. I’m going to talk today about doctors deceiving patients. Patients also deceive doctors, and there’s also the issue of doctors deceiving other doctors – you want to get that x-ray quickly or you want to get the patient on that ward, so you make them out to be ideal patients; but what I mainly want to talk about is *benign deception* – doctors deceiving patients because they perceive it to be in their best interests.

Some of you may wonder: why have I spent several years thinking about this issue when it seems pretty obvious looking at the various codes of ethics what the answer is? The GMC says doctors must be ‘honest and trustworthy’. The American Medical Association is even more draconian: it says that doctors must always be honest with their patients and their colleagues and if not they should be reported to the authorities. What I want to say is that this is wrong and that it is acceptable in some cases for clinicians to lie to their patients. That’s a contentious statement and when I wrote a long article in the BMJ in 2007 not everyone was enthralled by my position. ‘Daniel Sokol’s article is deeply disturbing’ was one response, another was ‘I refuse to read this article’! And I got emails saying ‘I can’t believe this person teaches medical students’ and so on.

Doctors’ honesty has been an issue at least since the Hippocratic Corpus – in one place it says if a patient is going to die from his head wound you should tell him, but in another you should never tell a patient he has a serious illness as this will only make him worse. Plato makes an interesting parallel between a drug and a lie: if you think a drug will make a patient better then you should give it, and if you think a lie will do the same then you should tell it.

In the Middle Ages there was still discussion but the dominant view was that you shouldn’t give bad or distressing information to patients because they might take a turn for the worse. This was the dominant view in this country until 30 or 40 years ago. In the Japanese and Italian Codes of Ethics there are clauses that state that if you really think it’s going to be terrible for the patient then you may tell the relatives but not necessarily themselves. I first encountered this cultural difference a couple of years ago when I went to a rural part of India and worked with a surgeon there. The first operation I saw was an above-knee amputation in a man with diabetic gangrene. Later I mentioned to the surgeon that I was interested in truth telling and he disclosed that the patient he had operated on the day before didn’t know he was going to have his leg amputated; ‘the silly fool had refused the operation so I had to get together with his wife and we managed to trick him...’ I suspect that if you had asked the surgeon about patient autonomy he would have said ‘to hell with autonomy – my job as a surgeon is to do the best for my patients – my dominant principle is beneficence, this patient was medically unsophisticated and I had to protect him from a terrible decision.’

A real-life case

Now I want to present you with a real case, which I have oversimplified. Susan, aged 18, turned up a transplant centre wanting to donate a kidney to her father. They are very close, John has a life-threatening kidney disease and without that kidney he will die. During routine blood tests it is discovered that John is not Susan's biological father (although she can still donate a kidney to him). This happened seven or eight years ago in Canada and last month we had an almost identical case. The mother is out of the picture as they separated some time ago. I would just like to take a vote as to whether you would disclose this information... Who thinks you should...or should not? Who thinks this is a form of deception? Does it make a difference to your decision if you think it is deception? (*Audience fairly evenly divided*)

How would an ethicist go about analysing this case? One approach to medical ethics is called *the principle approach*: the two principles involved are those of *beneficence*, i.e. act in the best interest of your patient, and *non-maleficence*, i.e. don't cause net harm. In general in healthcare you take both these together. You could say that telling them would cause more harm than good overall: the patients may be psychologically distressed if they find out; the daughter might refuse to donate her kidney, which would lead to the death of her father; or the father might decline the kidney; the family unit might disintegrate; they might ask 'Why did you tell us this?' and lose trust in the medical profession.

Respect for autonomy: allowing patients to make their own decisions based on their beliefs and values may not be an issue in this situation because there is no duty to disclose here. Also this wasn't the purpose of the tests which was to establish whether or not they were compatible, which they are. You could also say that that it was a violation of the principle of autonomy but it was a justified violation. All of these principles are *prima facie* but they are not absolute and can be over-ridden by other principles.

Regarding the principle of justice: acting fairly, acting in accordance with morally acceptable laws, you could say that there is no legal or moral obligation to tell. You might want to apply a sort of *Bolam* test, and here we have a much respected body of medical opinion, and half of you decided there was no obligation to tell.

So these are the arguments for keeping it quiet. What about the arguments for telling them? You could say that in the long term you might do more good than harm. The risk of causing distress may not be sufficient justification for not telling them, as with telling people they have cancer. The risk of the daughter not donating the kidney or their father declining it though possible is very low. What if they find out later? Will they lose even more trust in the medical profession? It may be difficult for the staff to keep quiet; multidisciplinary teams are so big nowadays it is difficult to be sure someone won't spill the beans. As for respect for autonomy, the information is relevant to her decision to donate. It is also medically relevant: she is putting herself at risk. It may alter her self-concept and may affect her decision to have children if she thinks this is a genetic condition. As to justice, is there a legal or moral right to know here? I'm not sure about this, but there is an issue of consent: when Susan consents to giving her kidney, is the consent valid if she is not given this information? Do you have an obligation to put it in the notes? If you do the risk of detection is going to much higher. I would be interested to hear what a lawyer would say; the GMC say there is an obligation to keep good and accurate records.

Should you tell people that this sort of thing may be revealed when they give consent to blood tests?

We are thinking that from now on we should say that this is a rare possibility in the hope of preventing it happening again. But this was an incidental finding.

Would the situation be different if the positions were reversed – i.e. him donating to her? You are perhaps more likely to make a mature decision if you are older.

If this is your intuition...

Why tell the truth?

Why is important to tell the truth at all in life generally? One reason is that for society to function there needs to be an assumption that people are going to tell the truth. There is a truth bias, and even liars rely on the truth bias to get away with their lies. And if we are to respect people's autonomy we have to give them accurate and true information so they can make appropriate decisions. As regards to beneficence in medicine, generally it is thought that we are the best interpreters of our own interests so if you allow people to make their own choices they are more likely to make the ones that benefit them than if someone else makes them for them. This is an empirical point that most patients do want to be told the truth. Trust in the doctor-patient relationship involves an implicit promise that patients will be told the truth so they can make decisions about their care.

There is a trendy thing in medical ethics at the moment which is *virtutive* – not so much asking what is the right thing to do as focussing on the character of the doctor and asking what a virtuous physician would do. Of the various virtues a doctor is supposed to have, such as competence thoroughness and self-knowledge, nearly everyone would put honesty near the top of the list. These are all good reasons for telling the truth but the interesting thing is that in reality that although truth is the dominant position we do lie all the time. If your partner buys a dress and they can't exchange it you say you like it, or if you are invited for a meal and your hostess has spent half a day cooking this dish which tastes like feet you say it's delicious; or if you get out of the tube in London with your pocket full of change and a homeless person asks you for some you say I'm sorry I haven't any, rather than get lost. It's the same with Father Christmas and the Tooth Fairy. The philosopher David Nyberg wrote in his book *The Varnished Truth* 'It seems to me that communication absolutely free of deception of all kinds is suitable only for people who like each other very little, or don't plan to be together very long'. Most of the lies we tell are pretty trivial but some have serious consequences. I read in the paper that a teacher had been sacked because she told her class of nine-year olds that Father Christmas didn't exist. In Norman Dixon's classic book *The psychology of military incompetence*, he lists the failure to make use of deception as a component of military incompetence and cites the refusal of some British military generals in past conflicts to use surprise and deception against their enemy – 'that's just not cricket' – with catastrophic loss of life to British troops.

A few years ago I conducted a survey of doctors in Oxford. One of the questions was 'Do you think deception is used by doctors?' The results were: often: 45 per cent, occasionally: 46 per cent, rarely: 6 per cent, never: 0 per cent, don't know: 4 per cent. In reply to a later question 'How often do you use deception with patients?' The replies were: often: 1 per cent, occasionally: 25 per cent, rarely: 59 per cent, never: 14 per cent, don't know: 0 per cent. Even if this information is not very accurate it does raise the question that either there are a lot of doctors out there acting unethically or there is something wrong with the Code of Ethics. A conjurer can make a handkerchief disappear (*demonstrated by the speaker!*) which shows that that you can deceive people without saying anything and that deception isn't always morally wrong. When people think of deception they usually think of lying which is a prototypical type of deception, but there are many other ways to deceive such as gestures and nodding. It has been asked: why lie when the truth will do? I want to

make a distinction between telling the truth and being truthful; it is possible to tell the truth and still be deceptive. Bernard Williams suggests the example that the boss has been away for a week and while he's away you decide to open his mail and see what he's been up to. And when he comes back you say 'Boss – you won't believe this – someone's been opening your mail' which is perfectly true but is still a misleading and deceptive statement.

Gricean maxims and the cooperative principle

These were described by the philosopher Paul Grice in the 1970's. They are: *Quality*: saying what you think is true; *Quantity*: saying as much as is required in the circumstances; *Relevance*: the requirement to be relevant; and *Manner*: the need to be clear and avoid ambiguity. If one of these maxims is flouted then what happens is that we derive a *conversational implicature*. We use these all the time: for example, if someone asks 'Is Tesco's still open?' you may reply 'It opens tomorrow at 8am', with the inference that it must be shut now, otherwise it's irrelevant. They'd probably feel quite annoyed if they found out that it was still open, even if you said, 'but it does open tomorrow morning at 8!'

You can see how in medicine you can use this, and clinicians much prefer it to the outright lie. For example a patient asked an anaesthetist before an operation: 'Am I going to die?' The reply was "I'm not going to let you ruin my weekend" of which the conversational implicature inferred that she must be going to be all right, even if it was irrelevant. By contrast 'Someone's been opening your mail' flouts the maxim of quantity because you're not including something you ought to.

When is deception justified?

I shall be interested to hear of examples of using deception in your own practice. A common one is when someone has died to summon the relatives saying that the patient is very ill, even when they are dead already but you don't want to reveal this over the phone. 'Did my baby suffer when he died?' – You reply 'of course not' even when you know there was probably some distress, knowing that your reply may colour the rest of the parents' lives. You get some bad lab results and call the patient at home but because you don't want to tell them this over the phone you say you are getting the results tomorrow and will tell them when you see them.

An example from a PhD thesis records a real nurse's dilemma. 'I was in a Nursing Home caring for a woman who had Alzheimer's and she said: 'Oh, where is my husband?'. I'd been told she'd been a widow for 15 years. I said: 'Oh sweetie, your husband died 15 years ago' and the woman's grief was instantaneous. I felt devastated and in hindsight if that ever happens to me again, I might just say: 'He's out in the garden or he's gone away or he'll be back' only because I know that they'll forget about it in a couple of minutes. I have never forgotten about that. There are colleagues of mine who think telling the truth in this situation is an absolute requirement but to me it seems inhumane.'

But it does raise the question: is truth the supreme value? – Or are there things like the avoidance of profound suffering which are more important?

Another example is the case of a patient with a ruptured abdominal aortic aneurysm who was rushed to theatre. The Anaesthetist knows the prognosis is poor but just before the induction begins the patient asks 'I am going to be all right, aren't I doctor?' – A not uncommon scenario. What should the Anaesthetist say? Can he justifiably deceive the patient?

I asked a meeting of Anaesthetists about this and got a variety of replies. I suspect that the majority would somehow fudge it – 'We'll take good care of you' or something like that rather than 'to be honest...'

An aid to ethical decision-making

One of the reasons why my BMJ article was controversial was that my PhD supervisor at the time said 'This work is all very interesting with all the arguments for and against deception but frankly clinicians don't want all this – what they need is something they can use, so why don't you come up with something practical for clinicians', so that's when I came up with this idea of a deception flow chart which will help you decide whether a decision is morally acceptable or not. To take the example of the patient with the AAA, the first question on the flow chart is *Is your proposed action or omission deceptive?* Already we have a problem as we saw with the question about Susan: about half the people in this room thought not telling Susan was deceptive and about half thought it wasn't. So I say be harsh on yourself – if you're not sure call it deception. The next question is: *What are your justifications for the deception?* I have listed a few possible reasons: to prevent great physical/psychological harm to patient, to preserve or enhance hope, compassionate deception and where the situation is that the patient is not emotionally or cognitively equipped to cope with the truth. The second question is, *given the circumstances and your assessment of the patient's mental state, is the deception attempt likely to succeed?* It's a serious point – if you're likely to get busted, then don't do it! In the case of the AAA the patient isn't going to be conscious very long so you're probably going to get away with it. Next is: *Can the objectives be met without using deception?* I'm not sure in this case. You need quick thinking and very careful phrasing. *Will non-lying deception meet our objectives?* (E.g. we'll do our best – probably not in this case.)

There is a very old debate in moral philosophy about whether lying is worse than using a conversational implicature. Although there are different intuitions about this, generally speaking most people empirically think that lying ('I didn't open your mail') is worse than non-lying deception ('Someone has been opening your mail.') So given that fact, it is usually better to go for the latter. There is also a pragmatic reason: if you lie and you're caught, that's it, but if you use non-lying deception you can always say there must have been a misunderstanding and you can wriggle out of it.

Now we come to the important bit. *The objections to lying and non-lying deception.* Deception clearly violates one of the duties of the physician, to be honest and trustworthy. Your Code of Ethics and your professional guidelines tell you not to do it. You may also say that the patient has the right to know. And this is the most crucial thing: *Do the justifications outweigh the objections?* There is algorithm for this; you're going to have to work it out for yourself which is the most compelling. In the situation of the patient with the ruptured AAA who is going to die without immediate operation and there are no clinical alternatives, and that if you spend time explaining all this it is going to make the prognosis even worse, and that he is not going to have time to come to terms with the truth, I think the justifications for deception outweigh the objections. But this is my own view, and you may come to a different conclusion. You may think he might want to say a final prayer or pass a message to his loved ones.

You're making the implicit assumption that the patient is going to die but you don't know so my answer would be 'I'm not sure but we will do our best.'

There aren't many things that are 100% certain in medicine but you don't usually say I'm not sure...

I then have, and I acknowledge that people may disagree with my weighing, two safety checks. One is: *Would you be prepared to defend your deception or lying in a court of law or a hearing of your professional body?* In this case I think I would. The

Conclusion

So what actually happened in the situation with Susan? The transplant team decided to tell them. They were initially shocked and distressed by this but they were grateful for the staff's honesty and the transplant went ahead as planned. Interestingly, in the case that came up last month they decided not to tell them. So there are things which are genuine moral dilemmas. There are situations where there are equally compelling reasons for doing two different things. There may not necessarily be one right answer. There may only be various indefensible options.

There is one thing I want to stress: I don't want you to think that this Daniel Sokol chap goes around telling doctors they can deceive their patients willy-nilly. I think it should be exceedingly rare that you will get to the bottom of the flowchart. The norm, the standard is that you should be honest with your patients, because deceiving patients erodes trust in the doctor-patient relationship and the medical profession generally. It restricts the patient's freedom to choose autonomously and may cause more harm than good in the long term. But my main argument is although truth is very important it is not always the most important thing. There are some things like the preservation of life or the avoidance of profound suffering that are more important than telling the truth.

I want to end with a quotation from the American journalist H.R. Menken:

For every complex problem there is an answer that is clear, simple and wrong.

I've thought about the issue of truth-telling for a very long time. It's a very complex problem which is why physicians have struggled with it for thousands of years. I have come to the conclusion that the absolutist position that clinicians should always tell the truth and never, ever deceive their patients is clear, simple and wrong.

Discussion

The context in which the issue of deceit arose last year was that of the deliberate use of the placebo or context effect. Pain clinicians have traditionally spent a lot of their time doing interventions which involve sticking needles into people and freezing, burning, poisoning and stimulating things, none of which have terribly good RCT evidence that they actually do any good. The other strand was that all treatments, even the use of potent drugs, depend to a much greater extent than we've previously been willing to acknowledge on the context effect, including the attitude of the doctor, for their efficacy. So if we are desperate to make the patient better we really want to do everything we can to enhance those effects so we consciously or unconsciously try to sell our treatments which involve implying that there is much better evidence for them than there really is. Is this justifiable deceit?

I guess it's a question of degree. There comes a point when you start advocating efficacy where I think I would draw a line... It's like when as teachers we encourage students who aren't very good and I don't think there's anything wrong with that. It's very difficult to draw a line where you say 'this treatment works very well for many of my patients' and going beyond that point and saying this is the best thing since sliced bread and you start making things up.

I think you can often guess the patient's reaction and the likely effect of uncertainty. I regularly deceive about placebo. One thing that regularly occurs [in rheumatological practice] is that patients ask me about glucosamine /chondroitin which everybody thinks is wonderful but there is good evidence that it only works as a placebo and

indeed that it's no use at all. Lots of my patients say it's really helping and should I keep going with it? I usually say well I don't think it's doing you any harm...

When I worked in the West Indies some years ago the professor of surgery used to do amputations of the penis [for cancer] without telling the patients beforehand because he knew damn well that they wouldn't agree to it. Another story is one that I was involved in the days before clinical ethics committees of – to all appearances– a very attractive and beautiful woman who was known not to have a womb and was married and came in to have a small lump removed from her groin. The Urologist realised during the operation that this was in fact a rudimentary testis and she was genetically a man. The question came up: Should her husband be told? We (an ad hoc ethics committee of two at the operating table) took the decision not to tell, and the testis went into the bin, not the lab, and there was no record in the notes.

I should probably have done the same thing.

Regarding communication with and between people, psychologists have shown that 7-10 per cent is semantic knowledge, over 50 per cent is prosody or emotive language and the remainder is gathered via facial expression . Surprisingly, semantic content is the least important thing for human beings, but we spend a lot of time talking about it in the context of deception and this is not necessarily a profitable concern when it comes to regaining and maximizing the health and well-being of our patients. As with so many things, it is not what you do, but how you do it which counts in the end.

*Let me share with you how I usually discuss health issues with my patients. I am very frank with them, though I use my experience and familiarity with the patient, to determine exactly how I talk with them. Usually patients do not accurately understand nor want to understand the semantic details of what is happening to them. They want to well comforted and be given reasonable hope for some acceptable resolution in the future. I speak in a manner which is reassuring, hopeful, and upbeat as possible and use my authority as a physician to make sure they **feel** that the two of us can do what must be done! I look into their eyes and watch their facial expressions so I know how to adjust my language.*

In my medical encounters, when a patient asks me if they are going to die, I reply, 'of course you are going to die, everybody is going to die, but the question of when is unknown to all of us – even God. The issue is not when you are going to die, but what you are going to do about it – how you are going to live the remainder of your life.'

I have found that conversations are not always centred on being factually accurate – I can adjust this as needed – but about how am I going to help you. Physicians tend to be on the side of doing no harm first... a very good rule for all of us to remember. But, minimizing harm requires understanding the true needs and priorities of other human beings, something the Medical Boards, especially in America, forgot a long time ago.

Yes, some people would say that answering literally in a situation like this would be inhuman, and some would ask 'What is the truth behind that question? The truth in this situation is a request for reassurance – it's not a literal question.

When I do lumbar epidurals for nerve root pain it sometimes occurs that I can't get in. Many people would say you have a difficult back and we will get you back and do it under fluoroscopy. I don't do that: I give the injection paravertebrally where it's not going to do any harm and don't actually tell the patient I didn't get it where I intended.

I do this because there is a strong contextual effect and the patient may still get benefit.

I do the same... (Laughter, looking at the MPU speaker!)

The risk is probably less than putting it in the right place and it may work.

In this case you may benefit the patient physiologically possibly and psychologically probably...

And the downside of getting a patient worked up for a procedure and then saying I screwed up is potentially a nocebo

But if it doesn't work terribly well then you've destroyed their hope - I mean I've done it too and they are so devastated that the injection you have sold to them has done nothing then...

So what do you tell the patient with the misplaced epidural?

At the time I just say I've finished – I wouldn't lie if they asked me if I'd put it in the right place but when I see them at follow-up, if it hasn't helped I may suggest repeating the procedure... but it may have benefited them...

My experience is that it works as well or better when I've missed than when I've put it in the right place... I think the trial that needs doing is does it matter where you inject the stuff...

If that's so should you be doing the injections at all?

A moral code is developed when people get together and decide if their behaviour is acceptable... what our conscience tells us. We're not talking about a moral structure here – we all have a sense of fairness – we admire people who try to behave as their conscience tells them ... to adhere to the highest standards of behaviour...

The problem with conscience is that it can be wrong. There is the famous example of the Nazi extermination camp commandant who overslept one morning and felt dreadful because he hadn't killed his daily quota of Jews... His conscience was getting at him. So conscience isn't always a good tracker of what is morally correct – it may be of what we believe is morally right but...

It might be that he was guilty because of the rigid structure he was working under but I would argue that as doctors – you would hope that I would do what my conscience dictates based on my experience.

Another problem with conscience is that sometimes it's coloured by all kinds of bias and prejudice... There may be some clinicians who don't want to tell the patient the truth and the real reason is it's damned unpleasant – they don't want the patient crying in front of them. They may think it's their conscience that's telling them what to do but underlying this there are all sorts of less altruistic motives.

I was taught at school that conscience represents a high structure of doing good to other people and yet a lot of people take society's moral values and call that conscience... it may not feel right ... if I try to do the greatest good for everybody...

I think that's OK if someone is fundamentally morally good but I wouldn't trust Shipman's conscience for example – he may have acted in integrity within his own moral code but...

I wonder if doctors are not a bit confused.... They should be looking to move the patient on if the procedure fails, otherwise they become dependent on you when it all breaks down again and they haven't changed anything in their lives

I've given up doing injections because I think they are deceitful – I think the patients are hoping and feeling that they are going to get something they won't.

If I see a patient with a painful knee and they are desperate to be able to take part in their daughter's wedding in the next week I give them an injection and tell them it will keep them going for a couple of weeks I think that's perfectly justifiable...

Absolutely, but that's not the issue here – that's not chronic pain management.

A multidisciplinary approach is essential – there's no question that the combination of injections with physiotherapy and psychology is very helpful. And some patients do get long term relief – sometimes months.

I have patients who have had their problem for 25 years, and a few months is nothing – in fact it disrupts their adaptation

This is why it has to be combined...

To return to deception – it's a matter of context: Sometimes we need to select what we say in order to be kind. (As a pain psychologist) I can't tell patients whose life problems have become medical they have crap lives, I'm trying to nudge them into acknowledging this but I can't do this if I tell them the truth. The other thing about the benefit of truth: if people have been sustained in a biomedical model and haven't been told – look, this isn't going to do you any good unless you address these life issues you aren't going to move on, or this isn't going to work for you and you need to engage in self management.

Unless you face the elephant in the room everything else is a trivial distraction. Sometimes they need a big push, not a nudge.

There are situations where it's appropriate to be economical with the truth – some patients need nudging and some need to be confronted – it's a matter of judgment.

[Inaudible question]

I think sometimes it is too easy to say let's use deception here when a more acceptable approach would be to tell the truth in a way that ... one of the things I'm trying to promote is the idea of advance decisions and some clinicians tell me that's really difficult and they need advice on the exact wording to use. I've just written something on advance care planning before major intracranial surgery. In this situation you may have to say that you may not be able to make decisions for yourself so would you like someone to make decisions for you etc. but there are some neurosurgeons who are very resistant to this idea: they say you can't mention this as it's too distressing. I think with good communication you should be able to do it without causing unnecessary distress. Although it's inevitable that there will be some distress I think it's necessary....

.....the patient wants something from you – they are hoping for a quick fix, and you know that's not going to happen. I always tell them the truth that it is not going to cure them... but there are some patients where an injection is necessary because they are too terrified to move... And lastly can I ask Willy: if that patient had been ugly would you have come to the same decision?

That's a valid point as this does tend to affect our judgement but in this case the issue was around the destruction of a relationship so the answer is yes.

And it's reductive to say that being a woman is just a matter of genetic composition

Regarding communication: you see a patient who has had a chest X-ray and you see a shadow on it: do you say 'I think you've got a cancer' straight away? I go on what the patient asks me; the patient is anxious to know but I disclose as little as I feel comfortable with in that situation – if they ask me outright 'do I have cancer' I tell them yes but they are going to see the specialist next and they don't need any more information at this stage than they can digest. In the case of the young man with cancer ... you have to prepare them and give them the option to ask... this is the real dilemma and it's a day to day one (in general practice).

I have a current problem I would like to share with you: I have a patient who is just 18 and tomorrow she is going for a major fusion on her back and I'm seriously worried about this. There are all kinds of other reasons why she has back pain that we are trying to deal with. She came to me last week having decided that she wants to have the operation. What do you do? – do you say this will be a disaster, which I think it will be, or do you say that she should ask lots of searching and relevant questions of the surgical team about outcomes and so forth, which is kind of fudging the issue. I think it's going to happen and I can't see any practical way I can prevent it, and I don't want to undermine...in a way which will only make this mess worse. What is in her best interests?

You've raised the interesting point that what counts as deception may depend on what you believe the role of the doctor is. If you believe this is just to lay out the options and their pro's and con's and say you choose...but if you believe that his role is partly advisory you would have to say that you wouldn't advise that particular option, and by the principle of non-maleficence, not causing net harm, withholding that may be deceptive.

It's conceivable that there may be good orthopaedic reasons I'm not aware of...

Should you communicate with the surgeon or express your misgivings to the patient?

I've taken the decision to communicate with the surgeon.

You have communicated your discomfort in a way – the patient now wonders if there are outcomes she doesn't know about

But people don't always pick up on that – sometimes we rely too much on the patient especially in some cultures where people are very reluctant to ask the doctor questions.

Consent: 'In modern law medical paternalism no longer rules'

Jayne Modolynski

'Changes in the law have become increasingly relevant and have brought consent into the frame of clinical negligence.'

Times are changing across the board in medicine with things like European working time directives. The GMC have made a number of changes since 2003. They were heavily criticised by Dame Janet Smith during the Shipman inquiry, and it was felt that there was an erosion of public trust in medical organisations. The GMC's document *Consent: Patients and Doctors making decisions together* came out in June 2008 talks about partnerships with patients. Changes in the law have become increasingly relevant and have brought consent into the frame of clinical negligence.

The GMC say we should have a partnership with patients based on good communication, openness and trust. They say that we should give the patient the information they need to make a decision: that we should present the information, and allow them to make a decision. You can give them the option that you think is correct but you cannot pressurise them into accepting your decision. You cannot make any assumptions about what the patient wants to know; every conversation about consent is different. Essentially what you tell them is about the diagnosis, and the GMC emphasise that you must tell them about any serious risks that may be part of that treatment even if they are rare. They also say that you should tell patients about more common risks which may be less serious but are more likely. We cannot ignore their guidance and in all their publications they state that if you do not follow their guidance then your registration is at risk. The GMC are increasingly involved in doctor's lives and in Manchester we see hearings everyday and interim orders involving suspension for 18 months pending the outcome of investigations. Although their guidance is difficult and can be very rigid in places it's difficult not to follow it. They are very interested in doctors' activities nowadays including even their lives outside medicine.

Part of the guidance booklet is about *capacity* – this is probably based on what you are doing already – essentially you cannot make a decision for any adult that has capacity. If they do not have capacity then you can use the best interest test. Capacity is decision specific – some people might be able to make a decision about something simple but not something more important: they have to be able to understand the information and retain it, weigh up the pro's and con's, make a decision and communicate it. You have to make every effort to help somebody make a decision including recruiting the assistance of interpreters and speech and language therapists etc. You have to take account of possible fluctuations in their capacity.

If they are deemed not to have capacity then you have to make a decision based on their *best interests*. There is extension guidance on this. It is not just their medical best interests. Where the GMC guidance is very clear about the question: *How do I know what that patient wants to know or feel is important unless I tell them?* It's easy to say based on my experience I would do X, but I have no idea of that patient's social standing or financial circumstances. You need to speak to parents, family etc. If you think the patient is going to improve they recommend 'taking the least resistance path.'

We've all encountered the patient who doesn't want to know, for instance about the spinal injection you propose to give her. The GMC say you should give them basic information so that consent is 'valid' and you still have to tell them about a needle in their back and any risks, and tell them if they do not listen to the information then their consent may not be valid. It's difficult to be sure what they mean by this as they don't go any further. But they stress that you must be satisfied that consent is valid before you undertake any examination, investigation or provide any treatment. You can delegate the obtaining of consent to somebody else but it's still your responsibility to ensure that the patient has adequate information. The GMC also say that you have to tell patients what might affect the side-effects of the outcomes including your personal risk record for certain procedures and they even say that you should suggest that if the procedure is done in another hospital there are different risks and outcomes.

Legal recourse

Why aren't we accused of assault or battery in medicine? Assault is defined as an *act that creates apprehension in another of an imminent, harmful, or offensive contact*. Battery is harmful or offensive touching of another. I shall be discussing negligence in more detail later but essentially (based on the judgement in *Chatterton v Gerson 1981*) as long as the patient is informed in broad terms it isn't battery or assault. If you put your arm out for a blood test then that's implied consent.

Negligence

'Bolam is often quoted: 'A doctor is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art'. (From the case of *Bolam v Friern Hosp Management [1957]* which involved a patient receiving ECT who wasn't given a muscle relaxant and suffered a number of fractures). He said the doctors were negligent because they hadn't told him about the risks, and that other people would have given him a muscle relaxant so he wouldn't have suffered the injury. He didn't succeed because the inquiry determined that a reasonable body of doctors would have done the same thing. Another case was that of Bolitho who was a Paediatrician involved in a case where a child suffered hypoxic cardiac arrest and brain injury. She was asked to attend (when the child had breathing problems) together with her junior whose pager was not working. She didn't attend because she was in clinic. The original judgement found that she was criminally negligent even though there was a responsible body of opinion that would not have favoured intubation at that time (and the Specialist Registrar said she would not have intubated even if she had attended) and the judge preferred the opposing opinion. This was not upheld at the House of Lords appeal, where it was said that it was not up to the judge to choose between conflicting bodies of opinion.

In order to prove negligence you have to show a breach of the duty to care, a breach of duty, and causation. The latter is where most claims of medical negligence fall down, because it is the most difficult to prove.

Consent

The case of Mrs Bold in 1988 shows how things have changed since Bolam and why consent is mandatory now. She was sterilised and at that time the risk of failure wasn't mentioned. She became pregnant and alleged negligence; at the first hearing she succeeded because the judge rejected Bolam, saying that if there was a

percentage failure rate, who were doctors to say they needn't tell the patient? On appeal the court maintained that the reasonable body of opinion had to be accepted except in exceptional circumstances, and that 'the judge was not free, as he thought, to form his own view of what warning and information ought to have been given irrespective of any body of responsible medical opinion to the contrary' – thus reinforcing Bolam.

Concerns about Bolam, and the reasons why attitudes to it are changing, are that it involves the medical profession deciding what the patient needs to know about the risks and what's important rather than the patient, which is seen as paternalistic, and doubts about the definition of a 'reasonable body' – it's not a majority. Another case was that of Mrs Pearce: in 1999 she was two weeks pregnant beyond her due date and requested induction or Caesarean Section. The known risk of stillbirth in this situation was between 0.1 and 0.2 per cent. This was refused and she went on to have a normal delivery and the child was stillborn. She argued that this was clinical negligence as she hadn't been informed of the risks. The judgement that there wasn't negligence was based on the facts of the case, mainly that the incidence of stillbirth was so low, and it was felt that even if she had been told of the risks she wouldn't have gone ahead with C section because they were so low. But the judge opined that 'If there is a significant risk which would affect the judgement of a reasonable patient, then in the normal course of events it is the responsibility of the doctor to inform the patient...', thus moving away from Bolam, from a reasonable body of doctors to what a reasonable patient might expect to know or judge what is significant.

A case that has caused quite a lot of concern in medico-legal circles is that of Mrs Chester (2004) who had back problems which had been treated conservatively, and had seen a rheumatologist, had a scan which showed disc protusions at three levels. She was referred to a Neurosurgeon. During the process of obtaining consent she said 'I've heard some horror stories about this operation' and he replied 'Don't worry, I haven't paralysed anyone yet, but you could be the first.'! She suffered *cauda equina syndrome* and permanent neurological injury. She went to court with the initial allegation was that the operation had been carried out negligently but this was not upheld. At appeal her barrister successfully argued that if she had been told of the risk of paralysis she would not have had the operation on that day. She said that she might have gone away and thought about it and asked for a second opinion. She was not saying she would never have the operation, just that she would not have had it on that day. The judge found for her. The case eventually went to the House of Lords who found for her on a majority of 3 to 2 and Lord Steyn said that 'In modern law medical paternalism no longer rules and the patient has a prima facie right to be informed by the surgeon of a small but well established risk of serious injury'

It raises the question of *omission*. In the courts an omission is essentially a deception, as in this case. Although the surgeon may have had the best intentions to put her at ease he didn't answer the question and was found negligent. We are all occasionally guilty of this sort of thing because we think it's in the patient's best interests but we have to be careful and be aware that we can be vulnerable to negligence claims. There was a case a while ago of someone who did a brachial plexus block for shoulder surgery and didn't ask the patient's occupation. It turned out that he was a concert violinist and this had to be the one case where nerve injury was sustained. The settled claim was substantial.

Conclusion

So that's the problem – it seems easy for me to make a decision about the patient in what I think is in their best interests but I can't make the decision for them without sufficient information. I must not make assumptions about the information a patient

might want or need, the clinical or other factors a patient might consider significant or a patient's level of knowledge or understanding of what is proposed. Every conversation has to be different – some patients want lots of information and some very little, and there are constraints of time, but we have to strike a balance to make sure we're not on difficult ground.

Discussion

[partly inaudible]...If you tell people bad things it doesn't necessarily have bad consequences ... but is there any evidence based medicine about consent? Is over-information beneficial in making a rational decision? In my experience most of us can't make rational decisions particularly if we're not expert in that area. There is a potential quandary of forcing a decision on the patient where it should be a team effort. Have any experiments been done on the best way to do consent?

I'm not aware of any. I agree: I was talking with a colleague the other day about pressurising patients but where does gentle persuasion fit in? How many of us at 4am discuss with the patient the pro's and con's of the best anaesthetic for them? I'm sure I'm guilty of pressurising people in this situation. And you are right, the GMC advice is not evidence based.

I'm aware of at least two strands of research on that subject. One is in the context of clinical trials where there has been extensive qualitative research done both with patients and doctors asking them about the whole process with in-depth interviews. There has been a lot of this and it basically shows that neither side knows what the hell is going on at all: doctors don't get equipoise and don't understand it – equipoise [balance of forces or interests; OED] is the basic principle of an RCT. Doctors in general are not in equipoise as they just want to get the trial done. Patients don't understand the principle of randomisation at all – there's a lot of research that shows that's all nonsense. There is another even more important issue: qualitative research done by Oonagh Corrigan who looked at the whole business of information giving in the routine clinical situation and showed that too much information is actually extremely unhelpful in decision-making. The title of her paper is Empty Ethics: the problem with informed consent [Social Health Illn. 2003 Nov; 25(7):768-92] and it shows that if you give too much information the patient just gets confused. We have a major problem here because I think the empirical research shows that the GMC guidelines are nonsense.

I'm not here to defend the GMC. But we (at the Medical Protection Society) have had a huge increase in the number of cases with the GMC – probity issues inside and outside of work. They love to add probity to the charges – that's their favourite catch-all: Are you honest? We had a judgement recently where because someone didn't admit (their error) initially and tried to defend their actions, the GMC increased their sanction to the maximum, as their initial action threw doubt on their probity. There is a quote on the GMC website which implies that they are less interested in an individual practitioner's registration than in how he and the medical profession are seen by the general public. They are very bruised and battered since the Shipman inquiry. They've had their panel taken away so they're no longer judge and jury. But the problem is that you're not likely to be referred for one single incident involving the issue of consent but if you come back they will have a list of allegations which will include all instances where you have breached their guidance. This might not be evidence based but that is the standard by which you are being assessed.

In interventional pain medicine by far the greatest risk is that of failure. But if we are completely frank about this when we obtain consent we are probably going to greatly reduce the likelihood of the procedure actually working. Does that justify not being frank?

I don't think the GMC would think it would. If there is a percentage of failure the patient should be told – if it's been quantified...

The trouble is its very subjective – people keen on doing these things do believe they are going to work otherwise they wouldn't be doing them!

And their success depends on both patient and doctor believing in them...

I wanted to ask: what is a treatment? We are supposed to fill in these forms at the first appointment so we can comply with the 18 week thing etc. We have agreed that we can stop the 18 week clock at the first appointment on the grounds that as soon as we pick the patient up from the waiting area we are starting the pain management. In terms of consent, if that's a treatment do we say – would you like to sign a form to come and talk to me again in 18 weeks? So is a treatment just a physical thing or are we talking about psychology etc. as well?

It's a matter of risk: the more serious the risk the more robust the consent procedure has to be. You can have verbal consent for some things. If you're doing something to facilitate something else like an epidural for surgery you don't need a separate consent form but you would for an epidural for pain.

(In psychological pain management) you're stirring up cans of worms that could potentially make someone jump off the bridge...

In the psychotherapy arena – certainly the psychodynamic side – it's a live issue as to whether we should be obtaining written consent for a procedure which can make someone initially much worse and potentially suicidal.

The written form isn't really worth anything except in the situation of a dispute later – if you've ticked 'sore throat' it will help your case enormously rather than relying on recollection. If your recollection and the patient's differ, the GMC and the courts will find for the patient because for him the episode was a one-off but for you it's something that happens several times a day. It's the dialogue you have with the patient that is important and what's actually discussed.

I find all this very upsetting. It strikes me that suddenly the patient is the expert and we're just the technicians. This idea of giving a patient a choice like from a menu – they can do that on the internet. The problem is it's de-professionalising us as the experts. Many patients say to me 'what would you do doctor?' because they don't have a clue. I find it all rather strange... this paternalistic attitude has been over emphasised.

Things have changed: the GMC really wasn't fit for purpose, and as so often in medicine we've gone too far the other way. The important bit is that you explore it with the patient: if they are asking you you're not pressurising them. It does sound very defensive – we were very nervous after the Chester case that it was going to open the floodgates but it hasn't happened – just one judgement.

I got quite cross the last time I went to see a doctor and he started on this nonsense about – well you could try this but it has those side-effects... and I said I know all this – just tell me what to do!

Can I ask you about the burden of proof? The situation in Germany for at least the last 20 years has that doctors have been much more nervous about consent issues than here, at least until 2004. Even if everything went completely right but there was a rare side-effect and the patient suffered, if this side-effect was not mentioned the case would be lost by the doctor. The burden of proof was with the practitioner to show that this was mentioned in informed consent and if this could not be provided the case was indefensible.

Legally here it's civil law, so it's balance of probabilities, but if it's not written down it tends to go with the patient

In Germany, for instance for endoscopy, there is an eight page document which the patient is supposed to sign – everything is in there. Even for drugs they have to sign the patient information leaflet. There is probably less prescribing as a result!

We have talked about physical and psychological harm but what about social harm? In a PMP people spend a lot of time thinking about their relationships with other people, and it's not unknown for them to go home and have significant difficulties with relationships, affairs and even divorce. Should we be telling people about this possibility? Is this a 'risk'?

If it's common it probably should be mentioned

We do – but probably not so boldly! We say it can be life-changing and this may include splits – or babies...

Their consent is implied by their continued attendance...

But they need the information...

But it's their choice...

But by the time they get to this stage they are heavily enmeshed in what you're doing...

How small a risk should we mention?

The 1 per cent isn't based on anything. Any rare but serious, like the 0.1 per cent stillbirth should be mentioned and any common

There's a total fallacy in this sort of concept of numbers. It's about risk to this patient and we get these numbers from inappropriate surveys of unrepresentative people and say this risk is X per cent but the risk for instance of a young fit mother is hugely different from an older woman – there's an intrinsic scientific nonsense in all of this. How does the legal profession handle that?

Even if it's rare but known you can quantify risk. For instance people have different dural tap rates in different populations. The main thing is mentioning it – after all what does 1 per cent mean?

People in general don't understand risk.

That's an interesting issue – maybe it's worse in America where the legal profession determine what happens in society – not just lawsuits. So with consent the driver is the legal system and the consent form is for legal purposes and nothing to do with medicine

Consent is essentially to do with protection – yours as well as the patient's...

The modus operandi of a physician, at least when they are at medical school, is to do caring. For an attorney it's mostly about making money; it doesn't mean that some guys don't go off and do civil rights and stuff like that but mostly doctors and lawyers are opposite professions, and least in America. It's interfering with good medical care which is much worse than it was 20 years ago with all its paternalism and so on. What gets me angry – and it's my fault too – is why are doctors such wusses? Why don't they tell the lawyers to f--- off?

I don't think it's as bad as that in England. We have Crown Indemnity in NHS hospitals. The main worry here is the GMC; you can make a clinical negligence claim go away but you can't make the GMC go away – they can finish your career.

I've been involved in medico-legal work in Britain and Canada and I think it's just as bad in both. My experience on advising the MDU and its equivalent in Canada is that the effect on the doctor is totally devastating - it doesn't matter if he wins or loses the process is so destructive – both claims, which are much commoner, and the GMC. The cases drag on for years and most people even if they come out clean do not return to the kind of practice they had before.

Is that not just the catastrophic cases? – *not at all* – most of the claims involve GP's who are likely to have several in the course of a career.

I got a letter from the GMC about a complaint from a private patient to whom I had given a successful epidural for labour. The obstetrician confirmed that she just didn't want to pay her fee. I was investigated for 12 months – they wrote to everywhere I worked – and got a clean bill of health at the end...

We too have doctors that have never gone back where the GMC is involved, but not with claims, most of which aren't contested.

There has been a massive increase in the number of nurses being referred. We have lawyers come and talk to us in post-registration training and take us through the process who tell us that we may have this experience once or twice in a career and for doctors it's 4-6 times on average....

...it isn't quite as bad as that but it is on the increase...

...so is there any preparation for doctors?

We do give lectures to doctors and students. Dental students are encouraged to attend courts, but not medics – I think they should, and coroner's courts. But preparation is not universal and I think it should be.

Pain doctors are particularly vulnerable partly because we rely on a degree of deception to 'sell' our treatments but also because a lot of pain patients are quite combative. They may have a hidden agenda which is not necessarily to do with getting their pain sorted out – for instance it may be to do with validating another area

of their life. That means they are more likely to come in conflict with you and shop you to the GMC or sue you. Have you any guidance on how to square this moral/legal/ethical circle?

If there were a simple answer it would probably be wrong! One of the GMC's favourite maxims is that you have to be able to justify everything you do. So there probably isn't a right or wrong answer, and the important thing is showing that you've thought about it and documented your reasons, and you won't get in trouble with the GMC. If they are combative you have to be even more careful about documenting things, advising about risks etc, etc.

There is a Cambridge doctor with legal training whose name I have forgotten whose advice was: With this increase in frequency of claims and the impact they may have on our professional and personal lives whenever you see a patient you should have someone with you who can act as your advocate.

Yes, with awkward people you are wise to have someone, and to ask for a second opinion and so on.

What about recording? I have a claim against me by a medico-legal client; she asserts that certain things were said which were not said, so it was my written record against her recollection. It helped a little bit that she'd sued everyone else who had seen her including three lawyers and had made a complaint against the trial judge! Nonetheless the College of Physicians which is the equivalent of the GMC (in Manitoba) advised that in similar circumstances I should make an audio recording – it's now in their guidelines and I have done this since at every medico-legal consultation. The patients are offered a copy for which they have to pay.

In this country we have the Data Protection Act but in theory there's nothing wrong with that.

What does that do to your trust relationship?

This doesn't apply in the medico-legal situation.

Some people do it in clinical consultations – even as part of the therapeutic process.

I did this a few years ago, with the patients' consent, as part of the process of moving them from a biomedical perspective. It was very popular and patients liked it.

You would have to say what its purpose was and you couldn't then use it for legal purposes unless the patient had given express permission for this.

I would like Daniel [Sokol] to comment what Jayne has been telling us about the GMC etc as it does conflict with some of the things you were saying earlier.

There are some lawyers (including my father) that feel that there is a link between them and doctors because we are both dealing with people in need. But if your main priority as a clinician is to stay out of trouble with the GMC and the law you probably won't be a very good clinician. And you wouldn't be happy as you would feel your integrity was in question all the time. If your primary goal is to act in your patients' best interests I can see a conflict between that aim and trying to stay out of trouble. As to truth telling: some clinicians especially in the USA are criticised for 'truth dumping': telling patients everything possible including you might die, to avoid any risk of not giving enough information. Giving *too much* information might be seen as

deceptive, manipulative and even paternalistic. It's quite possible to deliberately bamboozle a patient by giving them so much information they haven't a clue; you are actually reducing their autonomy. Could a patient sue you for thus confusing them?

You have to give them enough information *in a way they can understand*. But the cases we see are about serious risks...

There is an article by Jones titled *Informed consent and other fairytales*. This whole consent business is just a construct of ethicists and lawyers, and in practice, do patients understand enough – who knows. But we must strive for an ideal and do it as well as we can.

Communicating, in my experience, is a lot about manipulating. This doesn't necessarily have a bad side to it – it depends on intention. The legal system is manipulative by nature especially if it's adversarial. So if the system is based on manipulation, why should physicians be held to a different standard?

I've thought a lot about manipulation – I spoke to some lawyers the other day about audience manipulation and I was quite shocked – like doctors they think they are aiming for the truth but they do manipulate quite often. One barrister described how when he was cross-examining he would ask a lot of easy questions at first and just as the witness was thinking 'I can deal with this guy' he would ask the killer question. I was talking about the job of a doctor as performance and comparing him to a magician. A skilled physician can probably manipulate the patient in any way they want by the way they present information. Although I'm not advocating doctors using the strategies of a magician to deceive, I think it's important that even subconsciously they may use certain strategies to manipulate their patient into saying yes to a certain procedure. These need not be verbal in content or even in tone – little mannerisms and so on can be very influential.

Let's move on a little and talk about evidence. There is quite a lot of evidence, which never gets mentioned in GMC documents, from research which shows that by and large patients don't understand so-called informed consent when they sign the bit of paper. To take prostate cancer as an example: no-one knows whether it's best to do surgery, radiotherapy or nothing. There have been several trials to find out which have failed because men do not consent to the trials. It was discovered that this was entirely depended on how the question was put to them. For example, what was labelled as a 'watchful waiting arm' was interpreted by patients as 'I see - you watch while I die.' Once the wording was changed quite subtly everyone gave their consent and the trial is nearing completion. You could call this coercion: they still didn't understand what they were consenting to but there was now a form of words that would subtly lead them to consent. I find that sort of data quite worrying. The other sort of data is that provided by Oonagh Corrigan, that patients she talked to said that the doctor had tried to explain everything but after a bit I didn't really understand so I thought I would go along with it anyway because he seemed a nice guy... The concept that this is a shared decision is a bit blown apart by this. So there is a lot of data around about how much doctors do use deception. A simple survey from Germany which was published recently asking doctors and nurses how often they used placebos deceitfully and about 50 per cent of doctors and 80 per cent of nurses said they did. By far the commonest condition they were doing it for was chronic pain.

So whatever the GMC tell us what we're actually doing is different, and that the ethicists' and GMC guidance is not actually meaningful anyway. I really worry about this mismatch.

I just wonder if this is an impossible circle to square. You're always going to know far more than the patient, so is it ever going to be possible to describe all the risks etc? I wonder if the GMC guidelines are too idealistic, that we can never approach this ideal and that we should be trying to define good practice in a more realistic sense.

Absolutely. I think conversations such as we have been having this morning should be opened up more and driven by common sense, and what is morally sensible.

Your point is absolutely valid but I think we must try to discover why there should be this lack of understanding: is it because of the intrinsic complexity of the procedures or is it other things. I have no doubt that a lot of the time it is other things like the junior surgeon having to obtain consent from five patients in ten minutes on the day of the operation, or doctors going automatically through a spiel. I compare this with when I used to work in a restaurant as a magician. I used to 'table hop' and use exactly the same patter for every trick. For each diner this was the first time they had heard this story and I really seemed to *mean* it which made the trick more magical and I got better tips! This is just the same for a patient who is hearing what you say for the first time even though you have said the same thing God knows how many times. There are lots of barriers and the research has to identify which of them are insurmountable, and which can be lowered or removed. This may be quite complicated.

Yes, the process needs to be explored properly, as well as the fact that so many people taking consent don't really know what they are doing. My daughter signed a consent form for a neck operation recently and found that she had consented to an operation that might make her a horse!

I wonder if in obtaining consent we may be making what the philosopher Gilbert Ryle called a category mistake. We are asking someone who is not a clinician to make a clinical judgement. For instance if you're asking a patient if he wants a spinal cord stimulator put in he says he doesn't know – what are the risks? And you say there is a 1 per cent chance of things going wrong, you know that that 1 per cent includes people with other factors which may affect the outcome of surgery like they happen to be fat but the patient doesn't know this... It's a question of capacity and very few patients have that capacity.

Clinical judgement is part of it – it may be your clinical judgement not to tell the patient anything at all but in deciding between treatments for breast cancer clinical judgement is only part of it and you're making a value judgement as well.

Would it be easier to present the patient with the things they need including something like your sense of yourself as a woman... and ask them the question: are you prepared to take the risk? ...and include things like this that only they can make a decision on.... There also seems to be stuff missing like Ian's patient who is going to have a spinal fusion – she doesn't seem to know the level of risk.

There is a distinction between medical best interests and overall best interests; some clinicians interpret best interests as only meaning medical ones.

When we talk about autonomy we usually mean patients' autonomy but what about the autonomy of the doctor?

When you have a clash and the patient requests something that goes clearly against your professional judgement you have the right to exercise your own autonomy and say I'm not going to do this.

But no one of the core principles is designed to be given primacy in any given situation and autonomy may not necessarily be the one...

In India, autonomy is given a very low status. I tell my students that I am teaching Western bioethics and that there are other cultures where for instance family autonomy is given far higher priority than the individual's.

There was a case history about a child that they wanted to publish in Anaesthesia which they couldn't because the patient's family objected and said they would sue even if it were anonymised. The editor wrote that he had taken the ethical decision not to publish it out of respect for the family's autonomy. My counter argument is that in this situation justice, which demands that the lessons of this case should be shared, counts far higher than family autonomy.

From the patient's point of view he is on a journey through the process and risk will be a question that the patient has for the person that's treating them. Are we coming from the right end thinking about all the possibilities? So shouldn't the first question be 'what are your worries about this procedure?' They may have a perfectly simple specific question – perhaps because they know someone who has had a problem after this procedure - and not be worried about other risks or don't want to know about them. An example which frustrates me is patient information leaflets: it is up to us to warn patients not to operate machinery but we don't talk about Stevens-Johnson syndrome or neuroleptic syndrome although we know that these are serious potential dangers of some of the drugs we use. Rather than going with the figures of a 1 per cent risk of side effects or a 1 in 250 risk of damaging a foetus with amniocentesis or whatever we should ask the patient what they perceive the risk to themselves as the figures are pretty meaningless to them. I suggest that patients think about everyday risks like crossing the road – we don't think about a statistical risk when we run across as the lights are changing but we know it is risky.

The other fallacy here is that we think we make rational decisions – we don't. This whole thing is built on the idea that we're rational beings – we're not, particularly if we are ill; we're driven much more by emotion.

If I'm seriously ill I really want someone to make the decision for me.

When we are asking people to consent to something we are actually trying to interpret what we think they would do, as in Daniel's case involving genetic matching. As to risk, I have the perfect answer for patients who ask me about this. I tell them that the risk of being struck by lightning in Saskatchewan is 1 in 1000 per year. Compared with the risk of any drug combination I use that's huge!

I don't know if this is universally true but I feel that the pain doc's I have met over the years (as a Psychologist) are more risk-taking; they are more prepared to go out on a limb for the sake of their patients. Nothing would change if people weren't prepared to take risks – there would be no innovation. And the GMC is making practice much more defensive but they are fudging it: what they call guidance is in fact protocol as if you don't follow it you're stuffed but they don't want to call it that because it would make them liable. .

In palliative care our consultants nearly always have someone with them when they are breaking bad news and advise patients to bring someone too. After that patients are given the opportunity to come back a couple of days later. And patients with breast cancer will normally have seen a specialist oncology nurse and will have discussed the issues you have been talking about and are usually very well prepared nowadays.

I'm glad you said that as I think some of us are raging against what Jayne has been saying but we mustn't lose sight of the fact that a lot of things have improved.

And what Chris is saying (about palliative care) is emphatically not driven by medico-legal considerations but by humanitarian ones.

In Georgia, they have been looking into how not to waste money in court. So it is possible to have an iron-clad consent to treatment which people sign when they come in. It is a 50 page document and everything is in there but you don't have to be specific as there isn't going to be surgery. It includes a Choose Agreement which allows somebody to sign away their civil rights over certain issues. So I used to make them sign a choose agreement and explain why I was doing this. What happened in real life is that every time I sat down to suggest something there was never a consent agreement per se, but an entry in the notes which said that I had discussed the issues and the cost benefits to his family and himself of doing this procedure, one or two side effects, and given them an opportunity to ask questions; their major issues were this and this and he had asked my opinion which was this and had been given time to make the choice... And I never had any trouble, I never got sued in over a thousand patients, and I managed to separate the medical from the legal. I was saying you've got to make the choice – I will help you as your doctor by giving you all the information you think you need...

But being a good doctor and medico-legal correctness are not mutually exclusive: If you do a good pre-operative assessment and consent that will stand you well in court; If you make good documents which will help patients and continuity of care that will stand you in good stead legally so a lot of it is just good practice. And in the USA if you agree to *open disclosure* – if something goes wrong and you admit it and say sorry – you will see settlements reduced by up to 50 per cent.

The truth, the whole truth or anything but the truth? Mechanism, magic and meaning in (post-) modern medicine

Jeremy Swayne

‘If we see medicine as a healing vocation it must comprehend and make real the meaning of our patient’s life. And the uncomfortable truth is that this understanding must start with the understanding of ourselves.’

Taking part in this conference is an opportunity to explore questions that have challenged me throughout my career, but from a different angle, the very challenging human predicament that is the focus of your work in the management of chronic pain. I have been hugely reassured to discover that my approach resonates with much of today’s talks and discussions.

One of these questions, stated explicitly in the programme, is the validity – the value and limitations – of scientific objectivity in patient care. Or, in the words of an essay by Trisha Greenhalgh, the problem of *Narrative Based Medicine in an Evidence Based World* (Greenhalgh, 1998)

All illness, all suffering, is part of the narrative of a unique life. All pain is part of a story. All pain has a story behind it. Unless we can comprehend the story, and engage with it compassionately and creatively, I doubt the capacity of scientific medicine to achieve much at all that we could properly call healing. And our ability to control pain, I believe, will always be subject to our ability to bring some measure of healing to the person who is in pain.

These themes will recur during my talk, with truthfulness (which Daniel has distinguished from simply telling the truth) as a common thread running through them. And to be truthful, I need to clarify one of the details about myself given in the programme.

I call myself a Scientist, not by virtue of any formal status, but for a reason that bears upon what I shall say later. I believe I have what Michael Polanyi calls scientific passion. The word *science* derives from the Latin *Scire*, which means to know. And I want to know. Not to acquire a vast store of information, but to acquire sufficient wisdom and understanding to equip me for my tasks in life; chiefly to enhance people’s well-being; which usually means enhancing their *whole-being*, as I will explain shortly.

And I seek to know, I hope, by properly disciplined observation, reflection and enquiry. For in addition to the empathy and compassion that we may bring to a consultation, I believe that ‘every patient presents us, in a sense, with a research challenge’ (Harris, 1989); that ‘doctors must remain scientists in order to serve their patients (and to make) a unique contribution to science itself’ (Willis, 2002); and that this science ‘relies on careful observation and inspired interpretation using the doctor’s faculties of emotional and intellectual intelligence’ (Stewart, 2005).

When it comes to homeopathy, which I have practiced for 30 years alongside conventional medicine, I know that many patients do better than they did without it, often dramatically so, but in any individual case I admit that I do not know for sure what part is played by the homeopathic prescription, the style of consultation, the

therapeutic encounter as a whole or the personal attributes I bring to it (Swayne, 2005). And this places me firmly at the heart of the deceit and consent debate.

When it comes to spirituality, I distinguish *faith* – by which I mean an intuitive God-consciousness, from *belief* – by which I mean giving intellectual assent to certain theological propositions. I am keenly interested in the relationship between theology and science, and believe that there is a great deal of common ground between them, and certainly no essential conflict.

Outline

First I will explore the elusive nature of truth and its place in medicine, and discuss what I mean by ‘the whole truth’; then the nature of suffering, and the importance of ‘meaning’ in the story of our lives and sufferings; and finally, ‘Trick or Treatment’, the issue of consent and deceit.

What is truth?

When we apprehend a truth – we seek by intelligent enquiry to understand something – of how things really are in their characters and relationships. Truth always lies beyond us, in its fullness. Yet we discern something of it.
Keith Ward

I believe that truthfulness is essential to a healing relationship; and that consequently it is essential in medicine, which should be the servant of healing. Often it is not, because, for example, it can allow destructive situations to persist, performance targets to displace personal care, and iatrogenic illness of various kinds to prevail. The truth in medicine is very often ‘I don’t know’; and medicine’s pursuit of certainty risks divorcing us from reality.

But truth is in any case an uncertain and precarious commodity. And truthfulness within the therapeutic relationship which is at the heart of medicine can be difficult and painful to achieve. ‘To write prescriptions is easy’, says Kafka’s Country Doctor, ‘to come to an understanding with people is hard.’ (Kafka, 1949)

Medicine’s truth is not the same as science’s truth. Science asks ‘What?’, and ‘How?’ Medicine frequently has to confront the question ‘Why?’ Science has to do with facts. Medicine has to deal with meaning. In this medicine comes close to theology. Science and theology are both exploring reality; different but inseparable aspects of reality. Medicine somehow has to accommodate the patient’s *whole* reality. The truth we seek is to understand things as they really are, knowing that in its fullness it will always be beyond us (Ward, 1998). But if we abandon it, we abandon our patient.

Ways of knowing

The analytical scientific method that has given rise to the biomedical model has achieved truly great things. But it is not the whole story and must not be allowed to induce a kind of scientific tunnel vision. There are other ways of knowing that can guide us to the truth, and that scientific method may incline us to disregard.

Informed empiricism is a term that describes the way GPs work, which I learned from Robin Pinsent, a co-founder of the RCGP Research Unit. It includes training and education, and research evidence relevant to the clinical task in hand, and, most importantly, to the patient in front of us. But it also comprises the doctor’s experience, and allows the ‘actual character of the encounter with the reality (of the patient’s life) to shape our knowledge and our thought’ (Polkinghorne, 2008). In fact it is true to the

original spirit of evidence based medicine, which was never intended to preclude the individual clinician's experience, insight and judgement.

Scientists are not inclined to subscribe to an a priori concept of what is reasonable – the physical world is too surprising – the actual character of our encounter with reality (must) shape our knowledge and thought.

John Polkinghorne, Physicist and Priest

Inference to the best explanation is rather like differential diagnosis – a discerning choice between different theories to select the most coherent and intellectually satisfying explanation; weighing evidence and judging probability in the absence of proof. Darwin's great thesis, for example; and geology, cosmology, the origin of life, historical research, all involve inference to the best explanation.

Motivated belief (Polkinghorne, 2005) justifies commitment to a point of view or a line of enquiry in science, theology, art or life, where evidence is difficult or impossible to adduce. In science it depends on faith in the rational intelligibility of creation. In art and life, motivated belief guides our judgement of the quality of a painting, the beauty of a piece of music, the truth of literature, or the character of a friend. It is founded in reason, but makes no pre-emptive judgement of what is reasonable. As Einstein said, 'The most incomprehensible thing about the universe is that it is comprehensible.'

Reason is not to be identified with the possession of indisputable proof, but with the careful search for well-motivated belief.

John Polkinghorne

Tacit knowledge (Polyani, 2002) describes the things we know without knowing how we know them – like how to ride a bicycle. All activities, arts, crafts, science, everyday life, have components that we just know how to do, or that we discover by doing. All apprenticeship, for example, in any field, generates a wealth of tacit knowledge in addition to the technical skills that can be taught. The acquisition of grammatical speech in small children is tacit knowledge.

Intuition is immediate apprehension that bypasses conscious reasoning. It has been described as 'an inward and immediate vision of reality that contrasts with the knowledge gained by the systematic application of our intelligence' (Spiro, 1998). It is closely allied to empathy. It does not depend on intelligence, but has paved the way for prodigious feats of intelligence, of which Einstein's intuition of the nature of relativity is a famous example.

I would be very much surprised if, in the midst of the inevitable uncertainty, all of you do not employ all these ways of knowing regularly, in medicine and in life, and find them essential in making sense of your own and your patients' experience.

The whole truth

To achieve its enduring goals medicine must clarify what knowledge is represented by knowing who a person is, and mediate any conflict between the two kinds of knowledge, which we call the 'scientific' and the 'personal'.

Eric Chassell

Whole person medicine is not just a romantic notion. It is probably what we all aspire to, but often find difficult because of the constraints of the biomedical model, and the targets and guidelines that are its political manifestation. Reconciling the scientific and the personal is the holistic goal we strive for if we wish not only to control disease processes, but also to enable and empower the self-regulating and self-healing properties that we know our bodies and our minds to possess. To achieve

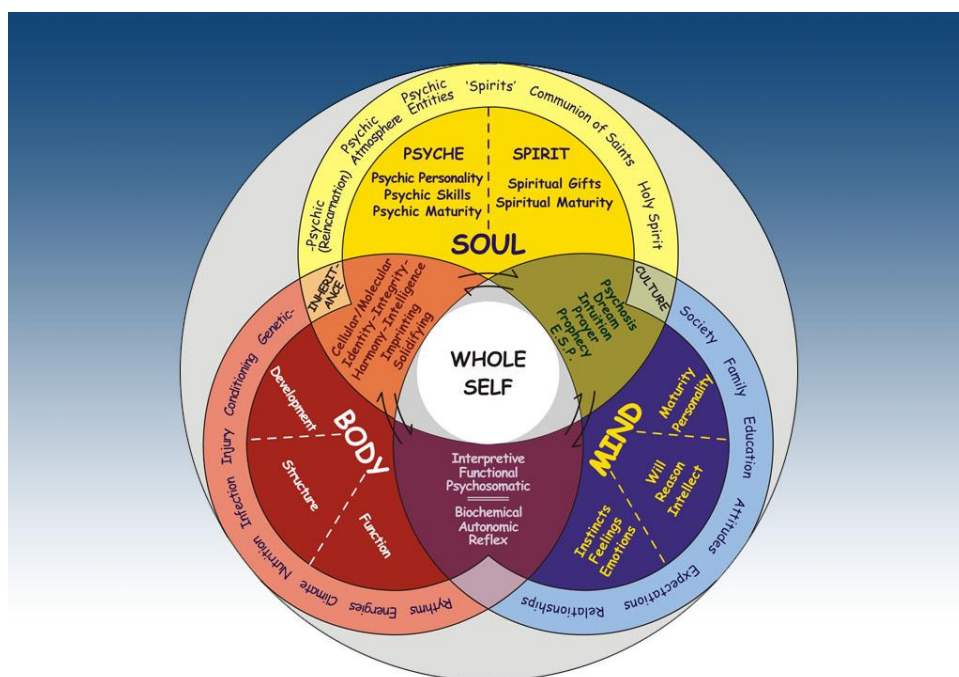
this we have truly to comprehend each person as a unique and integrated whole, body, mind and soul – dynamic, interpenetrating, interactive and interdependent elements of our being, intimately connected with the physical, cultural, social, psychological and spiritual milieu of our lives (Swayne, Homeopathy, Wholeness and Healing, 2005).

Of course we cannot have knowledge of all of this in anyone, including ourselves. But we must be open and attentive to as much of it as is revealed to us; or that we become aware of by whatever means of knowing is evoked. This is a huge challenge, stretching our personal and professional resources to the limit; at odds with the narrow biomedical focus we are trained and equipped for. But if we do not accept it, we build up a bow wave of unresolved illness ahead of us: at least a burden of continuing high consultation rates and minor morbidity; at worst real suffering, and perhaps chronic pain.

This wholeness is the inherent truth of every patient's life. If medicine is not to be completely divorced from healing, then whole-making is part of our responsibility. We must be responsive to this instinct for wholeness which is at work in everyone, whatever their condition, and however apparently lacking in self-awareness, or the ability to express them, or to determine the course of their lives. And we can do so in the first instance by allowing and encouraging the person to tell (or have told for them) the whole story; a story that will greatly exceed the scope of the formal medical history, and that will demand our whole attention.

But I don't mean to imply the lesser importance of the body within the story. On the contrary, I strongly affirm the value and importance of the flesh and blood creatures that we are and for whom we care. I believe that we must remain closely in touch (literally, if possible) with the wonder of our patient's body. However sick, damaged or distorted, it is the unique vehicle of a unique individual of unique value. Our patients' bodies should be an object of 'worth-ship', and our dealings with them a reflection of our sense of that worth (Swayne, Homeopathy, Wholeness and Healing, 2005).

Fig 1. The structure of wholeness (copyright J. Swayne 1995)



[Referring to picture above] I completely agree with the concept you present but it is extremely difficult to say what is soul, what is mind and what is body. There are some people who would not accept soul – where does soul start and mind begin – it looks wonderfully comprehensive but...

I actually created it a very long time ago when I was in general practice but I haven't seen much reason to change it since. It reflects what you have said in the way it is designed to reflect these areas of interaction and overlap. And I know the difficulty of representing the soul as a meaningful and active component of peoples' lives. But this is essential to me because working as a GP I learnt that these things actually matter to people; they are real parts of their lives which you learn if you listen to the story (and I changed my practice to give me more time for this). I needed to make sense of these stories and this is how I did it.

I have found in my practice of medical hypnosis that the physician has to be well-versed in the particulars of each patient's personal narrative - for hypnosis proceeds more effectively when the practitioner is capable of weaving a new narrative for the patient using the life motifs, archetypes and important words and interpretation of events stressed by the patient. It is not difficult to modify a patient's current narrative so as to make it much more positive, hopeful and success orientated, but it does require effort on the part of the practitioner to gain some understanding of how the patient maintains his or her story. For example, if a patient is a Christian and believes in the literal veracity of both the Old and New Testaments, the practitioner is well advised to use helpful biblical stories to move the patient into a healthier and more rational psychological state. By using the belief system of the patient for structuring one's suggested changes, the practitioner will minimize resistance in the patient, form a much stronger therapeutic alliance and insure that the patient completes his or her therapy.

You have to be willing and sometimes courageous enough to do either or both of two things. One is to 'meet the person where they are', that is to respect the language of their particular culture or belief system, but also you may have to help them to escape from a kind of slavery to those things. I have invented a kind of syndrome called 'doctrine abuse' which is the bad application of religion in their lives, and I have met many people with this. It can cause a lot of suffering. There is a dual responsibility to handle such stories very carefully, insightfully and respectfully but sometimes to be aware of the lie which for that person that is bound up in their story, and help to free them from that lie.

I wholeheartedly agree with you about listening to the story but, with respect, you do make it sound a bit too simple, because I don't think the patient knows what their story is until they start to tell it. The story unfolds and modifies and in my [psychotherapy] practice this may happen over weeks, months or years of sessions of up to an hour at a time.

I agree with you absolutely. Sometimes the context of the conversation or the whole manner of the process can release the key ingredients of the story at a surprisingly early stage...but I fully endorse the value of the 'long distance story.'

...But the story changes, doesn't it and I want to challenge you on equating the story with the truth. I never understand why lawyers believe in truth because – to give a

trite example, if six people see a car accident you get six completely different accounts of what happened: each one is the truth for that individual person but they can't all be true. So in our narratives of ourselves that keeps changing, and external events change the narrative. So even in a short therapeutic period people change the priorities and even the story. So where is the truth in all that?

I didn't actually say that I equated the story with the truth, nor do I see the story as necessarily revealing the truth...

... So what is the truth?

The truth emerges, and what you cultivate is an attitude of truthfulness. It's an enabling process that allows truth to emerge in the narration of the story. It's not a question of taking the facts the patient tells you literally and it's often a matter of challenging or re-presenting those facts to allow the story to develop.

The patient is telling you the story in their own words which may be limited. It's allowing them to tell the story and trying to understand it because that's their truth...

I mustn't give the impression that the story exists only in the words. We've discussed the ways in which we can influence the messages that go between us and our patients. The story is in the patient: as well as the words it's in the non-verbal communication and within the empathy we establish with that person. There is present in all of us at least some intuitive awareness of other people. There is a new book by a psychologist that argues that intuition is wired into our faculties.

They've found regions in the brain that respond empathetically.

I don't think human beings in their interactions have anything to do with truth in a Platonic or a gestalt or a church or scholastic perspective – it's really about how do we interact with somebody from our experience, intuition and training to figure out what is a more wholesome story for them. The truth of the matter is that there is no truth in anyone's story and the philosophers that talk about mind and epiphenomena are totally wrong, just like the neuroscientists and reductionists are totally wrong. When I talk to people over several years I see how easy it is to change their story ...

I have found that our lives are lies: they are confabulations of things we know nothing about – we can't see the brain, we don't know the million neurological things that are going on every second that make a mental picture, a gestalt, are not actually linked so we worry about truth and cause and effect but it's a red herring; we can't know the truth at the level we really need to – in terms of all the facts and all the inter-relations because that would give us access to actuality, access to God and God is pure essence and we can't.

I think we can know enough of the truth, if we are fortunate or helped, to live our lives as fully as we have, within fixed limitations, the ability to live them. There are personal truths that can be discovered and explored to the benefit of the individual. So the concepts you are introducing don't actually bother me at all.

One of our previously regular participants, Andy Graydon who is an Roman Catholic priest who works a lot with pain patients, talks a lot about absolute sincerity – what he calls sincerity of the heart – as an essential component of the bridge between patient and priest or therapist. When you talk about truthfulness is this the same sort of thing – or another facet of it?

Do you think there are untruths that a patient tells you or is it a matter of the patient trying to interpret what's happening to them in their own words?

It could be either.

Suffering

To manage the physical symptoms that lead to suffering, doctors must not only think 'pathophysiology' and 'body', they must think 'person' as well.

Eric Cassell

There are many causes of suffering, and pain is one of them. There are many causes of pain, and suffering is one of them. In *The Nature of Suffering and the Goals of Medicine*, Eric Cassell, teases out this relationship most eloquently and instructively (Cassell, 2004). If medicine fails to comprehend suffering, it will fail to comprehend pain. If it fails to comprehend the person, it will fail to comprehend suffering. If it fails to comprehend the story, it will fail to comprehend the person.

I have had one experience of continuous severe physical pain. It only lasted eight hours, but it taught me the difference between suffering and pain. My *suffering* was relieved at times by the kindness of a nurse, and of a young doctor who tried unsuccessfully to relieve the pain; and also when I remembered to call on my spiritual resources. Nothing modified the *pain* until the necessary surgical procedure was affected. But when the suffering was modified it made the pain easier to bear. It was a fairly circumscribed event, but even so there was a story attached to it. It had elements of fear, embarrassment, loneliness, uncertainty, self-doubt, self-reproach, just a few of the many possible ingredients of many other stories of sickness and suffering.

Pain may or may not have a specific physical locus, but the response to pain is always multi-factorial and individual. It involves to a greater or lesser degree an undercurrent of suffering. And suffering always has to do with meaning.

Meaning

Encounter with meaning is central to the human experience (Polkinghorne, 2008). That is a metaphysical truth that even the most determined materialist might find hard to deny. But 'meaning' is an imprecise word. Like suffering it has many ingredients.

Following Cassell, I propose five words that are core ingredients of 'meaning':

- *Identity* – Who am I?
- *Integrity*, or *integratedness* – Is my life authentic, real?
What makes me who I am?
- *Purpose* – Why am I here?
- *Value* – What is my life worth?
- *Belonging* – Am I truly loved? Where am I really 'at home'?

These questions are the essential framework of our lives. The answers are the scaffolding that supports us or the fault lines that undermine us.

There is a human need to make sense of everyday events. To create a framework of meaning and causality. The framework doesn't have to be scientifically valid (much less 'true'), but it does need to work for us, as a day-to-day explanatory model.

David Misselbrook (Misselbrook, 2001)

If we see medicine as a healing vocation it must comprehend and make real the meaning of our patient's life. And the uncomfortable truth is that this understanding must start with the understanding of ourselves. This 'meaning' is critical for the healing process in ourselves and in others. And it is revealed and can be explored and made whole through our stories.

The crippling flaw of the (biomedical) model is that it does not include the patient and his attributes as a human being. Yet in the everyday work of the physician the prime object of study is a person.

G.L. Engel (1977)

Throughout the 100 years or so since scientific medicine became established, partly despite and partly because of its great achievements, dissident voices within and without medicine have bemoaned the subordination of this kind of perspective to the biomedical model; the subordination of the person to the disease. This tension between holistic instinct and biomedical process is a poignant paradox in medicine. It is present in doctors' expectations of themselves, and in patients' expectations of their doctors. And it demands of us a difficult intellectual and perceptual juggling act.

In *Reflections on the Doctor-Patient Relationship*, Moira Stewart reconciles these two main roles, within a framework of understanding, meaning and truth (Stewart, 2005). And of that other indispensable ingredient of a healing relationship - trust; so fittingly emphasised in a quotation from the superb section, 'Thinking about medicine', in the *Oxford Handbook of Clinical Medicine* (Longmore, 2007): 'Where there is no trust, there is no healing'. I cannot recommend reading this section too warmly and I am sure it resonates very closely with your practice.

While using the generalisations of biomedical science (we have) a constant duty to refocus on the individual, - - their experience and the meaning they attach to (it). - - - We cannot see (both) simultaneously - - we have to choose one way of seeing or the other. To maximise our understanding, (and) not become stranded and impotent at one pole of the dualism, we must learn to oscillate our gaze.

Iona Heath

I think the meaning that people attach to whatever their health issue is, is absolutely critical, and connecting with that critical for what we are trying to do. But it is often something that needs manipulation. If someone believes that their back pain is caused by cold winds from Russia you need to understand that that's their interpretation but it's probably not very helpful if you let them go on thinking that and give them a tablet. So I want to challenge you on whether you want to attach intrinsic value to the meaning – the patient's interpretation – or whether you play with it.

No ... I think meaning has to be helped to unfold in the way that you suggest. The interpretation that a patient puts on an experience may be wrong and even actually harmful to them and the meaning you want to uncover lies somewhere beneath that.

I was quite careful not to use the word wrong because it is their truth. Do you think you have a truth that's better than theirs? It is a real problem.

It is, and one of the problems of all therapy is the risk of imposing your truth and meaning on the other person – I take your point 100 per cent. The risks are huge, especially in psychotherapy, if the therapist tries to impose the meaning of their particular model or school.

We do it in general pain therapy as well – if we believe that spinal cord stimulators or epidural steroids are the way forward we impose that truth on our patients – and can do an equal amount of damage.

I'm not an expert on evolutionary psychology but if you assume that Darwin was essentially correct concerning the importance of specific selection factors arising from the environmental situation our ancestors interacted with over long periods of time, you realize modern man is going to behave in a similar manner. In the pre-modern period of human history, the primary daily factors that needed to be anticipated were how the change of season affected food supplies and living conditions--such things are relatively constant (normal human life span was about 20 - 30 years or so) and solutions relatively fixed. There was never much of a need to contemplate or consider what could happen in ten years, one hundred years or a thousand years, all that mattered was tomorrow and next month. Man did not have a great effect upon the earth at this time, other than perhaps an ability to over-hunt. So it is not surprising that modern men tend to be ignorant of thinking and planning very far ahead in time, of considering the various potential consequences of certain actions taken now. This is why corporations tend to look for profit only for the next three months rather than in the long term. Very few of us are actually advanced enough psychologically to deal successfully with the modern world. I find it interesting that as you go along...you put this overlay onto evolution it makes life much more difficult. I think there is no meaning in people's lives. You can establish purpose and things you want to do and cause and effect but meaning is an unnecessary thing.

I shall give you a personal example: I broke my neck in a fall as a freshman at university. I ended up by having severe stabbing pain in my neck and shoulders. I knew nothing about medicine or drugs at the time. I did not know how to fix it, but I did know how it had happened and the nature of the injury. Subsequently, my only viable option was to treat it as if it were just another sensory experience. It did not go away for about 10 years, but because I did not attach any meaning to it and thought of it as just a stupid random event... it was just what it was. Consequently, because I chose not to make up a story about the situation, or indulge my injury, I led an essentially normal life--the only difference is that sometimes I remembered that my shoulder was very sore

So the meaning you gave to it was that it just was what it was....

But what I've found with patients is not to put my meaning onto them, but if you can sometimes take away the confabulated meaning they place onto [their pain] you give them more space to work in.

So truthfulness is nothing to do with life. We didn't evolve with the church telling us what to do; we evolved in the world with interactions with people...

I'm afraid you and I have a profound philosophical difference here, but you are quite right about not imposing your meaning on other people.

Trick or treatment?

So now we come to the heart of the matter. *Trick or Treatment?* is a book by Edzard Ernst, Professor of Complementary Medicine at Exeter University (Singh, S. Ernst E, 2008), subtitled *Complementary Medicine on Trial*. I have reviewed it critically in the *British Journal of General Practice* (Swayne, 2008), but it provides a good title for this part of my talk.

If truthfulness is a keynote of my philosophy of medicine, how do I justify including in my repertoire of patient care two modalities that are held by many to be in error –

the spiritual perspective, which is perhaps by no means foreign to many of you here, and the homeopathic approach, which probably is?

Well, I dare to suggest that much of medicine is and has always been untruthful. Untruthfulness arises when medicine represents only part of the story. A diagnosis, for example, is only part of the story; a description of what is going on, rarely an explanation of why a thing is as it is; but often presented as if it defines the whole problem. Untruthfulness arises when a doctor gives an antibiotic for a self-limiting infection, or another inappropriate prescription; or offers a diagnosis when the truth is 'I don't know'; or tells an ill patient there is nothing wrong because the tests are all normal.

And untruth is introduced when 'the dogma of technological medicine ignores the therapeutic effect of the doctor and the self-healing powers of the patient' (Dixon and Sweeney); when 'doctors expect to find an answer to every problem if only they look hard enough with the right instruments' (Spiro). It happens because although technology allows us to practise with ever greater precision and is a powerful tool for understanding, it also creates powerful misunderstanding when unwisely applied (Engel, 1977).

As a generalisation I offer David Haslam's remark in his paper *Who Cares?*, that 'we use the medical model because the medical model is what we use, even though it may not be appropriate' (Haslam, 2007). David is Past President of the RCGP, and Iona Heath, whose disquiet at the dominance of biomedical thinking has long been well attested (Heath, 1995), is his successor, so I am not plucking dissident voices from the backwaters of medicine.

I don't say all this simply to castigate certain practices as bad medicine. Diagnosis, for one thing, is obviously a vital element of medical care, and in itself, even when erroneous or vague, can be a vehicle for healing (Brody, 1980). It can provide the patient with at least some sense of meaning, some sense of control over their predicament, and some sense of participation in resolving it. All these contribute to healing and coping. Diagnosis can be a vehicle for prescribing by the drug 'doctor.' It can contribute to the placebo effect; whose power, importance and prevalence in medical affairs we sadly neglect.

No, I point out the inherent untruthfulness in much of medicine not so much to condemn it, as to suggest that we must acknowledge that in a great deal of treatment, with the best of intentions and often with good effect, there is an element of trick. The fundamental untruthfulness is the illusion of certainty.

Deceit and consent to deceit are inevitable in medical practice whenever we imply, and quite possibly believe, that we know the truth of the matter; when all we really know are some of the facts of the matter. We are victims of the success of biomedicine because of the expectation that it encourages in us and in our patients that we have the answers; whereas deceit and consent are inevitable because we are always dealing with a high degree of complexity and uncertainty. The inherent truth of the patient's experience in its fullness will often be beyond us. But that does not absolve us from the responsibility to be open to that truth, and faithful to it - as best we can be and as fully as the patient invites us to be.

The *inexcusable un-truth* is to reduce the problem and our response to it to its narrow biomedical parameters; to allow the patient as a person to vanish from our gaze; to allow our attitude, role or intervention to be 'de-meaning'.

By reducing the body to a collection of parts, the patient as a person vanishes before the physician's gaze. That is literally de-meaning, and it does happen.

John Marcum

We can have no certainty about all that determines the course of illness and healing in any individual. We have to explore constantly and courageously the penumbra of uncertainty that surrounds our presumed certainties; while committing ourselves, in

full knowledge of the precarious balance of certainty and uncertainty, to what we perceive as best practice. Not primarily in terms of some abstract and generalised guideline or target, but in terms of the good of the individual patient.

Discussing how to judge a particular approach to healing with one of my mentors, he commented that it was not so much the nature of the practice itself that mattered, but *the sanctity of the practitioner*.

The sanctity of the medical practitioner, we might say, comprises the scientific attitude of disciplined observation, reflection and enquiry; self-knowledge and integrity; intellectual and emotional intelligence; the understanding, wisdom and discernment that those attributes should yield; the honesty, humour and humility that another quotation from the Oxford Handbook recommends; and that indispensable sense of worth-ship towards the whole person of our patient.

These attributes do not *displace*, but assume and comprehend proper respect for evidence and scientific method, clinical knowledge and skill. But they also leave room for flexibility of mind, and openness to the inherent truth of the patient's experience. An openness reflected in the assertion by physicist John Polkinghorne that 'Scientists are not inclined to subscribe to an a priori concept of what is reasonable - - the physical world (is) too surprising. The actual character of our encounter with reality (must) shape our knowledge and thought.' (Polkinghorne, *Theology in the Context of Science*, 2008)

We have no more right to assume that we know the limits of what is reasonable and plausible today than at any time in the past, before new insights into the nature of things were achieved by Copernicus, Newton, Darwin, Pasteur, and other pioneers in the exploration of reality.

You will understand by now my scepticism towards scientific objectivity and certainty; my esteem for the variety of ways of knowing which shape the actual character of our encounter with reality; my insistence that medicine must serve healing; my concept of healing that embraces the whole person, body mind and soul; my insistence that the process that enables that healing to proceed must be attentive to the whole story, the inherent truth of the patient's experience.

And so, finally, to –

The example of homeopathy

However implausible, I am open to the possibility that homeopathic medicines have biophysical properties, because the physical and biological world is too surprising for me to submit to any a priori concept of what is reasonable. My clinical experience, informed empiricism, and inference to the best explanation encourage my motivated belief in that possibility.

But regardless of the question of the specific effects of homeopathic medicines, I value the homeopathic approach because it involves the most whole-making kind of therapeutic encounter that I know of. Its non-pre-emptive appraisal (i.e. not assuming any particular diagnostic pathway or outcome to be likely) of the patient as a whole, even in a short consultation, gives patients a sense of themselves as a person, as an integrated human being, that they may never have had before. And it invites story. Moreover, I value the approach actually *because* I know that it maximizes all the non-specific and placebo elements of the therapeutic process.

The goal of medicine is to increase the well-being of patients and enhance their capacity to be fully themselves and lead a full life, as free as possible of suffering and disability. If that is the outcome, I will not be gullible or credulous, but I am willing to remain agnostic as to the mechanism. And the capacity to evoke such powerful healing responses gives pause for thought. Clearly what is happening is a completely natural process of self-regulation, but it defies our usual expectations and

experiences of physiological and psychological responses to treatment. Patients often describe it as miraculous. Is what we usually describe as miraculous in the religious sense, I wonder, perhaps not so much *super*-natural, as *perfectly* natural?

I have no sympathy with the suggestion that the popularity of complementary medicine (or CAM) is simply a manifestation of a post-modern culture. I believe it is largely because people seek in complementary medicine some or all of the qualities that I am describing in this talk. Whether they find them or not is a different matter, because sanctity and a truly holistic approach are no more the prerogative of CAM than of any other form of medicine. And our need of them is neither ancient, nor modern, nor post-modern, it is just essentially human.

Conclusion

So my closing thoughts are not to be hung up about the notion of deceit in medicine. It happens. Sometimes it cannot be avoided. It may be necessary. It may do good. But we must be discriminating about where the deceit lies and where the truth resides; be prepared to admit that there are different and legitimate ways of knowing; be open and faithful to the inherent truth of the patient's experience, rather than to some objective guideline however evidence based; be open to the unforeseen consequences and possibilities that a true contact with reality may provide; be willing to be surprised.

If we cultivate the kind of medical sanctity that I have described, we are unlikely to go wrong. And we will have earned the trust of our patients that justifies their consent to what we do, even if it does include a small dose of deceit.

Bibliography

- Baum, M. (2007, May 1st). Quoted in 'Homeopathy is worse than witchcraft'. *Daily Mail*.
- Brody, H. (1980). Diagnosis is treatment. *The Journal of Family Practice*, 445-449.
- Cassell, E. (2004). *The Nature of Suffering and the Goals of Medicine*. New York: Oxford University Press.
- Greenhalgh, T. (1998). Narrative based medicine in an evidence based world. In T. H. Greenhalgh, *Narrative Based Medicine*. London: BMJ Books.
- Harris, C. (1989). Seeing sunflowers. *JRCGP*, 313-319.
- Haslam, D. (2007). Who cares? *British Journal of General Practice*, 987-993.
- Heath, I. (1995). *The Mystery of General Practice*. London: Nuffield Provincial Hospitals Trust.
- Kafka, F. (1949). *A Country Doctor, in In the Penal Settlement*. London: Secker and Warburg.
- Longmore, M. W. (2007). *Oxford Handbook of Clinical Medicine. Seventh edition*. Oxford: OUP.
- Misselbrook, D. (2001). *Listening to Patients*. Newbury: Petroc Press.
- Polkinghorne, J. (2005). *Exploring Reality*. London: SPCK.
- Polkinghorne, J. (2008). *Theology in the Context of Science*. London: SPCK.
- Polanyi, M. (2002). *Personal Knowledge*. London: Routledge.
- Porter, R. (1997). *The Greatest Benefit to Mankind*. London: Fontana.
- Singh, S. Ernst E. (2008). *Trick or treatment? Alternative medicine on trial*. London: Bantam Press.
- Tarragon Press.
- Spiro, H. (1998). *The Power of Hope*. New Haven & London: Yale University Press.
- Stewart, M. (2005). Reflections on the doctor-patient relationship. *British Journal of General Practice*, 55(519):793-800.
- Swayne, J. (1976). An uncertain healing. *World Medicine*, 74-85.

Swayne, J. (2008). Book review: Trick or Treatment? *British Journal of General Practice* , 58 (555):738-9.

Swayne, J. (2005). Homeopathy, Wholeness and Healing. *Homeopathy* , 94:37-43.

Swayne, J. (1976). Medicine and healing: A broken marriage? *New Society* , 491-2.

Swayne, J. (1976). On our best behaviour. *Journal of the Royal College of General Practitioners* , 560-564.

Ward, K. (1998). *In Defence of the Soul*. Oxford: Oneworld.

Willis, J. (2002). The sea monster and the whirlpool. (p. Keynote address). Birmingham: Royal College of General Practitioners.

Discussion

Do you have to be ill to need healing?

I regard illness as an agent of healing but not as a prerequisite. If we see healing as a process that involves becoming, that has to do with life and with the realization of our unique personhood then it is something that is going on throughout life. There are many experiences in life that we don't describe as illness but which are a kind of disorder, for example in our relationships or our ecological attitudes. There is a whole range of disorders and behaviours that is unwholesome in one way or another. So the need for healing is part of the human story.

So could I ask you to expand that into a definition of healing?

Healing is the process of becoming as fully as possible the person that I have it in me to be. I could expand that very simplistic definition by describing what constitutes that person. One thing healing and wholeness do not have to do with is perfection, and indeed themselves accommodate imperfection. The imperfection in the people we care for makes a contribution to the healing of us and the community. There is a theologian called Frances Young who has a profoundly mentally and physically handicapped child who was a huge challenge to her whole sense of meaning in life. She writes very insightfully of this whole issue of imperfection and the importance of imperfection in the healing of humanity: our ability to respond appropriately to imperfection in others – physical, moral or anything else.

I think you have just described the first two of the Four Noble Truths of Buddhism: that life is inherently unsatisfactory – you can call it suffering – and the reason for that is ignorance by which they mean being unable to face the whole truth. So the cure for suffering is seeing life as it really is, which is almost impossible for most of us, but the more you can the less you will suffer.

Our society is dualistic. We make imaginary oppositions, in metaphysics, temperature, entropy – they're just degrees of the same thing. If medicine is a contrast between being healthy and being sick that's a very bad untruth to tell patients. Our biomedical training has left us with an idealization based on optimal functioning of every physiological system. If a person was truly healthy they would be in the optimal state you were talking about – the optimal state of functioning given everything they have in their life, biologically and psychologically. I have found that when you take duality away from patients slowly and carefully and have them see that it's a matter of degree of how much you have it's a lot easier for them to become healthier because they're not trying to fit into this or that category. I say find what works for you so you can maximise your life and be as wholesome as you can possibly be at the current state off time – not last year or next. If they are encouraged in duality no wonder patients don't get better.

One thing you didn't do, as I thought you might, was to try to persuade us to accept theories about the original solute imparting 'energies' to the water in a homeopathic medicine or otherwise changing it in some way which to a lot of us seems like pseudo-science, so do I impute from that that you are saying that if there is any truth in homeopathy we have to find it by a totally different route from conventional science?

Whatever is the biophysical truth about homeopathy we don't have the instruments to measure it. People are using very sophisticated tools to look for it and some have claimed to have demonstrated it but I'm open-minded about this. That is a very interesting and challenging question as if these biophysical properties do exist then physics has to rethink a number of its precepts. That's not a subject that I am qualified to speak on with any depth. What is obviously more significant to me is what is happening to people ...

... that's what I mean by a totally different route...

Yes – it's informed empiricism. We all use placebos in one form or another – we all rely on the context effects of the conversation and non-specific effects of treatments – they are part of all medicine – and are part of the effectiveness of any intervention of proven efficacy - an important distinction and the effectiveness of anything we do is independent of its efficacy. When we measure efficacy we often can't be sure how much we are measuring the effectiveness of other ingredients of the process. I see things happening – I've been a doctor for 40 years, 12 of them before I had even heard of homeopathy. I value the psychotherapeutic approach, and I'm used to spending lots of time with people and incorporating all sorts of different perspectives into the context of the therapeutic encounter. Introducing homeopathic medicines made a difference. Now it's quite possible that the difference made was wholly contextual but there are many things...

I talked about my informed empiricism and my inference to the best explanation. I don't think the dynamics of the placebo effect have been studied in any detail at all, whereas the dynamics of the response to homeopathic medicine has been studied in great detail. For example it is well documented that when people respond to whatever it is changes take place within the body and the mind according to a certain sequence (more deep seated problems or those at the top of the body resolve first.) It has also been observed that in the process of recovery the thing that matters most is that the person feels better in themselves: you have people whose physical symptoms don't improve but whose sense of wellbeing and energy and so on do. For instance someone I was treating for asthma told me his asthma was no better but he was enjoying playing the violin again and getting on better with his wife. You can make of that what you will but the point is that there are observations of what happens to patients after you treat them that are not replicated in studies of other responses to placebos. Another phenomenon is the transient reappearance of symptoms people have had in the past, as if there were a reservoir of an unresolved disorder which needed to be remedied as part of a healing process. So these are the things that inform my empiricism and leave me open to the possibility that what is going on may not be wholly contextual.

Can I pursue that a tiny bit – it is interesting to speculate – and I am coming from a little nearer the reductionist end of the spectrum than I think you are – I think what you are saying is that there is a black box which is the diluted medicine but there are lots of other things in it. There are two approaches to this; one is the reductionist approach which says we must unpack the black box and perhaps throw the diluted medicines away and identify the other active ingredients; research tends to take that

line. The other approach is to say we mustn't attempt to unpack the black box because to try to may destroy it. Are you in either of those camps or somewhere in between?

I think I'm coming from somewhere in between. I have this scientific passion and insatiable curiosity that makes me want to unpack the box. On the other hand I'm not entirely persuaded that it's a fruitful thing to do. What we need to do is to demonstrate which black boxes actually work. The research done at Bristol Homeopathic Hospital a couple of years ago which Edzard Ernst rubbished comprehensively because it wasn't a controlled trial showed that over 75 per cent of the patients benefitted from treatment. These were all patients that had been referred by other doctors; a large proportion had been on conventional medication for the presenting complaint for years. Here were a lot of ill patients who were getting better, and the better we can understand what had happened the better. If we can use that black box more effectively for more people – hooray!! But there is a tendency for the black box to be thrown out with the bathwater. The problem with complementary medicine, as Ernst rightly points out, is that it is such a mess, as a whole it is a nebulous entity and there are all sorts of things that go on that I would regard as entirely disreputable and need to be debunked. But we do have certain tools that obviously help people to get well. Some of the reasons they do this are the ones I have been talking about this afternoon and these matter very much. We must take these seriously and not be dismissive of them. We need to define the questions that they ask very clearly; to accumulate the evidence of what goes on. There are some interesting things about what is called the response to the remedy in homeopathy – all sorts of physiological and psychological responses which are not documented in any other clinical context.

I think the reductionist approach is a very bad one and we are getting into trouble because of it. The pharmaceutical companies are already beginning to realise that there is never going to be a single drug to treat pain I think we have to go back to the black box and perhaps try to understand what's in it from a holistic approach.

In hospice care they talk about total pain and the value has long been recognised of a combined 'humanistic' approach where you look after all the elements that create suffering - financial and social etc as well as pain. I wonder if we should be doing more of that in chronic pain management.

Yes. I warmly recommend *The Nature of suffering; the Goals of Medicine* by Eric Cassell – a very remarkable book which does unpick some of these issues and deal with them very eloquently. He not only addresses the issues such as the one you have just raised but also discusses how these things can be brought into medical education.

*You're actually a very good theoretical physicist! Because one thing that theoretical physicists stopped talking about a long time ago was objects - quanta and particles etc – the only thing they talk about now is energy exchange and information exchange What happens when objects interact with each other? Even when people who know f***- all about physics try to introduce quantum mechanics into medicine they don't realise that there is a real analogy here between the uncertainty of quanta and the uncertainty between human beings about what they actually do and their unpredictability. And I think that real medicine – real health care – is about interactions just as you say. It's not about objectifying things – it's about information and interaction with compassion and kindness – and helping someone to be healthier.*

I absolutely agree. The core dynamics of life are about information and relationship. This applies to everything we have been saying today about – exchange of information, the proper eliciting and offering of information and it applies to everything from human relationships to the sub-molecular world. I have been particularly influenced by John Polkinghorne who is both a highly regarded physicist and a priest, and who is working towards an understanding of the dynamics of life in terms of relationship on all these various levels.

I've been thinking about this need to define what is real and there seem to be some parallels with the chap that taught me to dowse. He was a famous dowser. He could dowse from a distance and tell a drilling rig where and how deep to try etc... How does that work? – But there was a result. So perhaps there is too much of the reductionist attitude that you have to understand how something works for it to be real. But dowsing works – drilling rigs use it – so it must be real.

John Polkinghorne makes a point about allowing our actual encounter with reality to shape our knowledge and our thought. At the moment we have it the other way round. We believe certain firm pieces of knowledge and 'proper' pathways of thought and apply those to our encounter with reality. Somehow we need to get this the right way round.

Homeopathy is used a lot in veterinary medicine which I find fascinating. A lot of the models we're talking about don't apply to animals who don't have the same understanding of the world or experience suffering in the way that we do but we observe change in them after homeopathy.

I know a remarkable young South African surgeon who is trained in homeopathy. He works out in the Bush where they have no conventional medicine, and all he has to work with are homeopathic medicines gifted to him. He is producing extraordinary results in profoundly damaged native people. The people who so easily dismiss homeopathy know so little about it – they have no experience on which to make their judgement and just make this presupposition that it can't work.

General discussion of the day's programme

Are we talking about what makes a good doctor? – I use the expression in its broadest sense. A lot of the problems about clinical trials and surveys of practice is that none of them take into account the abilities of the doctors concerned so you get these general results: this obviously works and that doesn't work. I'm wondering about homeopathic medicine: if you have a very caring doctor who gives a lot of time and empathy it's hugely therapeutic in itself, regardless of what treatment you are giving. I'm wondering how important that is in any doctor-patient relationship.

That's the key to good medicine. The problem is that the evidence based medicine 'religion' and the false air of certainty that it brings is devaluing the art of medicine.

Are we not forgetting that the evidence base is actually population based, not individual based.

People are now talking about different forms of medicine: relationship based medicine, individualised medicine – I don't think we're there yet but there is a kind of middle ground now known as stratified medicine. One of the problems is that the evidence is not only population based but skewed, not representative, so to apply the results of the evidence base to the individual is not going to work. Guidelines at the primary care level don't work because doctors understand that, and this probably isn't right for Mrs Smith because she has co-morbidity. I write the guidelines for treating osteoarthritis but I don't use them! Trying to treat everyone as individuals and each one as completely different is perhaps going too far so the idea of stratified medicine which recognizes that there are groups of people who will respond to this or that approach may be a way forward.

There is something else that we often fail to acknowledge. This is a little surprising considering that most pain doctors are anaesthetists – it is the huge gulf and lack of understanding and communication in secondary care between acute medicine and chronic medicine. So much is driven by acute medicine practitioners who completely fail to appreciate the chronic medicine scenario.

Yes – I tell medical students that if I have an MI during that lecture I want the best clot buster according to the latest guidelines straight away – don't bother with asking me how I feel – just get on with it. But six months later when I'm not feeling well, don't bother with guidelines, they won't help you. The problem is that chronic illness constitutes the bulk of the problems (the NHS has to deal with), not the acute stuff.

The slide about sanctity of the medical practitioner ... reflects a description of someone who has been practicing for 20 or 30 years, and a large proportion of our doctors in acute medicine are young doctors who haven't got to this level, and nowadays are not being given these sort of characteristics (of 'sanctity') because they don't even know who their consultant is.

But if this were remedied and they were apprenticed to people who exhibit not only these definable skills but all the tacit knowledge as well we might escape from that – but that's a utopian hope...

It probably happens in some degree with young doctors coming through general practice: they know so much stuff that I've long forgotten and they see so much stuff they don't understand because it's so different from what they've seen in hospital. It's a reminder of how much we in general practice have moved away from an acute model to a practical model. The new way of training for young doctors which involves

spending time in different specialities including general practice is probably very helpful for the future.

I have on a physical basis to deny homeopathy, but not on a medical basis, because too many things work – but if I were a Homeopathist I would use modern medications to make remedies because I know exactly what they do. Just because something works is a not sufficient ground to not study it because the human response to an intervention is so high. I'm sure blood-letting killed some people but a lot of people got better or they would have stopped it a long time previously

What I took away from what Jeremy was saying about this was that what we've not been doing is studying the phenomenology and the idea that there might be different explanations for different types of context response is interesting. It certainly intriguing that all the literature about homeopathy comes up with these phenomena which are not actually recognised as part of any other types of context effect.

One of Jeremy's slides that has stood out in my memory was the quotation 'the Fundamental Truth is the Illusion of Certainty'. Does that imply that objectivity is illusory?

Has anyone read 'Personal knowledge' by Michael Polanyi? It's a difficult but interesting and challenging book in which he is teasing out whether scientific objectivity is a reality. He says it isn't. For example he points out that many of the measures by which we determine objectivity in science are actually matters of consensus and rules of probability have been arrived at by a scientific consensus – they are not written in stone; there's no absolute source for these kinds of precepts. So he turns the thing on its head and says that what we call scientific objectivity is really a kind of subjectivity. There is an objective frame of reference from which we may gain by some kind of input of information. The idea is that we then have a responsibility to put to the test. These are the ideas that we would normally call subjective because they arise de novo in me. He suggests that there is an objective reality that exists beyond this that we can relate to and that can guide us in our scientific work and we then have a responsibility to explore it, always accepting that we may turn out to be wrong. So my scepticism about scientific objectivity is widely shared, not least by John Polkinghorne who distrusts what he calls coercive proof which he regards as somewhat unreliable.

I have also been thinking about this quotation and its implication. I used to have a GP who seemed to accept this and every time I saw him would start his comments with 'well, I'm not sure about this but...' which I have to say rather had an impact in the amount of trust I had in him! So I do wonder if you start qualifying all your clinical statements whether this will have an effect on trust and other things like hope that we think are important. There comes a point where you can't keep on qualifying or people will go off to someone else who appears more knowledgeable.

I quite agree and I wouldn't do that – but we have already agreed about the illusion of certainty. But we have to have some way of managing uncertainty – and this is part of the legitimate face of medical untruthfulness. We have to live with uncertainty and discriminate between certainty which heals and certainty which harms – and an illusion of certainty which we use to heal.

This is skirting at the edges of postmodernism ...

I don't think of myself as a post-modernist....

It's in your title!

That was meant to be ironic!

Moderator's concluding remarks

Paul Dieppe

I have found the day very liberating. Daniel's talk showed a practical way forward in dealing with the problems of deceit. Although I found Jayne's talk in some ways depressing considering the idiocy of the GMC and the medico-legal position it was also liberating because what came through in the discussion is that it is such a false position the GMC have adopted, based on nothing but paranoia and defensiveness, and that we shouldn't feel much constraint or get into this defensive mode. And we have learnt from Daniel and Jeremy and the discussions that if we are true to our patients and true to ourselves we shouldn't run into big problems too often, and we shouldn't get too hung up about the problem of deceit. This is all very liberating and valuable and helpful. I think what we are talking about is *goodness*: good communication, humanity and humility, and if only we have good people in healthcare everything will be OK. We don't know who good people are or how to make sure that people who get into training in health care are good people – but I suspect that this group are self-selected good people.

A final point – one that hasn't been much alluded to – concerns flexibility. There are so many contexts of medicine – so many diseases and so many different situations – that there is no formula to any of this and what we have got to learn is that the art of medicine is having the flexibility to respond to different situations: the different places that patients are in and the different points on their illness journeys that they are on; and to respond to that as another human being, not driven by rules or guidelines but responsive in as many different ways as necessary.

Surprise – you get what you expect! What hypnosis teaches about the placebo/nocebo response

Michael Kell

‘Chronic pain is really a memory – it is a deficient life story that is relived and relived and with all the proper physiological responses.’

This morning, I am going to talk about stories, life stories, my life story – your life story – everyone’s personal life stories. For without ongoing narratives, created automatically so to make sense of our lives, we would be nothing. This is probably the primary function of our conscious minds, to take the events transpiring in our lives and composing stories which appear causative and explanatory – which they are not.

Our real-time narratives were initially composed by our family and social institutions when our reasoning powers were quite primitive. We are fed various themes and facts important in our culture so to create a core story of our lives, a core upon which our elders can embellish and develop a socially acceptable narrative for each child. These developing narratives having been spoon-fed into our little brains, without conscious consent, without conscious awareness; some of it useful and much of it not helpful in the long run.

After many years of using medial hypnosis in my psychiatric practice, I have come to the conclusion that we are not suffering from depression, drug abuse, chronic pain or anxiety as such, but because our life stories are defective and do not function usefully. I think this is primarily a result of our long history of evolutionary psychobiology, and whenever I find that I do not understand something I begin thinking of some adaptive reason why human beings might have developed this particular quality. We start to learn language and we go to school.

Children are very expansive - they are very open, easily hypnotised and very easily accept information. As we go through school, our elders place more and more restrictions upon what to think, to feel, to do; and we become very limited people. As we mature our parents and every other adult tell us the same basic story, a story passed down for generations, a story about what is needed in life, what a man or a woman should do, what you should be and so on.

Unfortunately, we don’t realise how susceptible our children are to suggestion and want to follow authority. As ‘they’ used to say, ‘garbage in, garbage out’.

Some fine points in evolutionary psychology

Let us begin with discussing the placebo. Is it only an irritating aspect of drug studies or is it something much more fundamental about human beings?

One of the earliest forms of religion was *Animism* which is still practised in parts of Southeast Asia. It was involved in the Greek mythological stories of tree-nymphs and water-nymphs. So for a very long time there was this belief that every object within the universe was animated, had intention, was living and conscious. Early humans had no reliable explanations for the weather, famine, failed crops, good crops, successful hunts and on and so on. Consequently, human beings realized early that they don’t have much control over their lives. Ancient people didn’t understand why there were wildfires, floods and illness. To overcome anxiety

associated with not knowing why, the ancients began to ascribe voluntary actions to other objects and forces. We still suffer from this human mental trait, and it is the source of magical thinking. Now magical thinking can be employed in a useful manner, such as in medical hypnosis, to help people change their life stories by demonstrating to them that they actually do possess some modicum of intention and power to change their current and future life situation, not so much through learning to control the outside world of other persons, but rather how to change their attitude and themselves. Believing that external things have control of us is a real problem particularly for pain patients.

Another problem area of evolutionary psychology 'hold-outs', I call the fallacy of conscious intention or the 'authorship in action exclusion' fallacy. If you close your eyes and lift your arm you inherently believe that you're choosing to follow my instructions, it's your arm and how it is positioned is your choice. But is this really true?

What has developed evolutionarily is this feeling of voluntariness – the feeling that we do have some control over our own body. It's very important in a group living situation for its members to decide who caused the first action. An American psychologist has been studying which actions are voluntary and which are not. After a long series of experiments he finally came to the conclusion that our feeling of voluntariness may be an illusion. Our responses are actually triggered by unknown stimuli from the environment that cause us to make the movement, it takes about half a second before you are consciously aware that you made a 'decision' to move, and then only about 100 milliseconds to decide whether to move or not.

People learn under hypnosis how automatic they really are; they are programmed – like a computer but much more complex - to respond in a certain way. If you honestly watch what you do you will find that what I am relating is true. What you teach people under hypnosis is that yes, you are in many ways an automatic machine, that you really cannot change what may happen in the future, but you can modify your understanding so to deal more effectively with what shall happen ahead. So we teach people how to be future-oriented towards their lives and to pay attention to what's actually going on, not what they imagine is going on. Most of us never pay attention, unless we really get stressed out about it, and then we don't observe, we just react.

Whenever major things happen to us that we find displeasing, we need to remember that usually these do not have much to do with the voluntary motor system. Rather they involve our feelings, emotive reactions, sensations, pain problems, anxiety, grief and anger. When we look at our lives most of the stuff that we see just appears to happen to us. You understand why, if your wife leaves you, you are depressed; but you feel you have very little control over your state of depression and anxiety. Panic attacks are another good example. Pain patients are often in an animistic fallacy. They think their pain is caused by something else – their emphysema isn't their fault – even if they smoked. There is this feeling that this illness isn't part of me – it's something happening to me – it shouldn't happen to me; it's part of something else and therefore not part of my voluntary actions. As long as people think their problem is outside of themselves, they won't face it. And the inference from hypnosis (and placebo) is that it is *their* problem – not that they necessarily caused all of it – but if you own a problem you can actually make some differences and changes. A major therapeutic error among some psychotherapists is that they do not work to show the patient why their problem is 'their problem'. When we take ownership of our problem, we can develop methods to alleviate, sublimate or eliminate our problem.

Placebos are standard fare of normal living

This all brings up the interesting question of what a placebo is; in particular, how come placebos require somebody else to activate them? I think this is because we have evolved as animists – not consciously but at heart. We ‘grew’ up with charms and amulets and other physical things associated with healing and the incantations that go with them for thousands of years, so we have been programmed to get to a place where we really believe – its part of our psychology – that power comes from outside inwards. So a pill is no different from an amulet. We have been conditioned – and it’s a cultural thing to make our feeling system more optimal if somebody gives us permission to do it. This is why touch is so important. So I think placebo is something left over from magical days.

There is an article looking at antidepressants, old ones including TCA’s as well as newer ones, versus placebos over a 20 year period. The efficacy of antidepressants has improved from 40 per cent to 60 per cent over this period, but I don’t think it’s necessarily because the drugs are better. When they first started looking at this the placebos, as predicted in the literature, (including Beecher’s first article) were about 50 per cent as effective as the actual medication. Now, even though the medicines are still 50 per cent better, the placebo response has adjusted similarly to 40 per cent. So one could say that, as patients continue to learn that medicines are effective, our placebo response becomes more effective. Overall, placebos seem to be about 55 per cent as effective as the medication they are being compared against in a third of the patients. What is interesting is that if you’ve never had morphine or an antidepressant before, the placebo effect is still 55 per cent even though you’ve no idea how the medication is supposed to work. I can think of no biological reason why this should be so.

I think this whole thing has been created by medicine – by Beecher in his first article – because medical professionals tend to be trained to repeat what they have been taught and not ask awkward questions, so 50 per cent in a third of patients is what doctors expect. I don’t see how our bodies could be that smart.

Hypnosis is very cool to do!

Hypnosis is a magical incantation or invocation: when people are comfortable they start listening to what you are saying and focus on you – and they become much focused on the story, and all that becomes of interest is the story. There are different ways you can tell the stories. You can even invent a story – a myth. The therapist is using his animistic understanding of human psychology to interject insights into the patient’s psyche – insights and experiences and giving feedback to the patient. It’s very intuitive most of the time, trying to see what makes sense and watching how the patient responds. If they relax it’s probably a good thing, but if they become excited it’s probably an issue that needs to be dealt with. So under hypnosis you are violating the patient’s life story with their permission in order to reframe it and give them a better story. People like hypnosis – it’s not scary – and they invariably sleep better that night. They come back the next week and if there is something better in their life you ascribe it to hypnosis. It’s a very manipulative thing, but you have to use the patient’s mindset and their story to use proper manipulation.

This is quite different from stage hypnosis where they get a few volunteers from an audience of 200 who are self-selected as amenable to hypnosis – they may not know what it is but it still works. They are usually fantasy-prone and will easily demonstrate post-hypnotic amnesia, just like in the movies. The trouble with most hypnosis research is that they always pick highly hypnotisable subjects who can easily be persuaded, for instance, that their arm rose by itself. Those people are the easiest to

work with as they are very easily convinced. The downside with those guys is that the environment can easily induce them back.

There is a well-documented story of a gentleman with advanced cancer who came into hospital asking for the latest anticancer drug he had read about in the papers. He was told he couldn't participate because he didn't fit the protocol. But the doctor relented and gave him the shot. He immediately felt a lot better and happier and started breathing better. He finished the series and in a week or ten days he appeared to be tumour free. Then a report appeared in the papers that this drug wasn't any good. His tumours came back. He returned to hospital where they told him that this had been a bad batch of the drug and readmitted him to the trial, but just gave him saline. His tumours regressed again. About three months later it was reported that the drug definitely wasn't any good. He came back into hospital and died within three days. There are only four documented cases of remissions like these in the world literature.

Even though this gentleman would have been highly hypnotisable, having what the psychologists term a 'free floating ego', and although this was an outlier, I have learnt that all of us, while we may not be able to get rid of tumours, have immune, neurological and endocrine systems that are much more powerful than we have been led to believe; which is why the placebo is such an important thing. It allows us to convince patients that they have much more control over their pain than they currently believe.

Let me tell you about my own practice. I love ritual. I like having forms and charts for patients. And when patients come to my clinic they all have to go through a ritual of sitting in a certain room and filling out forms and seeing other clinical people, and by the end of the day they are brought to me and I look quickly through the paper-work and put it aside. Then I say: 'I don't want to hear about your problem right at this moment, for I have learnt over the years that people can fix their own problems, regardless of what they are. Unless you think God is punishing you, and I have only ever had two who did, everything I do is going to work, but you should not just believe me until I prove it to you.'

I spend a lot of time talking to them, explaining how methadone works: it's the best agonist there is; it's good for depression and anxiety, it doesn't hurt your immune system – it's a really good and powerful medicine and in my experience it works 94 per cent of the time and it's going to take away your hurting. I tell them that their depression and anxiety will take about two and a half months to fix, but I can have you fix your pain in two and a half weeks. I talk to them for about an hour and a half and their eyes get wider and wider because in actuality I am doing a hypnotic induction on them; I then call up the nurse (who is good looking which is part of the ritual) who takes them down to the methadone dispensary where they get their medicine. Before they leave I tell them that it is not a graded response: it either works or it doesn't, although it may leave a residuum of discomfort which everybody has, but if the pain is eight now it's going to go down to one or two or zero. It's a biological response and you cannot fight it. But I'm only going to give you a little bit or it could kill you. They come back the next day and the men say you were quite right doctor - after half to three quarters of an hour the pain went away for about half an hour to one hour and then it came back, just like you said. Sometimes a woman will say it didn't work and when I ask them what they did, they say they went home and cleaned the kitchen for the first time in ages and when I ask them how they did it if they were in pain they say – oh yes, it didn't hurt for a bit. Methadone does work – if you only give them a low dose only for a short time. When they tell me this, I stand up and shake their hand and say: thank you! – You've just told me something I love to hear from people – that you can be pain free. I don't care if it's the methadone or what it was, you told me something you can never go back on now. This whole hypnotic thing was to put them into a bind where they learnt that they could shut off the pain.

I have come to believe over the years that chronic pain is really a memory – it is a deficient life story that is relived and relived and with all the proper physiological responses – I think our motor system is feeding back into our sensory system. We were talking about trigger point injections and nerve blocks - I think that when people get fixed in their minds that they can't do certain things and this gets reinforced all the time, you can do almost anything that's unusual to change the sensory system and it will help them to move again.

I can have seen homeopathy work well with some pain patients. I am doubtful if homeopathy has any biological effect, but it works sometimes – homeopathic practitioners spend a lot of time listening and talking to patients, it's like a hypnotic trance and what they are transmitting to the patient is *hope*. And as long as there is hope patients will get better.

Discussion

We were talking yesterday about fibromyalgia and irritable bowel and wondering if there were centrally open pathways that make people more aware of their bodies and consequently pain. You've just suggested similar thinking on those lines?

I heard a talk from someone who had seen literally thousands of patients with limb and nerve injuries and concluded that CRPS was very unusual unless they had a lot of psychological problems, and unless he dealt with these there was nothing he could do.

I want to challenge you on your assertion that triggering the placebo response needs another person. I'm not sure that's true: there's a lot of stuff available over the counter or off the internet and I suspect that people are getting good responses from these things without the intervention of another person.

I probably over-generalised. The drug companies have built up this mythology – medications are one of our myths (TV ads for drugs are a very bad idea). The literature on antidepressants suggest that they are only 20% better than placebo and with the side-effects they cause, 20 per cent isn't really worth it. I wonder how the old country doctors did it? Hypnosis is essentially British – even though Mesmer first described. It was a Scottish surgeon, James Esdaile who performed 500 operations in India under hypnosis and tried to introduce it to the world – but anaesthesia was just being discovered.

Actually it was something the old doctors used to do all the time. When I was in casualty there was a little old lady who used to come in all the time and I was told to prescribe Esotcal and make sure it was the blue pills – and Esotcal was lactose spelt backwards! – And her pain was always controlled.

There's a very interesting corollary in homeopathy with what you were saying about patients not realising they were better. People will come with a specific complaint and they're looking for relief for this. When they come back and you ask them if there has been a change they will commonly say no. Because you've taken a detailed history of other complaints and symptoms you go over them and they will say – oh – I haven't had that for weeks – it's much better, or I'm sleeping much better. They are unaware of the extent they have improved because their main complaint hasn't. There seem to be effects going on at different levels not necessarily including the presenting problem.

In hypnosis you're doing the same thing – you're trying to find things that have changed to reinforce the patient's new view. If you have a good rapport with the patient and they are suggestible... if they are religious I might say God is always working with you, but you've got to open up to it. For a non-religious person I say that the "machine" is designed to work in a beneficial way and the only thing that stops it working is the constraints that you put on it. People want to be better but we have to find ways to convince them that they are getting better...

But how does this relate to the focus on the presenting complaint?

People stay depressed because our feelings are what we focus on. People don't realise that they are really complex creatures – therapists and homoeopaths realise this. In pain management you have to get them from one point of view to a better one by being sly – by suggesting that they really are feeling better. Most pain patients have problems sleeping: hypnosis and methadone help sleep and I try to get them in a double bind - "if your pain is no better how come you can sleep? – it must be better..." Patients aren't very good at reasoning and what you're trying to do is to reframe – to refocus – the patient to a healthier aspect than the illness.

So you're trying to take the focus off the presenting complaint and give them more to think about...

And the presenting complaint becomes less important. What I don't like about modern medicine is that it's too rushed, there are too many time constraints such that doctors no longer get to talk to patients any more – even psychologists can't talk to patients because of these stupid rules. And the only way to change people is to show them a different way to live their lives... A lot of patients in the South are very fundamentalist so I always go to the first page of the Bible and ask 'What did God give you dominion over – yourself?'... 'It doesn't say that'... 'Quite right – God has dominion over you as your father to help you deal with life so you have a place to go back to.' For them it's a very powerful metaphor. For a Jew, use Jewish metaphors – for a Buddhist something else. You have to use the language of the patient to put them back into a healthy place. This is the natural place to be – otherwise how would you have spontaneous healing or recovery?

One of the things you're illustrating is that whenever you do a clinical trial what is not taken into consideration is the clinician involved. Patients get a lot from the clinician and a caring attitude is therapeutic in itself.

The Institute for Conscious Evolution and Human Development has developed a simple and effective method, the 'Freedom Exercise', for teaching people how to successfully handle the many emotional states arising in daily life, "by letting go... and returning to and remaining within a natural state of peace, joy and well-being". Details can be obtained by emailing kellmj@aol.com

Images of Pain: Understanding pain related distress from the viewpoint of semiotics

Owen Hughes

‘Should we be making a point, as part of clinical assessment, of asking people to describe their pain, not just in words but pictures?’

Words and what they mean are not necessarily the same for everybody. This is an area I got interested in right from the start of working in psychotherapy and particularly when I started working in pain. People wouldn't tell me about nerves etc. They would tell me a story or describe a picture of what they felt was going on either in their lives or in their bodies.

The pain and chronic fatigue centre in Bronllys where I work is in the middle of a sheep field miles from anywhere and is a very different place to be for most of our patients who come from the cities and valleys of South Wales – it's very quiet and we encourage people to start talking and thinking of things differently.

Understanding pain

I want to talk about some of the ways we develop our understanding of pain. We all have our 'truth' about what pain is and we ascribe our own meanings to it. Then I want to look at some of the images used by patients and indeed by practitioners, and the placebo and nocebo effects of words and images. The meaning intended in the doctor's words are often not what the patient is hearing. And I want to reflect on how this affects how we go about helping patients with pain.

So where does our understanding of pain come from? There is some evidence that the foetus can feel discomfort and the newborn's early experiences are of discomfort and finding means of alleviating that. Newborn children are very good at telling people that they are not happy. But they haven't got words, and cannot put them together to help them understand what's going on, until they are at least a year old, and don't become fluent until they are two or three. So they are going through the world and experiencing things and understanding things as they become more adept at living in their environment. So the question is: what are they using? My answer is that they are probably using images – not just visual pictures but auditory and kinaesthetic pictures as well – of the world around them and how things work. I don't think we ever stop doing that. We go through our lives with a visual understanding of what's going on. In this meeting we spend a lot of our time using words but when we go to open the door to leave the room we won't be using semantic language to do that but a visual image of what's behind the door and how doors work – a kinaesthetic anticipation of how the handle is going to feel.

One of the things I came across when I was doing my undergraduate degree was Paivio's dual processing model of how we understand the world. There are two separate pathways: the verbal and the visual. We use the verbal pathway to use and receive words. We take them in, check them against the vocabulary we have in our heads, say that fits in with that idea and move forward. When we are producing words there is a whole series of processes we go through before they come out of our mouths – mostly a checking process that stops us saying anything inappropriate or things that we don't mean to say. Paivio's argument, backed up by research, is

that the other pathway, the visual one, is very different because it doesn't have the checking process that we need to produce language. It doesn't have discrete symbols like words and there aren't any grammatical rules. It's an implicit thing and involves tacit knowledge. But it is quite concrete as regards the pictures that are formed. So it is very fast and is a lot faster way of interpreting things than producing words.

Pain and semiotics

The word 'pain' will produce in most people a similar image. We are constantly being told what a complex thing pain is. When someone gives a talk on pain one of the first images that comes to mind is Descartes' picture of the boy and the fire. In this situation, pain is the signifier. If we take that a step further and ask: what about back pain? What is the image that comes to your mind? Is it an anatomical structure? Or a type of person? Of that signifier there will be something that signifies for you. It may be the skeleton or the nerves or a variety of other things. For one of my patients it was a digestive biscuit. He came in walking very gingerly and when I asked him about his understanding of what was going on in his body he told me that the doctor said he had a crumbling spine. He visualised his back as like a stack of digestive biscuits and every time he moved a bit fell off. So he daren't move! I'm fairly sure that that doctor didn't have the signifier of digestive biscuits in mind when he told him that. That's the danger of using words without checking the picture that they generate in someone else's mind. If you tell someone in their 30's or 40's they have 'a touch of arthritis' they may have an image of a granny in a wheelchair and think that's going to be them, or years of going to the doctor for prescriptions. This may represent loss of dignity and status especially if the doctor is seen as all powerful and whose instructions you have to follow.

When I was doing my master's degree I would ask patients to tell me about their pain and if they were to draw a picture of their pain what it would look like; and if I were to take a picture of their body what would I see going on. Such descriptions included 'like being shot in the back', 'it's as if the skin is being ripped off from the inside', 'my spine is being pulled apart', 'someone is sticking a knife in', and 'like having a blow torch on my skin.' I imagine you will have come across this sort of thing fairly commonly. But just take a moment to think about the words and what the pictures that go with them might be. Bear in mind that those pictures are going to be faster, unchecked and more powerful. If every time I have a pain I have one of these pictures that's what I'm going to react to first and the anxiety kicks in and a whole lot of other things with it. An image of your skin being ripped off is a hideous one and is going to cause a lot of distress if it's unchecked.

A whole range of issues came out of this research but there were five basic areas where the pain impacted on people. Firstly there was a huge impact on their self-image in terms of their worthfulness, their strengths and their personal agency in life. Then there were some really interesting ideas about where the pain was coming from. Very rarely did it seem to have any basis in fact when you looked at their notes. They constructed their images based on other experiences in life, with very little resemblance to any anatomical details or pathology. The issue of locus of control was always interesting, especially the idea that the doctor was in charge. Some people who had always felt they were in control found it very difficult to give up that control to other people. People often talked about the different modalities involved in the pain. These might be expressed in kinaesthetic terms like different temperature, sensation, texture or weight – "my leg has become a lot heavier" – and visual ones such as being a particular colour or a particular shape.

Using imagery in therapy

At Bronllys we find it very useful to use images as ways of helping people to manage the experience of pain, and spend a lot of time thinking about this. If you can change the image you can change the experience, and this can have a very powerful impact. It is a very useful source of healing if we can give people a more adaptive meaning to their experience.

People get some very strange ideas of how their bodies work: “you’ve got some notches in the middle of each side and that just locks up”; “and the stitching, you know the tail, that’s sort of crumbling”, and misinterpret what doctors tell them: “Mr T, at the pain control, he said there’s so much where they’ve cut into the spine the nerve endings they’re just jumping”. Now I’m sure Mr (actually Dr) T wouldn’t have said this but this was what they heard, and this brings us on to communication and how imagery can be used to create a better understanding between clinician and patient. I find pain drawings very useful, and are the first things I look at when I get the patient’s pack of forms because they tell me so much about the patient’s experience and distress. Often there are little additions to help me understand their problems. [Other images of pain were shown at this point]

What is your image of a typical pain sufferer? This [a photo of a woman playing golf] was submitted by someone who had been through a PMP and was determined to the image she wanted everyone to see was not someone in a wheelchair.

So pain is very multidimensional not just in terms of words but also the visual elements for different individuals. The old Descartes picture with the single wire is one a lot of people still seem to have in their heads, and when that gets added to it can become very peculiar.

Some images of pain introduce a spiritual element such as martyrdom [picture of the flagellation of Christ] and the idea that it may lead to spiritual enlightenment. Historical perspectives on pain are fascinating in this respect. The concept of pain as in the hands of the gods externalises the locus of control.

Examples of the therapeutic use of imagery include MacIver’s and Oakley’s publications on treating phantom limb, Moseley’s on [Complex Regional Pain Syndrome](#) and Hilgard & Hilgard’s 1975 book on the use of hypnosis in pain.

Should we be making a point, as part of clinical assessment, of asking people to describe their pain, not just in words but in pictures? Asking something on the lines of: Explain what I would see if I took a photograph of your pain? Or indeed one that represented your life? That is very effective shortcut to finding out a lot – people put their priorities into their ‘photographs’. Should we be making more out of pain diagrams than simply getting an idea of the distribution of pain? Should art play a greater part in pain clinics given that it has this immediacy for people and can be very therapeutic in itself?

Epicetus is often quoted: ‘Men are disturbed, not by things, but by the view which they take of them.’” So pain is what the patient says it is, and truth is what the patient or the doctor thinks it is.

Discussion

Are there images that patients have that potentiate their pain?

Absolutely. As soon as patient realise that their back is a much more solid thing than they had been led to believe, and cannot be ‘ripped apart’ or ‘crumble’, they can start to move – that’s what pain management is all about.

Sometimes I show people pain diagrams they have done some time apart. I suggest: isn’t it funny that your pain is different to what it was? Things can change. Because

we as doctors and nurses have been trained in anatomy and physiology and see scans we have a particular pictorial view – but patients don't have that. So if we try to convey our view to them it may not make any sense at all – we may show them pictures of the spine etc but we all think in metaphors – so physicians have to use metaphors when explaining things to patients.

Yes, but the danger is that the metaphor becomes concrete for them.

The imagery that we use can mislead: MRI scans show discs that are black – so they are dead!

Patients come to psychologists and say the doctor says their spine is crumbling and we say it's not like that. It's only just struck me how readily people give up that idea when you're the person who has sat down and listened to them and taken them seriously – so it's not just about an image, it's the whole business of relationship and communication...

Yes, but using imagery in that conversation helps communication.

I think it highlights the way we are constrained by language. When we meet a patient and they tell you what they think is wrong – you may think you are using the same language but the image of that is different in different professionals. I sometimes ask patients to close their eyes and tell me the colour of their pain. Very often it is bright red – and look at that over the course of treatment.

It came to me the other day that many of the images people use about pain are images of war – fighting pain – they hate it. There are a lot of imperatives that come with this – they must do certain things. We are both subject and object of pain and if we fight it we are fighting a war with ourselves...

The danger is that we're such an educated profession - we have to write words: essays, dissertations, papers – it's all about words, and we may forget that perhaps the most effective form of communication doesn't use words but pictures.

People come with images which are part of beliefs which are so deeply embedded they are impossible to correct. How can we educate osteopaths and chiropractors - even orthopaedic surgeons and some GP's – not to use alarming imagery and to appreciate the power of words to create these images which close and brick up doors for patients which I simply cannot open?

I've seen patients in wheelchairs in their 20's because of this.

Following the last two points I'd be interested in your opinion of the use of the word battle in the context of coping with cancer – is this positive or negative.

I think it's unhelpful because that image causes anxiety in itself.

The Marsden have done some work on the effects of a positive mindset on breast cancer and have shown that you can slow progression by inducing a positive mindset by psychotherapy.

But work on the use of battle imagery has shown it is unhelpful.

I usually tell people there's no winner – no battle is fought without losing something, even if you win the battle – and we move on from there. The other image is of hitting

your thumb with a hammer – you stop and suck it and then you go on knocking in the nail because you know what you've done and why it's hurting; but when it happens to your back you don't understand this. If someone uses flashlight photography at a wedding you expect this but if one goes off unexpectedly in a darkened room you're going to worry about it. If you suddenly have a back pain you're going to worry about it and the anxiety won't help – and this approach seems to help people understand and accept the situation with less anxiety....

As long as you don't develop more negative ideas

One thing I heard recently was instead of wear and tear: wear and repair! I thought this was wonderful! I always use it with patients now and find it very positive.

The verbal examples people gave you were all examples of torture, but my understanding is that most chronic pain patients don't live their lives as if they are being tortured – they just get on with them any way they can, but they are giving us those images at the beginning because nobody has ever taken them seriously – they have to keep upping the ante – it hurts doc! - well take a paracetamol - but it really hurts!

Yes, and as images come with that they may help to generate more distress.

I disagree – if someone describes a pain as like a knife sticking into their back that's not upping the ante it's just describing what the pain feels like

But it's the image ...

I need some practical help with changing the image – what's the best way of correcting a picture of crumbling digestive biscuits? – I don't think some of our patients are intellectually or artistically able to turn it into a tree or something.

You ask them questions – like do you really believe that your back is like the biscuits? - and wouldn't something else have happened if it were? – and helping them to question their imagery ... *but doesn't that take time? – I only have time to tell people things* - no, a bit of Socratic questioning is actually faster than trying to tell people things, and after a quick tell they're going to be back more often.

One word from an orthopod can set up these negative images – how come one word from me won't have the same effect?

A lot of it's about the authority of the doctor – the nurses in my clinic complain that patients accept in one word from me something they have taken weeks to get over.

I can't form images in my mind and when I had a chronic pain I never had an image – perhaps that's why it didn't bother me – it just hurt.

Complementary therapists spend much more time with patients, they're clearly interested and go into much more detail and by the time they come to the end of that the patients accept the image they are given – their spine is misaligned or whatever – this is a terrible problem in a country [Canada] where chiropractic is Government funded – I spend all this time correcting their images and next week the patient goes back to the chiropractor...

We have a very difficult job – I used a quotation yesterday about chronic pain being a cry in a foreign language, and I'm at risk of making a mistranslation – it's asking quite a lot of this to get it right every time.

Timing is everything. People go through stages on the pain journey and they are sometimes ready to change and sometimes not. And as regards going back to the chiropractor, people are doing this sort of thing all the time. They are getting health advice from lots of sources and we think we've got a premium – when they come to me they're my patient and what I say matters – that's rubbish! They are going to dozens of other people and may take more notice of the lady next door, and we have to be conscious of that. Its luck really if they come to us at the right time when they are ready to change and we're the right person to change the image ...

I'm not sure it's like that – there is a quotation to the effect that when the practitioner is ready the patient will appear and when the patient is ready the practitioner will appear.

It's probably better to assume that everyone who comes to you is ready to change—just some need a lot more work.

We live in a time when physical pain gets the attention but for a lot of people its emotional pain and a lot of these images about pain contain a suffering component. Pain is what it says on the tin but it's what is in the tin ... a lot of other stuff...

That's what I like about pain diagrams as they can communicate the suffering.

Painting over the cracks

Creativity when art and medicine collide

Diana Brighthouse

‘Exposure to art can lead to positive physiological and psychological changes in clinical outcomes...so why isn’t more being done?’

When I entered medicine I had a clear if naïve picture of medicine as a healing art and I have held on to that idea throughout my career, which explains why I am no longer practicing in the NHS.

I have evolved from a jobbing consultant anaesthetist through a mixed-pan doctor and anaesthetist to a fulltime pain doctor and into a psychotherapist and now I’m approaching my final year of a fine art degree, and along the way I took a master’s in spirituality. But I think in all of those things I have been looking at medicine as a healing art.

Inter-textual space

The inter-textual space will be familiar to anyone with a background in philosophy or the arts. It’s sometimes called the interpersonal space but that’s not strictly accurate. To put it simplistically, the inter-textual space is the third space where something is created in the interaction between subject and object. That subject and object might be two people, but might be a person and a piece of literature, music or visual art, or a landscape. That is the place where creativity occurs, where the healing art of medicine occurs, and where art and medicine collide.

Public space art

I’m going to talk mainly about public space art and not about art therapy which are quite different things. I undertook my art degree because I had thought initially I would extend my training into art therapy but psychotherapy is an incredibly circumscribed territorial profession, and even if you’ve done five years’ training as a psychoanalytic therapist they want you to do another four as an art therapist. And in the UK art therapy only exists as a tiny part of the mental health sector, and exclusively in this – so it is virtually unavailable and not directly applicable to any of our practices.

It is actually used in palliative care.

Public space art on the other hand is something we’re all exposed to every day. It’s not just the visual arts but includes architecture, the performing arts and music. There is a lot of literature about narrative and writing therapy – getting patients to write about bad experiences can be quite powerful, and in the pain clinic if you get even the most poorly educated and inarticulate patients just to write down words about their pain it can be quite a powerful way of getting into their world. Drama therapy is used quite a lot in adolescent mental health but not to my knowledge in any pain clinics, although it might be very powerful.

The biggest and most comprehensive body of knowledge about art in medicine can be found in the Arts Council of England 2004 report *Arts in health: a review of the medical literature* edited by Dr Rosalia Staricoff and reviews 400 papers. It is available online, and anything I am going to quote comes from this.

[There followed a slide show, mainly of pieces of art, illustrating these and the following points]

Some of the most compelling evidence is in the study of the environment on rates of healing and recovery. The implications of this for the architecture, design, decoration and setting of healthcare facilities cannot be underestimated.

Arts and health: research and evidence 2009

I have some visionary examples of new hospital build inspired by this principle but nearly all are in the US. I haven't any pictures of purpose-built wards – one of the most famous being the Bart's breast cancer unit – but there is evidence of a reduced length of stay in medical wards just by changing the environment, with reduced analgesic requirements. There has been a lot of evidence in the mental health sector that if you get rid of the old big asylum type wards with something more homelike you reduce patient aggression levels. Perhaps more surprisingly there are consistent figures to show that you reduce staff absenteeism and improve retention just by providing a better and more pleasant working environment.

There is an organisation called *Painting for Hospitals* which leases and in certain circumstances gives out paintings for hospitals to improve their visual environment. The paintings are almost all by Royal Academy's provided on a charitable basis.

Participation in art

Participation in art is getting patients to participate in art projects and is not the same as art therapy. I think it may be what is used in palliative care. 95 per cent of patients report that they are more relaxed and their minds lifted from other things. This mirrors what Michael [Kell] was saying earlier – if you are relaxed and lifted from other things then maybe those things aren't as bad as you thought they were. 93 per cent of medical and surgical patients reported increased happiness and contentment and this was linked to early discharge. You may suggest these were fairly nebulous measures but we're not dealing with easily quantified things and this seems very worthwhile. 90 per cent reported improved mood and 48 per cent that their pain and symptoms were relieved, and this was reflected in decreased analgesic use and increased mobility. Another study showed that visual arts and live music reduced levels of depression by a third in patients undergoing chemotherapy.

Another project which might be used in the pain clinic involved asking people to paint their dreams: most of said they couldn't paint but they were encouraged to see what happened when they tried and there were some fascinating results. If you were an art therapist you would be doing one-to-one work, interpret the painting and getting the patient to free associate and so on.

Experimental subjects responding to a controlled pain stimulus looking at paintings or a blank panel rated the pain as 33 per cent less intense when looking at paintings and this was confirmed by reduced electrical activity in the brain. Patients viewing art-work postoperatively demonstrated reduced blood pressure, lowered heart rate and reduced skin conductance, with reduced requirements for analgesic medication.

Out of the 400 papers reviewed by Rosalia Staricoff there were very many which showed similarly positive results. There are clear economic benefits if you are sending patients home earlier and using less medication.

Effects on staff

What about effects of environment and art on staff? Where medical student training included visual arts, history and philosophy of art, semiotics and so on they demonstrated improved observational skills and an increased capacity for critical analysis. Neurosurgical trainees subjected to a similar module which included life drawing classes were found to have improved 3D thinking and practice. In the mental health services staff exposed to similar training showed improved communication skills, and in nursing training an increased awareness and empathy with the emotional aspects of illness.

Conclusion

Two quotations lend authority to my contention that there should be greater awareness of the value of art in healthcare:

The arts can enrich all our lives but they are also a powerful force for healing. Arts in healthcare will inspire, inform and encourage new partnerships between healthcare professionals and artists of all disciplines. This new initiative represents a significant contribution from the arts to healthcare and the wider social inclusion agenda.

Gerry Robinson, Chairman of the Arts Council of England

I would like to see the benefits of participation in the arts recognised more widely by health and social care professionals, particularly those involved in commissioning services for people with mental health problems. This is not some kind of eccentric add-on – it should be part of the mainstream in both health and social care.

Alan Johnson, September 2008

In sum, exposure to art can lead to positive physiological and psychological changes in clinical outcomes, reduced drug consumption, and shortened length of stay, increased job satisfaction, improved doctor-patient relationships, improved mental healthcare and development of empathy across gender and cultural diversity. So why isn't more being done? The evidence is clear, the government awareness is there, but it doesn't seem to be filtering down.

Doctors heal your body and mind; art heals your soul
The Central Louisiana arts and healthcare Inc.

Discussion

I don't think you need be so despondent – there is plenty going on. Our new oncology unit [in Leeds] is a very beautiful with wonderful use of space and furniture

Our health authority stripped out everything from our outpatient department. The walls are bland white, the only decoration stickers imploring you to use hand gel. Where there were some good paintings which have all been sold off to staff. The reason given was prevention of MRSA and C.Difficile

I have been involved in the commissioning of a new neurological rehab unit in St. Richards in Chichester and there was a requirement that any piece of work had to be able to be steam cleaned or have industrial cleaner on it once a week.

Part of the problem is nobody knows what is the best painting. When you go to old folks' homes they have nice little views of trees and cows – but you might want something a bit more modern. Is there any evidence as to what is best?

There is some evidence from America that landscapes are calming and soothing and that strongly figurative painting can be quite disturbing in mental health centres. But there is no British work that I am aware of and the American work seems to involve dialogue between clinicians with a vested interest in what they are pushing.

One problem is that we're inclined to generalise about what suits patients. There are several things you showed which I quite liked but if I had to stare at them for three days while I was trying to recover they might start to get on my nerves – maybe we should show people a lot of slides – we could clean the walls and give people a choice...

We have a new pain clinic at St. Mary's and the hospital art council came round – they have a huge collection and they stuck pictures up without asking what we wanted. They are screwed into the wall so they can't fall off...

We [in Calgary] have a new children's hospital which from the outside looks like something from the Blackpool play beach and inside is a riot of colour – everything is child size... play areas everywhere – everything designed from then beginning for children and adults have to adapt to it and it's wildly successful: stays are shorter, counselling needed is much less, and less family disruption.

There is top class RCT evidence for what you say – the reason it isn't taken up is because there is no easy explanation of why it works on the biomedical model, and of course this rules. As regards medical education, one of my reasons for going to the Peninsular Medical School is that they have one of the biggest and best medical humanities curricula anywhere. The challenges in pursuing this agenda are that you can show short term gains but it is difficult to show that these are sustainable when there is this huge input of things like genetics and molecules bombarding them. We don't know that yet but the PMS has got its first graduates as far as F2 and there has been an interesting study which suggests that one benefit attributable to humanities is that they are better at dealing with uncertainty than other medical graduates. One of the big problems with the biomedical stance is the fallacy of certainty – we think we know the answer, the effect size is 2.3 – but life's just not like that and it looks as if the humanities curriculum helps people cope with this.

Can you say something about colour? The easiest way to change the environment without discussing the best pictures ... there is something in the back of my mind in Germany called colour therapy where certain colours were ascribed to certain personalities ...

When (?) hospice moved to St Charles hospital they got one of the top interior designers and they painted the interior all in primary colours and it looks very dramatic – not like a hospital at all.

You talked about using pictures to evoke recovery – a healing response – and I wondered in the light of earlier discussion whether there would be anything to be

gained by having pictures which might actually evoke the patients' experience of pain and enable them to talk about it – or might it have a negative effect.

That's more in the realm of Deborah Padfield's work...

I was involved some years ago in some work on décor in GP's surgeries and it was pointed out that you need different décor in different places. In the waiting area it needs to be of a fairly calming nature, but in the clinical areas it didn't matter because the whole focus was between clinician and patient – trying to get information across in minimal time etc.

Some time ago American medical schools thought that the doctor patient relationship would be enhanced if they took in more humanities students without adequate scientific training but they switched back because the former were so bad at critical thinking and it was easier to teach the science students to be more humane than the humanities students to be more scientific. Have you gone through this phase in England?

It's an ongoing thing - some schools have introduced graduate only entry with more arts students but the data isn't yet there.

Some years ago I was seconded to another palliative care unit which was failing – it has lost its manager – when you walked in the whole atmosphere was depressing. I was told I had to be creative with my time and resources so I couldn't have a lot of new equipment and things so what I did first was to rearrange the chairs in the waiting area and got Paintings for Hospitals to come – for free – and within days we had changed the environment and made it a more welcoming place.

The Creative Arts in Palliative Care: The Art of Dying

Nigel Hartley

‘We emerge deserving of little credit; we who are capable of ignoring the conditions that make muted people suffer. The dissatisfied dead cannot noise abroad the negligence they have suffered.’ Professor John Hinton *Dying*

Listening

In a sense, the above quotation summarises the motivation for Cicely Saunders and her peers in the 1960's and 70's to develop what we now call palliative care. Cicely Saunders is famous for her insistence that *you* matter until the last moment of your life. What does that mean? One of the things I am really passionate about in life and in my work is how do we engage when listening to each other. Here you are listening to me – or not. Some of you are making eye contact with me: what we call active listening; some are holding their bodies in certain ways, but in reality I have absolutely no idea if you are listening to me or not. Most of us learn to give a very good impression that we are listening to each other. We all do it – there is nothing wrong with it, we have to survive and get through the day. If I've seen that patient 20 times before and they start telling me that story I think – Oh God , not this one again; so I sit in a certain way and nod in all the right places and make eye contact, but in my head I'm planning what I'm doing later in the afternoon. But what I'm interested in are those times when we make a connection with another human being and how we might articulate those experiences. They may be very fleeting – sometimes you're walking down the street and you catch someone's eye and in that moment there is some kind of connection that happens and something you know about each other. What we normally do as it's all a bit uncomfortable is to pull back from it and get on with what we were doing. What happens if we actually stay with that moment? What possibilities does it make available? So what I want to give you is some examples of what is possible if you actually stay with that moment, and where it might lead us.

In healthcare nowadays it's very trendy to go on courses to learn how to listen. Some years ago I went on a day course because I was intrigued. We had a really lovely time; the guy leading it taught us about body language and active listening and eye contact and what he did in reality was to teach us to give a really good impression that we were listening. Not once did anyone mention what goes on when you really make that connection. We all know that it is very difficult to articulate. I remember thinking that if we have to teach health professionals to give the impression of listening then we really are in trouble. In reality we are teaching ourselves not to make connections – to protect ourselves and to keep ourselves safe so we don't get into trouble. What happens is that we lose the possibility of taking risks with the people that we work with.

Those who are unhappy have no need for anything else in this world, apart from someone who is capable of giving them their attention.

Simone Weill

A middle-aged lady had been given a diagnosis of HIV/AIDS some years before I met her. She had been abandoned and shunned by all her family and friends and was living in a flat on her own with practically no human contact. She came to the hospice to see the medical consultant regarding her drug therapy and he suggested everything he could think of, like coming to the day hospital, to ease her isolation but she refused every offer. Eventually for some reason she consented to see me, and I saw her regularly for the last few months of her life. For much of this time she was totally withdrawn and refused to make any eye or any other contact. Any questions were responded to with a shrug of the shoulders; there were long periods of silence and her only words were yes or know. I tried everything, like music, that I knew. I found it very distressing. After some time I asked her what she came for and she shrugged her shoulders as usual but I thought she must be getting something out of it or why did she turn up; so we went on sitting in silence. Eventually she became very ill and was admitted. After a few days she was a little better and came to see me and I sat with her, in silence, for about an hour. At the end of this time I once again asked her if there was anything else she would like and suddenly she began to sing. I was completely shocked and pulled out of my comfort zone, but I started to play the piano very quietly with her. She sang in whole phrases, not like her usual monosyllables, at first without words and then she started to use words which are apparently the Brownies good night song:

*Oh Lord our God
Thy children call
Grant us thy peace
'til the sunrise...
Goodnight...Goodnight*

*(and then she started to speak)
Keep all our family in your care,
Love us all, as we know you do.
Still, Goodnight and God bless
to friends, family and those that we love.
(and singing again)
Goodnight... Keep us in your care.
Amen...Amen.*

It was always as if she was using this as a ritual to say goodbye to her family. When she finished I looked at her and asked if she thought she would die soon and she said yes, very soon, and in fact she died the following morning.

(A recording of this followed)

So what did you hear?

She was interacting with you.

Yes – one of the things that music does well is that you can actually hear people listening which you can't do in language. It's so immediate, we're doing it at the same time as each other – it's a very different frame in which to be in relation to someone.

Did you let her family have this? No, I never met them.

Do you think there was release and acceptance?

Yeah ... it's difficult ... all I know is that I was in the room with her and this happened ... you can interpret till you're blue in the face but you'll never know.

I can't *pretend* to listen to the someone in this situation – I just have to listen acutely to every note she sings and improvise around that – we're just making it up together.

That could influence her a lot

I think that's the key to your question about how you articulate the problem of how do you give someone your attention. I would insert the word 'whole' – your whole attention – you were surrendering yourself completely without any inner preoccupations or reactions...

I think I would articulate that as getting myself out of the way. When she started singing... I'm human and my first reaction was please don't do that! But you can't invite someone in and then tell them to stop. My craft (a word we are in danger of losing in modern medicine) at that point was to use music. Once I started to hear her I played as I would with any other musician.

I got a sense of her listening to you

For her it was having the courage to do something.

Did it make a difference to the way she died?

I don't know. I think in asking this we are in danger of losing the sense of the *now* and what's really important – the health system we work in always wants to ask: Did it make a difference? It certainly made a difference at that moment.

When people are dying they are invariably depressed – they may not act depressed but they are inside. This involves an imbalance between the right and left hemispheres – the emotional stuff is in the right hemisphere – this lady is severely depressed or has right hemisphere damage from her AIDS – we have to remember where the patient is and not where we are.

How did it change your day?

I don't know – it was 10 years ago. But it has probably changed my life...

And may have changed ours...

What do you feel when you hear it again as you have many times?

That's an interesting one: it goes back to this whole idea of listening and how we listen, I think there are three levels of listening: the first is personal. When I listen to someone my first response is always a personal one: that makes me uncomfortable or makes me want to cry or laugh etc. When you are working with people who are vulnerable you have a responsibility to hold them and support them. That's not a very good place to be and I think we need to get out of it as soon as possible. It doesn't mean we can't learn from it, but in order to work with someone we actually have to do something. If I stay in that first place a lot is going to be about me. So the next level is to listen to what someone is doing and in that case she started to sing so it gave me a world I could join her in which was music. She starts with a minor second – E flat and D so I put a C minor chord in; not because it makes me feel sad but because it takes me into that musical frame. So I'm listening on that level which is very

straightforward. There's also a level of surprise: gosh, this is working – something's happening. In order to be there I have to stop listening because otherwise it goes inside me and I stop paying attention to what is going on between us. Music lives in that space between us – a lot of the arts do and language does. Real love requires a distance – it's not about consuming or drowning them – it's being in a balanced position with someone.

At St Christopher's we have a team of artists who work in the community, in care homes and all over the place using the arts to help people tell their life story, or create a legacy they want to leave behind. Paul was an elderly Jamaican man coming to the end of his life in a care home. He is blind because of his cancer; all his family are in Jamaica, he has no visitors so he is isolated in this bed and in this room. He is just waiting to die. One of our artists went to see him and he asked her to set up a video at the end of his bed. He wanted to record himself, and the video to be sent to his family but also be seen by as many people as possible. It's very important that if we get a request like this that we do our best to see if it's possible. So she set up the camera, sat down and listened. This is what he said.

*I've been that fat black kid in the corner all of my life and I'm gonna end it.
Now I'm that fat black kid in the corner who can't see,
Whose hands are always held out, always in need.
When you're that fat black kid in the corner
You learn not to need too much, you learn to get by.
If a girl is willing to go with you, great guns!
But if she suddenly changes her mind, no hardship!
'cos I've always been big, I've always been careful
I'm no rapist, I'm no man who bullies his woman
Although sometimes I wish I could,
'cos I see them leave me for other guys who hurt them.
But I'm the fat black kid in the corner
So I watch and philosophise, I stand on the side.
Now I'm blind and I say 'How come I didn't grab one when I could see?
Like all my friends told me to
'Grab her! She'll do all right, she really likes you, you're really in there son!
Now I'm blind, where am I well in?
I'm well out of everything.
Lots of my friends, I've lost their telephone numbers
'cos I've lost my pieces of paper I used to write them down on
And there's no-one to search out all these intimate little corners for me anymore.
'cos I was the fat black kid in the corner
I did all of these things for myself
I knew how to repair things
I knew how to make things work
Because that way I wouldn't have to beg anyone anything.
I always stand in the corner and get by.
Bye, Bye. Getting by
Bye, Bye. Getting by
The kid in the corner
He'll get by.
He's blind.
He wants to cry
The end.*

I hear a quite resilient human being who has managed to get through his life despite what society has done to him. I wonder, thinking of this and the previous one,

how many people die without the opportunity to let that out – whatever that is. There is an energy which comes at the end of life and the tendency is to want to dampen that – it's too uncomfortable if people get distressed.

The family came over and heard the tape which was incredibly hard for them.

Pity they didn't come while he was alive...

Most people don't – they live so far away...

It's very sad that no-one helped him find those phone numbers and make those contacts – so many missed opportunities...

We are working with care homes and encouraging staff to listen and respond... it's an important duty of hospices, especially in a community of many races as in South East London, where it's very difficult – many don't speak much English...

It's not rocket science...

Actually for many people it is ...they're afraid of it ... but you can teach people to live in that emotional world and survive it.

What you said about the risk of making connections is very important. You are moving into uncharted territory and that's a bit scary. It's been given a reason why doctors stop listening to patients.

But I wonder if the energy it takes not to engage with people isn't more than it takes to engage – it takes a lot of strength to hold yourself back.

I was having coffee a while ago in our coffee area and overheard a conversation at the next table. Four young women, all coming to the end of their lives, were bemoaning the fact that they didn't look good anymore and never would – their clothes didn't fit them because their breasts had been cut off or their weight fluctuated so much, they'd lost their hair etc etc. My colleague and I went back to my office and phoned the London College of Fashion and described the conversation to one of their lecturers. He came to the hospice with a group of students where they met the women. Each of them worked with the students to design their own outfit and choose materials. Then they went up to the college and made them. We decided to have a celebration: we invited all their families, got in a jazz band who played in the centre of the building and everyone came to hear what was going on. The women came down a catwalk in their outfits and each of them spoke. [We put together this slide show...]

This is an example of something very simple as well as powerful of listening to what is the potential in what people are saying rather than being stuck with the negative bit of it. I have a gripe against the world of therapy which focuses on this and keeps people in this place for years of having to deal with the issues instead of turning it slightly on its axis and looking for what is possible as a way out of their suffering.

Have you done it again?

No – I think there is a danger of doing something over and over again to a point at which it becomes worthless. The next group of women may want something different. Hospices tend to stick to the same model till it really needs to be refreshed.

A woman with advanced lung cancer was with us for about three months before she died. I hadn't met her until the last two or three days of her life. I was passing her room and she beckoned me in. She was sitting up in bed on oxygen. She was very breathless. She pulled off the mask and said: someone told me you play the piano. She asked me to take her to my room, where she indicated that she wanted me to switch on my tape recorder. I tried to work out what she wanted but she shook her head at every suggestion. Eventually I just asked what she wanted. She wanted to sing. She had the words on a piece of paper, and sang the whole of the song without oxygen. She asked for a copy of the recording for her family. She died three days later.

*When death comes
like the hungry bear in autumn;
when death comes and takes all the bright coins from his purse to buy
me,
and snaps the purse shut;
when death comes like the measles-pox;
when death comes like an iceberg between the shoulder-blades,
I want to step through the door full of curiosity, wondering:
What's it going to be like, that cottage of darkness?
And therefore I look upon everything
as a brotherhood and sisterhood,
and I look upon time as no more than an idea,
and I consider eternity another possibility,
and I think of each life as a flower, as common
as a field daisy, and as singular,
and each name a comfortable music in the mouth,
tending, as all music does, toward silence,
and each body a lion of courage, and something precious to the earth.
When it's over, I want to say: all my life
I was a bride married to amazement.
I was the bridegroom, taking the world into my arms.
When it's over, I don't want to wonder if I made of my life something
particular, and real.
I don't want to find myself sighing and frightened, or full of argument.
I don't want to end up simply having visited this world.*

Mary Oliver

Hope, against the odds

Christine Chisholm

‘Hope in palliative care is not based on false optimism or benign reassurance but the belief that better days can come in spite of the prognosis.’

My experience is in palliative care but I’m sure a lot can be carried over into chronic pain management.

Patients equate hope with treatment, but often in palliative care we’ve run out of treatments that are going to affect cure and we need to respond in an innovative and creative way to maintain some hope for them. Disease and pain are multifaceted and need a multidisciplinary approach. This has been happening in palliative care for a long time, and we are looking not just at the disease but at the patients’ lives. You can’t prescribe just one thing that enhances hope; it isn’t that simple. You’re responding to the needs of each unique person. That’s very hard especially if you are working under time and money constraints and we do have the luxury of a lot more time in palliative care.

Marcel described hope as something that occurs between persons – a rational process inspired by love. Stevenson called it a process of anticipation which involves the interaction of thinking, acting, feeling and a future fulfilment that is personally meaningful. Determining what is personally meaningful for that person, which is different for everyone, is the important thing. Sotton said that we can influence hope by our presence and by communicating positive expectations and confidence in the patient’s ability to cope with difficulties.

There are lots of reasons why encouraging hope doesn’t always happen. For many nurses, for instance, physical care takes precedence. When even senior nurses were assigned to all aspects of patient care there were many wonderful opportunities, like when someone is having a wallow in the bath, to talk to people. On one occasion I was bathing a lady – a young woman with a husband and young child who had come in for symptom management and was going home to die. She asked me as I sat there if I was aware that there was another presence in the room – I said no – but she said there’s somebody here by my right shoulder. She could have been hallucinating – she said everybody tells me I’m hallucinating and my husband tells me not to worry about it. But I asked her what she thought it was. She replied that she thought it was an angel. She asked me: ‘Am I going to die now or soon?’ I replied that I didn’t think it was now but she was getting near the end. She wanted to know if I could see it – I said no but perhaps it’s not time for me, but there is no reason why I shouldn’t believe you: I have heard things like this many times. The conversation took place because we had time; I tell nurses they really can find time. There are moments when you’re on your own with the patient and you’ve got to listen. We’re all better at doing than being with people and lack of time can be an excuse for not entering into that patient’s vulnerability, which is a very difficult to do and can be scary. It may entail confronting things in yourself you may not want to. You may not have the answers – the longer I do this the less likely I feel to have the answers – but the thing is to keep quiet and listen to what they are telling you. We should never underestimate the value of listening.

We too need to be aware of our own expectations of hope. The attitudes you approach patients with will be reflected back. If you come across as miserable and unapproachable people are certainly not going to want to talk to you and you won’t

make progress; having a certain aura, so to speak, is part of the therapeutic relationship.

Stages of hope

Hope is closely connected with people's life stories – their past present and future. There are four stages of hope: the first is a cure, which most people are looking for. The next is treatment which people equate with hope, then prolongation of life and finally a peaceful death. Denial is a useful hoping strategy. My late husband had a brain tumour and his attitude was very positive: he'd had a Hodgkin's lymphoma earlier and had done very well with both conventional treatment and a spell in the Bristol Cancer Help Centre, and was cured. He believed that part of his cure was his own input. When he was told he had a *glioblastoma* and things weren't looking good he poo-pooed that – he could use his own input, train the other half of his brain etc – very positive. At that stage I was happy to go along with this for a while even though I knew it wasn't going to work. Denial can buy a bit of time for patients and relatives who are struggling – it's very important to give them that bit of space. Even the uncertainty about whether a new drug or treatment being offered can sometimes be translated into hope and that's very important too. They are not clutching at straws – they need something so they can go on hoping.

Another story: I was on night duty and we had just finished dealing with a lady with **Motor Neurone Disease**, who couldn't move and was totally independent by this stage and couldn't speak. We changed her pads and made her comfortable. But I could see in her eyes that she wasn't going back to sleep. We tried the obvious things like offering her a drink and changing her head position but still something in her eyes – her only means of communication – said she wasn't going to settle. We'd finished our other work and there was a book of poetry on her bed and I asked if she would like me to read some of this. She seemed to acquiesce so I chose three or four short poems at random, read them quietly and she went to sleep. The next night one of the other patients in that bay asked if I was the nurse who had read to Mrs X the night before. I apologised for disturbing her as it had been 2am but she said 'not at all – two of us were listening. I'm going home today but the next time I come in I probably won't be going home. You'll never know what comfort it gave me to think that when the time comes and I can't express anything and I'm nearer the end somebody will be bothered to try to find a way of communicating with me.' That taught me the lesson about doing those little things to try and make a connection even when it seems impossible.

Hope-fostering strategies

Eight hope-fostering strategies have been identified:

- Interconnection of yourself and others, and the world
- Purposeful activities
- Uplifting memories
- Cognitive strategies
- Hope objects
- Refocusing of time
- Light-heartedness
- Spiritual beliefs and priorities

This was in the context of elderly people nearing the end of their life with lots of limitations but still able to express what was important, to give them hope and the ability to cope with what was coming.

Hope is a complex multidimensional construct, a dynamic experience important for both meaningful life and dignified death. Hope in palliative care is not based on false optimism or benign reassurance but the belief that better days can come in spite of the prognosis.

If we take away all hope from our patients or shatter their hope by insensitive breaking of bad news they will resign themselves to their fate but they will isolate themselves from others, stop interacting with their families, and family relationships can be destroyed. A patient in his 70's who had been in the RAF in the last war, had been shot down and spent time as a POW. One of his fellow prisoners who was an artist had painted a big picture of the camp which he had kept and was very important to him. When I met him I had been trying to get back to work 18 months after my husband died, working nights with four children at home, which was a nightmare. I wanted to quit but was persuaded to move into day care. We had a wonderful day centre where we saw patients much earlier and did all sorts of things like paracenteses. This chap came as an outpatient quite early on with his son and daughter who had brought him although he didn't want to come. He sat there with one of our consultants who is so gentle and kind but he just wept every time she asked him a question and didn't respond. The son and daughter were very frustrated and said he just stays in bed all the time and their mother is sick to death of him. They weren't going to make any progress that day so it was arranged that I would see him alone in a couple of days. He told his story: it seemed that he was *angry* – he never mentioned his disease. He was angry about being shut away, but all this seemed to come from the past. He had the picture I mentioned earlier and other stuff from the war in his wardrobe but no-one was interested – except his grandson, but as he often cried when he was telling him about this the family stopped his grandson from seeing him as it seemed to upset Grandad. He said he would like to get out from under his wife's feet as he was a nuisance so we gave him a place in the day centre. He had lots of symptoms but these weren't mentioned at this point at all. I suggested that he wrote down his experiences but it turned out that he had got through life without ever learning to write and even his family didn't know. So over the next four weeks he dictated his life story to a volunteer: how he'd run away from school, been sent to a reformatory and worked on the land. Then came the war, and after several years in POW camp he came back and was a rag-and-bone man. He thought his life had been a disaster but it was fascinating. In the fifth week he came in wearing his old RAF uniform, walking upright without oxygen and strutting around. He brought the picture which we mounted and framed for him. The family had got interested and the grandchildren were seeing him again. The pain and restlessness had kind of got lost on the way. That to me was a very good example of 'non-drug' care just by listening to him. Often in our unit we used to get all sorts of people in to help, like local historians who would record interesting memories – all sorts of things to help people have a sense of worth again.

Holidays

Holidays are very important and something I am very passionate about. I have just completed the third edition of the *Accessible Holiday Guide*. I went to a lecture last month at the Royal Society of Medicine, given by Baroness Finlay of Llandaff on *Fairness in end of life care – quantity or quality or both*. At one point she said she was going to talk about euthanasia – it wasn't part of her subject but she said you're going to ask me anyway. She said she didn't agree with it; she had to admit that some people were going to go to Dignitas, but felt very strongly that palliative care should make it unnecessary. But she had a man in his 40's who had come to her for what he believed was the last time because he was going off to Switzerland ... She struggled to think of something she could say to make him change his mind, and all

her team had tried. So she asked him if there was anything he still wanted to do with his life. He said there was one thing which had been dismissed so he had stopped mentioning it: he wanted to go on holiday – on a cruise. She was astonished that something so simple hadn't been accommodated. All the problems that had been put in his way were easily overcome, and he went on this holiday. A month later he hadn't turned up, so she rang the GP, thinking perhaps he'd died on the cruise. She was told that he was fine, busy planning another holiday, and the whole euthanasia business had been dropped. I take many people on holiday (in a Jumbulance) who are near the end. We took one lady to the Italian Tyrol last year. She rang two days before we were due to go to say that she was very breathless and needed a pleural tap, but had been told there was no bed available till the following week. She came away anyway and had a wonderful time, went on most of the outings, and was much helped by massage and relaxation etc. Shortly after her return she went in for the pleural tap but died three days later. Her husband told me that he could not think of a better end for her – she might have gained a few days of life by missing the holiday and having the tap earlier but this was much better. There are so many stories like that: a man on the same holiday with spinal compression who had to be on a bed the whole time had never been abroad, his wife had left him and his life had been a mess. He too had a wonderful holiday, and decided after he came back that he could leave the hospice where he had felt secure; but he died three weeks later.

Before we go on these trips I always warn people that the travelling and things like bumping over cobbles may exacerbate their pain, they may need more medication, and to make sure they have plenty of it and to take it regularly. But when during the week I check on this I regularly find they have taken *less*! They will say I was so busy I forgot to take it.

So how do we foster hope when the prognosis is poor? There was a study done by Koopmeiners in 1997 that concluded that nurses can inspire hope by demonstrating caring behaviour, by giving information to help patients make decisions by themselves and by being there with them – basic thing in palliative care – but it went on to say that patients should have some control, achievable goals and should feel valued and accepted in their situation. I believe we can foster hope in patients by being honest and giving information, by accepting them where they are, by being genuine because they will certainly see through you if you're just putting on a front.

Touch and humour

Another important thing is touch – we're discouraged from this nowadays and it's different for nurses who are touching people in caring for them, but speech is said to be only 10 per cent of communication and touch is meaningful when words are no longer available. On night duty I once went in to see a patient whom I didn't know personally as my colleague was on a break. He was distressed; he wasn't in pain and didn't want anything but everything about his body language told me he was unhappy. I asked if he wanted me to call his family but he said no – my wife just can't cope, and I can't be with her anymore because it's so painful for her. I asked him what I could do: he held out his arms to me so I responded in the only way I could and held him in my arms. He wept and so did I. Sometimes touch is the only thing you can do, and it is very powerful.

Another thing we probably all use to cope with all sorts of situations is humour. Norman Cousins has written in the use of humour in palliative care and describes it as 'internal jogging'. It has been shown to lower cortisol levels, improve various immunological measures, and first raise and then lower blood pressure below its previous level. δ -brainwaves suggest that positive emotions put the brain at rest so healing can take place. We use all sorts of other things like poetry workshops to try to get through to patients at different levels.

Hope enhancing strategies

I made the list below some years ago to include in patients' notes to help nurses, especially new nurses, remember that there are so many different ways helping of helping patients beyond the usual symptom control, and not to lose opportunities – so many are lost; not to ignore unresolved social issues or spiritual or religious concerns; to remember that hope is a vital part of caring, which they need to be looking for and actively promoting.

Generalised/ Psychological

Listening skills/taking time to talk with patient
Psychologist/coping strategies/inner resources
Support groups/Day Care
Living wills/Advance directive
Being there (staying alongside — Therapoa)
Respect of patient's individuality/non judgmental
Inclusion in research/contributing to future
Medical care 'on leading edge'
Multidisciplinary team/optimistic/genuinely supportive
Active participation/partnership in care
Sense of fun/humour
Discussions on meaning of life/spirituality
Religious opportunities/prayer/non denominational services
Hugs/touch/caring/polite attitude
Honesty/Trust/Information

Particularised/Practical Specific Goals

Art/Pottery/Sewing/Knitting/Creative Therapies
Music/Singing/Drama/Music Library
Reminiscence therapy
Hobbies — new/old (Family tree/Gardening)
Memory boxes/love letters/creative writing
Audio tapes/video tapes
Complementary therapies
Pets/Making provision for pets future
Clowns/laughter therapy/entertainment
Volunteering/Community
Fundraising/Raising Awareness
Writing a journal/autobiography
Planning funeral
Writing obituary
Leaving a legacy/providing for family
Camping/Residential Group Therapy
Retail therapy
Travel/Holidays
Personal goals/wedding/birth of child
Relaxation classes OT /Physio
Exercise classes OT/Physio
Palliative rehabilitation
Regular reviews/Good symptom control

Patients can be encouraged to experiment even when they are running out of time. It's not the same for everyone – it's no use setting something up and offering the same stuff all the time; and sometimes one patient may trigger something. It's difficult and challenging and we don't always get it right, but we must never stop trying.

By creating a caring environment we can restore hope and connectedness. Am I too confident in thinking we can effect change and make a difference? In the palliative care world we can only remain alongside and perhaps enhance the patients' and their families' growth in this contractive phase of life. We cannot take away their losses but in the words of Dame Cecily Saunders "We can only say to the patient: *you matter until the last moment of your life. We will do all we can not only to die peacefully but also live until you die*".

Pallative Rehab

*I was in need of time and hope
Time to hope again
After the wild rush of a day spent doing nothing
Nothing worthwhile
Nothing of help one's fellow men
I was in need of time and hope
And that night I found it.*

*I found it sitting on the breakwater
Looking out at the calm sea
My thoughts once full of hatred, uncontrolled,
Moved outward gradually –
Until that black, weed-covered breakwater
Disintegrated in the cool sea breeze*

*Then, my imagination broke
I was what I had been made to be
A thinking being, alive. Acute -.
Acute to the sorrow of others as well as my own;
For God had made the sea
And me*

*But man had built that edifice, that mental breakwater
They had built it to break me.
To stop me swilling over the edge
The edge of conformity*

Anthea Penfold 1950 -

Positive Psychology

Wendy Callaghan

‘Can we cultivate positive emotions, such as hope, contentment, compassion and joy?’

This for you. Everything we do should be reflexive, and if it's good for us it's probably good for our patients, but principally I'm directing it at you because my impression coming here is that everyone works tremendously hard and gives a huge amount of themselves in their work, but sometimes put themselves at the bottom of the list.

The idea for this talk came from a study day given by Tim Anstiss. Several people have remarked over the years that I am a glass half empty person. I have tried to curb this tendency; if my first thought on hearing a suggestion has been 'oh but...' I have tried to keep schtum. But I had to try hard to take the second step of seeing the upside straight away. So I thought this day would be good for me, and I want to share it with you.

Positive psychology has its origins way back in the Greek Stoic tradition. In psychology it goes back to people like Carl Rogers who was very popular in the 60's but rather faded away when things like CBT and the disease model came to the forefront. The laudable aim of positive psychology is to change the focus from pathology and the disease/medical model to a focus on the behaviour, characteristics and environments which tend to a fulfilling life. Not many people would contest the fact that over time we have got wealthier, but mental health problems have not become less frequent. There is more obesity and there are more drug and alcohol problems. So what would account for improvement in prosperity not being accompanied by greater happiness? Wider wealth differentials may have something to do with it. Is this specific to our time or does every generation feel the same – that it's all going to pot? Did our parents yearn for the good old days?

It always happens – the situation was confounded by two world wars...

Nostalgia isn't what it used to be!

When I think about my own life basically it's pretty good, but when I look outside my life I do sometimes feel like we're on the verge of collapse of the Roman empire, and I think that's quite a common feeling: the government is making a mess of things, there's war and torture and all the other things. This leads to a sense of malaise and I think that's very prevalent in the health service. In society in general people are not feeling Panglossian – we're not living in the best of all possible worlds.

Do you think it's as we get older all the dreams we had as children are never reached and we're never going to achieve...

Buddhism has a lot to say about this...

In the NHS everyone is paid much better than they were but everyone is about 20 times more miserable than they were because of other factors such as losing autonomy, target-driven cultures and so on. I have heard people say that they fear

they won't be able to give the kind of care they want to. You may suffer from all sorts of things in your job such as overload or ambiguity about your role. As for a culture of continuing improvement – I wonder if we will ever arrive – given the lack of resources to pursue it. Oh woe! – that is our life!

I'm not going to talk about the academic basis of positive psychology – there are a few RCT's around which I didn't find very convincing as it is all correlational but don't let that stop us enjoying what we can get out of it! The authors of one study went around the graveyard of a nunnery and looked at how old the nuns were when they died and then asked the living nuns about them. It turned out that the happy nuns had survived for longer. In another famous study they looked at the year books of America schools and discovered that people with a natural-looking smile, when contacted later, had tended to stay happier, to marry more and to stay married.

Would you agree with the statement that seeking happiness however you personally define it is our prime goal – what we all strive for?

That's the problem. We are evolutionarily challenged in our society today. When I moved to Georgia I was very curious to know how the South was and talked to old people (as well as young and black people) and what I learnt was they felt separated: When they were young, people took care of each other. If a farmer was sick and couldn't do his harvest, both black and white people would get together to take care of it for him. It wasn't about them, it was about family, community, church and helping each other. It's our great rush to render everything unto Caesar rather than keeping anything for God so to speak that causes our distress. We're way over-challenged.

Yes, and there is a focus in materialistic societies on the individual and our own personal goals.

And independence – that's part of the problem.

So positive psychology seeks to find things and institutions that will promote lives that go well, positive emotional states, human strengths and resilience (resilience is a government buzz-word). I have heard so many people coming back from the poorest parts of Africa and Asia having noted that people who have absolutely nothing appear to be happier than we are. People in villages are very hospitable and will share all of the little they have. They seem to have dignity, self respect and self belief. This seems to be in marked contrast to our materialist society and the unease of it.

Can you increase your happiness?

So what the little research does tell us is that happiness is good for your health, and makes you kinder to other people, which creates a sort of benign circle. So how can you increase your happiness? Is it possible to increase happiness or was I born grumpy? One estimate is that it is 50 per cent genetic and only 15 per cent environmental, (as Diana was saying yesterday, things like hospital environment promote happiness) and therefore the rest must be under voluntary control.

Top Tips for Happiness (handout)

Remember, you may already be doing an optimal amount of some of these – you need to judge it honestly.

- Increase your contact with nature
- Become more active
- See your friends. Be neighbourly

- Cultivate a state of “flow”
- Some form of meditation
- Cultivate positive emotions – hope, joy, compassion, contentment, play, mastery
- Watch less TV
- Be less critical of yourself and others
- Stop trying to change things that are beyond your control
- Cultivate meaning

There is a lot of evidence of the benefits and power of increasing contact with nature, which is probably your experience. Physical activity is good for mental as well as physical health. Seeing your friends and being neighbourly is good. There may be occasions when you're too tired to go out or you just want a weekend on your own but it is too easy to get into a hermit-like state and stop having friends for meals and so on.

Cultivating a state of ‘flow’, or if you are religious a state of grace, involves trying to get to that place where you feel fully engaged with something so you're not noticing personal discomfort or any distraction, increases well-being. Meditation has similar benefits, but it can be difficult to find time, place and to free the mind from distracting thoughts – it is quite an art and requires practice. You may be too busy to find long periods to dedicate to this but can you find five minutes – or even one minute between each patient to let the tension go rather than letting it build up?

Can we cultivate positive emotions, such as hope, contentment, compassion and joy? I know that because of the strong link between thought and emotion, positive or negative thoughts about something or someone can affect the way we feel. I had two new colleagues trained in CBT. At first in our discussions I thought they were terribly Panglossian and would always see the upside of everything. I realised eventually that they really did see the positives in everything and it was absolutely brilliant to work with them. Things would get off the ground and we would start trying new things. So even if you can't cultivate your own good emotions you can surround yourself with people who do. You can for instance cultivate contentment by counting your blessings, being less enslaved to your desires, but savouring your pleasures. Compassion can be pursued by random acts of kindness. (On my way back from the study day I was going into the station when I noticed a man in a large car holding an empty biscuit packet out of the window. Feeling I should take this advice I offered to dispose of it for him. He accepted but laughed his head off. I soon found out why he was laughing – there are no litter bins in Liverpool station!!)

Reducing negative emotions is more difficult, but we can examine why we harbour them, and let them go. We can try to down-regulate them from anger to irritation and from irritation to amusement or even compassion.

Watching less TV is good – slumping in front of the box when you're tired is unhelpful, and leaves you less time for good stuff (like Sudoku!).

You should try to be less critical of yourself and others, but it may be a lot easier to be less critical of others than of yourself. Some of it is unconscious – constantly asking yourself: have I achieved what I want to in life – have I done enough? If you are being critical of yourself you're not necessarily having a good effect on those around you – there needs to be a balance between this and thinking you're marvellous. There is a tendency for the first thing to come out of your mouth to be self-critical and I think English people are particularly prone to being down on themselves. But this is too often hypercritical and doesn't make you feel good.

We are often tempted to try to change things beyond our control and we would do well to remember Kipling's advice; most things are out of control if we are honest about it and we could divert a huge amount of energy to things that are more pleasurable if we stop trying.

It is very important to cultivate meaning. I suspect a lot of you here get a lot of meaning in their life from their work. (Don't forget to prepare for retirement!) A lot of people get it from their children but they leave you.

We are all prone to thinking errors – we 'catastrophise', we have black and white thinking, we over-generalise, we personalise – all the things we say our patients do but we do too. It's good to check on these things with somebody else.

Building the strengths we need

I want to emphasise the importance of getting a balance between *doing* and *being*. I took the train to Liverpool to this happiness study day, and it passes through a sort of canyon which is partly natural and partly man-made; it is very old and beautiful. It is very mossy, with a graduation of colour from top to bottom, and there are lots of other plants. As I was gazing spellbound at this I noticed that everyone else was busy with their laptops. The conference I was at was near the Roman Catholic cathedral, and after some indecision I took a later train to give me time to visit it and it was wonderful! I felt really buoyed up afterwards and I would have missed it had I followed my natural inclination to take the first train home. Working on my laptop in the train and going home early would have been doing, but being with those things made my day.

Many of the top tips for happiness involve transitory things like exercise – unfortunately exercise has to be constantly repeated to be beneficial! But the good thing is that when you have changed things like positive emotions so they become part of your life you don't have to keep going back to the drawing board every day.

Can we use this to help pain patients?

We could add a question about strengths and sources of happiness to patient questionnaires which tend to read like a catalogue of losses and disabilities, and talk about them in interviews. In trying to help someone move from unrealistic goals such as pain removal we should perhaps be working more to building on their strengths, and encouraging them to develop new interests, and remembering to help them to choose goals that are in alignment with their values

Discussion

Regarding resilience: I recently took part in a seminar in Southampton medical school about bringing a more holistic perspective into the curriculum. One of the attributes that people thought needed to be inculcated was resilience in order to help medical student cope with the risks and vulnerability associated with the connectiveness we were talking about yesterday. Have you any thoughts about how that might be achieved?

One thing that helps psychologists in this respect is supervision, and the admission that it's simply impossible to contain it all and make sense of it all on your own. In sharing the burden not only do you partly shed it but you get something back which will help you cope better the next time.

When I realised the benefit of this in the clinical part of my psychotherapy training I started a weekly session for my colleagues in the pain clinic and the rest of the multidisciplinary team. We wondered why we hadn't done it years ago. Our psychologist offered to give anyone who wanted it individual supervision.

Is this sort of thing on the curriculum at the Peninsular Medical School?

No it isn't and this is a big problem in the medical profession: we persist in holding on to this macho culture – we can cope, we can do it on our own, we don't get sick. How we change that I don't know.

It may be easier than you think. I have noticed with anaesthetic trainees recently, particularly those going for a career in ITU, actually want supervision as they realise how stressful it is going to be. They look at their older colleagues and see that they are burning out after a few years and think it can be different. That's a real change in attitude.

The clinical needs often foster the macho culture so the student is caught between two stools.

One of the stock phrases in our hospital is 'don't bring me problems – bring me solutions' – this really isn't helpful.

When we moved into the new Hallamshire Hospital in Sheffield, from a two or three story building where you were bound to meet people in the long corridors and have a whinge about things, to a massive tower where you practically never did, the incidence of suicide among junior doctors went up astronomically. It didn't have to be a formal sharing of distress or confusion – that's the difference between support and supervision.

There used to be a thing called the doctors' mess

Perhaps the term supervision is part of the problem. When we started St Jemma's Hospice in Leeds we had a meeting every week that everybody from the cleaner to the medial director would attend – for two or three hours we would sit and chat about the problems. That did all the things... but it wasn't called supervision.

It's built in to palliative care – it's a life saver.

It works well in a relatively small group like this but they don't have it in a department of surgery.

Suffering in Silence?

Persistent scar problems following Caesarian Section

Hubert van Griensven

‘Given the number of hysterectomies carried out every month in this country we should be inundated with such patients but we are not’.

My interest in chronic pain after surgery was first aroused by a lecture by Bill Macrae. He had discovered that about 22 per cent of patients in the pain clinic had surgery as a contributing factor to their pain. But when he talked to surgeons, the one group you would expect to know about this they said no, it's not a problem, we never come across this. He then looked at surgical textbooks and found hardly any reference to it. But my waiting room is full of people with post-surgical pain.

The problem

Some time ago I started treating patients with a technique known as *myofascial release*. In essence the concept is that all layers of tissue including skin, superficial and deep fascia get bound together in scar tissue. You try to facilitate the line between different layers. I found that with this people would often get less sensitivity around the scar and reduced pain. So I decided to make scar problems following CS (as there could be no question that any pain was associated with previous pathology) the subject for my PhD. It wasn't easy; we have no method of measuring longitudinal scar mobility, and ethical questions arose about sensory testing in the pubic regions of young women. But the biggest problem was that I couldn't find participants for the study. I talked to gynaecologists, midwives and some very experienced GP's and they nearly all said this is not something we see. If you search the literature you find that it has taken till 2004 for a study to be published about Caesarean pain, which recorded a 12 per cent incidence. Last year a study of patients who had had a Pfannenstiel incision showed that eight or nine per cent of women suffered either intermittent or constant pain, which a similar percentage described as moderate or severe. Given the number of hysterectomies carried out every month in this country we should be inundated with such patients but we are not.

So my focus shifted from how do I get participants, to what is going on here if we have a patient group that we know has pain? Why don't they end up seeking help? At this stage my supervisor started getting restless and suggested that if they don't turn up in clinics it's probably not a problem worth investigating. I then did some internet research and just looked at discussion sites where women posted questions like 'Has anyone else had this?' and others relating their experiences. As a research method this obviously has huge problems: they are a self-selected group, you have no idea about the demographics or the background or sincerity of the participants, but after about 150 entries I began to get the flavour of what the issues were. They are not just limited to pain.

I used these findings to produce a framework of themes to have come out of this and to design a questionnaire to go out to 600 women to see how common these themes are, and also to see if there are things that are blocking women from seeking help, and their experience of trying to find help. That's as far as it has got at the moment. When I offered this talk I hadn't realised the problems of getting ethical

approval. There is more than one committee and they apply different criteria. I have spent the last year filling in forms and things and it's a soul-destroying process. But I still hope that at the end of it I will come out with some conclusions.

I have found from the internet analysis a whole range of symptoms from tingling to all sorts of weird sensations which are quite often described as 'severe enough to interfere with day-to-day activities, provoked by a variety of things from lying down to using the brakes on the car. I was surprised to find the timescale ranging from a few months to many years. In one group it had recovered and started again after a number of years.

There were many other issues which included appearance: 'I don't like looking at my scar'; 'My husband doesn't like looking at me'.

I also looked at interpretations of what was going on. Concerns expressed included that the scar was rupturing, that there were adhesions, whatever that might mean to them, failure of healing, and worries about pregnancy.

Problems with healthcare ranged from one patient who had had three laparoscopies and a hysterectomy till it was finally been decided that she had an endometrioma, to 'My obstetrician doesn't even want to look at my scar' and a GP who advised a young mother not to pick things up for a while! Other comments included 'My GP thinks it's either appendix or an ovarian'; 'I don't think my GP is too fussed' and 'My GP is just as confused as I am'.

I have little idea what will come out of my questionnaire when I eventually get it out but my guess is that a lot of women who have gone to their GP's and other healthcare professionals and not got the answers they were looking for. I wonder if this is linked with a pervasive medical model which fails to consider pain mechanisms and just looks at pathology – after all we have learnt about nerve damage etc. this is a bit disappointing. I hope there may be some recommendations to come out of this which will take things forward.

Discussion

One of the things that prompted me to organise the very first of these meetings was the feeling that for all our efforts and the huge resources reflected in the international meeting I was attending, we were barely scratching the surface of all the suffering in the world, and even now when pain services are more widely available there is still a huge amount of pain out there we are doing nothing about.

Surgeons ask for consent but don't know there is a 10 per cent incidence of chronic pain...

There was a paper in the British Journal of Surgery a few years ago about post-herniorrhaphy pain, and put the rate as around 60 per cent – that was a surgical paper.

As regards post Caesar pain, do you have any feeling about how many had epidurals and how many GA?

One study showed it was better after epidurals

I had a hernia repaired under local and the surgeon let slip that if the patient was awake he would go a bit more slowly and take more care!!

It's partly a gender thing – women are expected to get on with it and men are too scared to go to the doctor!

There are several studies looking at pain after vasectomy and prostatectomy and none after CS or hysterectomy!

What you were investigating was not so much pain issue as a help-seeking issue. I think we should be very grateful that most people in pain don't seek help! Less than 50 per cent of people with severe pain problems from arthritis seek help and there isn't a substantial difference in the severity of pain or disability between help seekers and non-help seekers. We don't know what the determinants are of help seeking. We have been out and interviewed non-help seekers with severe pain and disability and there are a variety of reasons they do not. This feeds in to something we were discussing previously, the difference between pain severity and pain distress. These people were reporting less distress than help-seekers. There are lots of messages there about how we approach pain problems. There is also a big issue of pain after joint replacement surgery. I would encourage you to supplement any questionnaire work with qualitative work because another thing we think is happening is that people are not reporting appropriately what is going on. There are all sorts of reasons for that: certainly misreporting to health care professionals is huge even with anonymous questionnaires.

The final stage would be following up the respondents with interview.

My jumbulance holiday patients weren't seeking pain relief apparently because they were enjoying themselves so much – there are good as well as bad reasons...

Do you have any flavour about why the ones who do present to GP's don't get referred further? – are you planning to survey GP's?

I will have to think about that when I eventually get the first part done...

We looked into this with joint pain and there is no doubt that the biggest block to getting help is the GP. Negative attitudes among GP's are a major factor.

Is there cost involved in referral?

Yes, that's a new development

My patients all tend to come from a few practices – there are others I hardly know exist – do they have no pain patients or do they deal with them or do they sweep them under the carpet?

The GP only has to say once that he doesn't understand it...or there's nothing that can be done ... and that's it...

You've said that many of the specialists don't acknowledge that these things happen. I used to work with an enthusiastic cardiac graphing unit and all their patients had median sternotomies. 40 per cent came to me six months later with burning chest pain which they had been back to the surgeon with, who had either totally ignored it, or said it must be something else and not due to the surgery – or sent them off for a new coronary angiogram, when all they had was traumatic neurogenic pain.

Did you get any sense of linking between distress and other issues like not wanting to look at scar?

It's too patchy to draw any conclusions.

At the 8-week check (after CS) I routinely ask about their scar healing – whether she's happy with it. The mother is in a different state of mind – the baby tends to – they have discomfort but they don't want to talk to me about it, perhaps because at eight weeks they expect it to go away. The question is when does it become a problem.?

I wonder if it's worth approaching health visitors who will be seeing the mother for five years after she's had the baby.

It may get worse if they put on weight. And hormonal changes with breast-feeding may make a difference to tissue laxity...

Please say more about the mechanism of your myofascial release.

You try to exert a shearing force between the different layers of tissue and hold that. That's the theory – there's disappointingly little research done on it. My success rate with post-surgical pain is about 50 per cent of at least improvement or reduction in spread of pain.

TENS is very effective...

I wonder if what you are doing is stimulating nerves – like TENS? ...

I'd like surgeons to stick lignocaine patches beside the wound...

While you do this do you talk a lot to the patients about what's going to happen?

I do beforehand and invite them during the treatment to tell me what they are feeling.

I ask because it is known that massage is an excellent time to do suggestion with them... there's something about touch which is very helpful.

It would be interesting to know if there was a bigger history of other pain issues in the past – migraines for instance – in people who suffer post-surgical pain.

There was a Danish study which showed that previous pain was a predictor for pain after CS.

I ran an aromatherapy and massage clinic for women newly diagnosed with breast cancer, and saw some of them post- mastectomy, with horrendous scars after radicals. Obviously there are lots of other issues here but teaching them to massage and stretch the scar was just what they should be doing. Teaching them to reconnect with that area – they were afraid of touching it, and were distressed by the disfigurement – was immensely helpful.

There is prevalent idea in physiotherapy that if someone is in persistent pain you stop touching them – you tell them about pain management techniques and put them through an exercise program but you don't put your hands on them ...

I wonder if we could widen the discussion again to the question of why there is so much untreated pain out there and why people are not seeking help. There was a stand at the last ASM run by a patient organisation dedicated to educating the public about the availability of pain services. They had discovered that the number of people who were not seeking help and didn't seem to have any intention of seeking help was enormous – thousands...

I lecture GP's a lot and get some very strange attitudes. I had one who said he didn't think we should be doing terribly much for our patients

Is there a 'it's all in the mind' stigma attached to pain?

It's very culturally conditioned – the GP's negative attitudes towards pain may reflect this. I'm not sure we should be fighting that too hard. It's said that 60 – 70 per cent of people are in chronic pain – you wouldn't want all of those coming to your pain clinics, would you? They are in pain but it's not a big issue and they don't need treatment – it would be quite a dangerous road to go down to say we should be treating all those people and medicalise it all.

Perhaps all we need do for a lot of patients is to say this is what it is, this is how you deal with it – it's not a big problem – it doesn't mean something has gone wrong.

We did a small study on older adults from the Afro-Caribbean community and found that their pain was troubling them but they had so many other problems, heart, diabetes etc they didn't want to take any more medicine. People may have other priorities.

The important thing is that we're not missing people who really do need treatment.

I take Paul's point that we couldn't cope with lots more people in the clinics but among all those thousands of people there are some that jolly well should come. The selection of people that do come sometimes seems little more than a lottery and surely that can't be morally right. But I'm not sure what we can do about it.

There is a fine line between the inappropriate medicalisation of pain as a fact of life and the neglect of pain that needs to be treated. It's rather similar to attitudes to death.

Sometimes when you've been dealing with a patient and you've not been very successful and you say there's nothing else I can do people will say; I've got to live with it then; thank you for trying. It's as if you're there and they will use the facility but if it doesn't work they are not particularly disturbed about it – they will carry on.

But we should be saying we can't cure it but we will be with you and make it more bearable and help you get on with your life...

But they may not need that if they aren't much distressed. They may have learnt as much as they need from their consultations. And a lot of people come just to see what's there, and that they haven't left any sensible stone unturned – and go away and get on with their lives as they were before.

This issue of the patient who says I've just got to live with it then: one of my stock replies is that you've been living with it a long time. And I encourage them towards recognising and internalising ownership of the pain and not regarding it as a monster they have to drag around with them.

Looking at the CMO's report again I have been horrified by some of the epidemiological data and one thing in particular: how is it that eight per cent of children experience severe pain? And the cost of adolescent pain is £3.8 billion pounds! Where is this?

The loss of the Ethos of Care in the NHS

Michael Platt

‘Have we lost the passion for patient care and how do we regain it? Or is it that we still have it and the system has lost it?’

I have been following the NHS changes with increasing depression and the loss of the ethos of care they involve has been worrying me. I have no answers and this is a call to you and everybody to think about what we can do about it.

Sir William Osler said ‘It is more important to know what patient has a disease than what disease a patient has’. Maimonides in the 12th Century said ‘May I never see in the patient anything but a fellow creature in pain. May I never consider him merely a vessel of disease’ – which I think we are in increasing danger of doing. Peabody, an American, wrote in a famous 1927 paper ‘One of the essential qualities of the physician is interest in humanity, for the secret of the care of the patient is in caring for the patient.’ The famous quotation ‘Guerir quelquefois, soulager souvent, comforter toujours (Cure sometimes, relieve often, comfort always)’ is on the statue of Dr Edward Livingstone Trudeau at Serenac Lake, New York. Dr Trudeau who was born in 1848 and died in 1915 was a physician with an interest in TB. He had nursed his brother with TB and then got it himself and went to the Adirondack mountains for a cure.

So – we’re good and compassionate at treating our patients, and we maintain this ethos of care in the NHS – or do we? *The Daily Mail* reported in 2007: ‘Dirty wards, feminism and the tragic end of Florence Nightingale’s ethos of care’. And in June this year, ‘Leading doctors demand end of target-driven patient care which ‘endangers’ lives’. This was published this year: ‘Staffordshire hospital scandal: the hidden story. Congealed blood was smeared on seats in the patients’ waiting area, the lavatory floors stank of urine and grime was encrusted on the sinks used by doctors and nurses. Terry Deighton had never seen anything like it’. That hospital managed to get foundation status and everything looked perfect. The report went on to say that patients were wandering round in confused states on the ward and there clearly weren’t enough nurses or doctors. They hadn’t replaced nurses or doctors as they left to save money. I don’t think there is anything to stop this happening again. Another headline, this from the *Evening Standard* ‘NHS staff told to show sick more compassion’. Compassion is in the news – people are waking up to the lack of it in the NHS. *The Guardian* reported that ‘Nurses are to be rated on how compassionate and smiley they are’ – from a speech by Alan Johnson. A nursing journal featured Respect, Empathy, Compassion and Communication as it seems we are recruiting nurses who have none of these things. The *BBC* reported that ‘the NHS is fast losing its compassion’.

I got a phone call from my medical director asking me get involved in a working group on pain across the trust as a result of something called the *Picker Report*. This is an annual survey of hospital patients with a postal questionnaire after they have gone home. They get about 4000 replies, i.e. a return rate of about 10 per cent. . A sample of the [35] questions are ‘Do you have trust in the doctors treating you?’, ‘Did doctors (and nurses) talk in front of you as if you weren’t there?’, ‘As far as you know did doctors wash their hands between patients?’, and ‘Did you get answers you could

understand when you questioned a nurse?' All of these were rated either poor or satisfactory, none good. Pain relief was rated as poor which was surprising as our surgical pain service had been previously rated as good but this didn't extend to A&E or the medical wards.

May I ask: with only a 10 per cent return are you picking up the dissatisfied ones?

I asked that, but the government and the hospitals use these figures. Perhaps it would be better to survey all the patients on discharge.

The word ethos comes from Aristotle's description of rhetoric: logos refers to the speaker's words and ethos to his character. Pathos is passion. Have we lost the passion for patient care and how do we regain it? Or is it that we still have it and the system has lost it? The phrase 'improving the patient experience' has become very fashionable – nursing directors are very full of it, along with 'sharing good practice'. This seems to be an example of the corporate approach: things like compassion can be measured and trusts scored on it. This is a list of recurring themes that our nursing director has picked out from the 2007 PEX (Patient Experience Team) survey:

- Why must I stay in mixed sex facilities? (accommodation, bathrooms & toilets)
- Lack of acknowledgement. Clinical staff talk in front of me as if I am not there
- I have a lack of confidence in clinical staff
- Do clinical staff wash their hands and observe appropriate cleanliness?
- I want to be involved in decisions about my healthcare
- I am afraid that my pain will not be properly managed
- I need to be properly educated about my discharge medication

I am surprised that involvement in healthcare decisions is still an issue as I thought this was the way we were going, and disappointed that pain relief still seems to be a problem, with nurses giving insufficient pain relief for apparently trivial reasons.

What do patients want? Typical responses include requests to:

- Treat me as a person, with compassion and empathy
- Treat me with dignity and respect
- Get the basics right first time
- Work with me as a partner and fit in with my life
- Involve me in decisions about my healthcare
- Ensure that the hospital/room/ward where I am treated are properly cleaned

What do the private sector look at? Four dimensions of customer satisfaction were identified:

- Emotional connection – compassion, empathy and recognition
- Quality of care, including treatment and environment.
- Customer Service – all aspects of care
- Value for money – efficiency and economy

How do private companies achieve improvements? They measure satisfaction. They use role models to try to improve mindsets and behaviours. (We used to use role models but don't seem to any more) They aspire to foster conviction and develop talent and skills. They endeavour to reinforce these things with the right structure and processes without becoming too process fixated.

How can we bring back the ethos of care?

So these are a few suggestions about ways of raising the bar. But we still have a long way to go. What I am uncertain about is what we can do to bring back the ethos of care into hospitals. A review of the 'journey' of the NHS: where we have been and where we are coming from, identified three stages:

- 1) Building capacity in the system: the NHS Plan saw greatest investment in the History of the NHS with more doctors, more nurses and better facilities
- 2) Introducing the Reforms: Patient choice and payment by results, foundation trusts and stronger commissioning
- 3) High quality care for all, involving the NHS Next Stage Review, local clinical visions, the national enabling report and the NHS Constitution.

Nowhere in these is there any mention of *care*.

Words of Aristotle are very apposite: 'We are what we repeatedly do – excellence then is not an act but a habit.' And I come back to Maimonides: 'May I never see in the patient anything but a fellow creature in pain. May I never consider him merely a vessel of disease.' I hope we can get back to that.

Discussion

Have you presented this in a grand round in your hospital?

I wouldn't dare!!

Isn't that the answer to your question about what do we do? We have to have the courage to speak up.

Perhaps patients are negligent in this – I don't see people putting more responsibility on to patients. Governments are taking more responsibility for patients and I don't think that's healthy. In the old days the whole family had an investment in the patient getting better.

I think you're right. I have suggested (in the context of pain in hospitals) that we get patients used to filling our questionnaires and tell us where we are going wrong and how we can improve.

That's still passive – that's still them telling you and they will always be looking for something more. We've got to treat them with respect and compassion, but they have to treat the system with a degree of respect as well, because it's the greatest good for the greatest number – people have to realise that they can't go to A&E for every symptom.

I'm a patient as well as someone who works in the NHS and I have used the system quite extensively between two children, my husband and myself and my experience is that it has been quite fantastic.

One thing we forget is that for my generation of nurses, 40 years back, there weren't so many options. Nowadays you have to be a degree nurse, which may exclude people who would have made excellent nurses, and there are so many opportunities for women – they can do anything now. Why work long hours and nights...

The Picker Institute is not going to go away; wherever you are it's going to touch all of you... it's on the website [partly inaudible] ... So it's advantageous to get your patients to buy in to what you are doing. And then you can get a handle on what your communication is and build bridges. There was a comment yesterday about when patients were drawing pictures of pain, and people were surprised about what they were putting on them and didn't know there was this gap with some of them, and what they were feeling or relating to; so your perception of what the patient comes in with may be mistaken.

I agree that Picker isn't going away but it's statistical nonsense. The Darzi Review which is the next stage is will be different and more validated. PROMS (Patient Reported Outcome Measures) have so far been instituted for surgery are now mandatory for all trusts. So far the return rate is over 90%. The forms include things like pain and satisfaction but also a number of other quite reasonable measures. We should get statistically validated data from these and this should be a better driver than the Picker stuff. Having said that I actually think the problem is of central control, of which PROMS is another example. I think it would be better if there were more local control. Of course that goes against the utilitarian argument, because you'd have more inequalities, but it would bring more of a sense of worth amongst the staff and their natural compassion which I am sure is there would have a chance to flourish.

The situation in the big city hospitals is different from the district generals where the staff do know one another and there is loyalty to the institution and to the community.

I think it's all coming down to a sense of ownership. If you're sitting at a desk on a Monday morning and you find your rota has been changed and you didn't know because you've never been involved in the process... we are seeing a whole lot of people who are demoralised and are not showing compassion because they have not been shown any.

There is a delightful book by James Willis, a GP, called 'Friends in Low Places – taking professionals in low places' point of view', and it's all about the title of your talk.

Taking an evolutionary view: the one thing tribes did not evolve with was centralised control. Take the American laboratory industry: it was built by a number of small companies. It was much cheaper to run when it was individually owned and you got good service. Then when they started buying up all the labs the costs went up astronomically because there was much more administration. There are now basically only three lab companies in the US and they're terrible. There is so much evidence that centralised control versus centralised oversight can't work. I don't know why we as doctors and nurses aren't more proactive.

Why do we fail to relieve pain?

Willy Notcutt

‘Inadequate pain relief may sometimes be attributed to sheer apathy among some health professionals: pain is regarded as only a symptom and has low priority.’

The trouble with being the last speaker in a two-and-a-half day meeting is that everyone else has sucked the lifeblood out of one’s presentation! So I’m just going to bring out a few pointers in the hope of getting some discussion going. This project started as a result of being asked to do an article for the *Postgraduate Medical Journal* by Len Doyal who is an ethicist and peripatetic Professor of Ethics at Norwich. We were talking and he was quite visceral about pain relief because when his mother had died he couldn’t get any analgesics for her. I had to acknowledge that there are still huge shortfalls although we have a history of morphine going back 200 years, opium 2000 years, we have the science, the technology and pumps and things, we know all about biopsychosocial medicine, we have palliative care, organisations, Clinical Standard Advisory Group reports etc., etc. and pain relief has been declared a Human Right. But there are still shortfalls in research and huge therapeutic gaps. We know what we can’t do but more importantly we know what we *can* do so why is there this reluctance to actually *do* it?

Despite all the advances in palliative care people like Prof Doyal’s mother are still not getting adequate analgesia. And there is procedural pain – in my medico-legal work I keep coming across complaints of pain from spinal procedures such as epidural steroids – *what is happening?* Obstetric pain is fairly well managed but we were hearing this morning about Caesar scars, and I see many women with painful episiotomy scars – does anyone ask them? Is this another group who may be struggling on?

Identifying the barriers

We started to try to bring all this together (for the purposes of the article)] into some sort of organisational structure. We asked what is stopping some degree of pain relief? We recognised that there are lots of people who are content to live with their problem, but there are a lot out there who do want something done and that’s where we were focussing.

I invented the neologisms *pharmacophobia* and *analgophobia* to describe the reluctance of some people to take even simple analgesics. Some people want a ‘natural’ medicine, some want a non-analgesic solution, albeit an operation or a complementary therapy. It may be cultural: in some societies boys are expected to undergo circumcision and women to have babies without any expression of pain. Then there is the belief that you can’t expect to get better without pain. Many are still influenced by religious concepts that suffering is good for you, or that it is some form of purging or punishment or reward.

A problem that has arisen since Shipman is that doctors, especially GP’s, have become frightened of prescribing opiates in case they were accused later, particularly if this is perceived as an act of euthanasia. There are also worries about the ‘dual effect’ but this surely isn’t a real problem – it’s quite difficult to kill someone with opiates if they’re using them. So people are still dying without adequate pain relief.

Another problem is analgesia in patients who are opiate dependent, and some addicted patients may be simply abandoned.

Inadequate pain relief may sometimes be attributed to sheer apathy among some health professionals: pain is regarded as only a symptom and has low priority. A useful development has been the contribution of fMRI to the perception of chronic pain as a disease process with acknowledgeable structural damage to the brain as well as physiological and psychological disturbance, but negative attitudes still lead to pain being dismissed.

Standards in cancer care are generally good but there are still areas where the need has not been examined. Pain in children, especially neonates, has only relatively recently been given adequate attention. At the other end of life the pain problems of old age and dementia are largely ignored. Another potentially neglected group are those with impaired mental or psychiatric capacity.

There is also apathy about pain of doubtful pathology and doubt if its sufferers are getting proper pain management either in primary or secondary care. In our hospital we have introduced a document on treating abdominal pain 'frequent fliers' to be attached to their notes to give junior doctors something to start with.

As I talked about last year, it is difficult even for pain specialists to give equal attention to all patients, and not to be influenced by likes and dislikes, or to be innocent of stereotyping and categorising them and treating them accordingly. There is the tendency to do more for more interesting patients, for instance those with neuropathic pain. There are several professors of neuropathic pain but none of nociceptive pain, and much more about it in the pain journals.

Pain ignorance and education

In trying to get a handle on all this for the purposes of the paper we found that pain ignorance comes back time and time again. We moan about poor practice but we are simply not getting the teaching right, in medical, nursing, physiotherapy, OT and pharmacy schools. Apparently it's better in veterinary schools! Is pain in postgraduate training programmes? – in surgical training programmes? The British National Formulary has a lack of guidance on analgesics as opposed to raw information. (It still recommends diamorphine 10mg 4 hourly for chronic pain!) Education remains one of the keys to improving matters.

There are ethical reasons for providing pain relief, encompassing rights, justice and fairness. We are beginning to get a little bit of political direction, although there isn't much vote-winning in chronic pain – cancer is still more eye-catching. The GMC don't seem to require any pain education in medical schools. But the priorities are still not there – pain is still at the bottom of the league.

Discussion

Should we be taking heart from the CMO's personal interest in the subject?

Most of the data in his report were taken from epidemiology – 'There are 11 million people in the country with chronic pain' etc. and the report focussed on this aspect. There is nothing about care, nothing about patient experience – all hard raw data, with no feel to it.

Has anything improved since I retired? (hollow laughter!)

A lot of pain clinics have been closed and membership of the pain society has decreased.

One of the commonest calls I get in general practice is from relatives of elderly people who they say are in excruciating pain. Mostly I find that they are well, ambulant, either not needing any medication or not taking prescribed medication ; the relatives come on a one stop visit and complain to nursing staff... Only about once a year do we find patients whose pain isn't being adequately treated. That's too much of course ... but you can't always foresee all circumstances...

There is an opportunity here. We have representatives here from at least two medical schools. Education is spelled out in the CMO's report; every totalitarian state knows that if you want to change something you start with the children and educate them rather than trying to change your peers which is much more difficult. Perhaps that's a subject for a future meeting: how to change the culture in medical schools and bring in pain education in a wider sense? Couldn't we invite one or two medical students as a starting point?

Reflecting on this week and last year when I first came, what I'm hearing in the background is a huge identity crisis amongst pain doctors. I'm not a pain doctor, I'm a rheumatologist, (one of an extraordinarily small number of whom who realise that pain is actually the issue. Perhaps pain doctors should be educating rheumatologists and neurologists and surgeons who are actually treating most of the pain). But I don't think you know who you are and what you are for. That's not unusual – I've just come from health services research and no-one in this knows what it is or why they are doing it. I think you need to reflect on this – what is your identity?

I think a lot of pain doctors do have a clear idea of their identity but they don't come to these meetings. We may be self-selected as people who do go in for soul-searching about these things...

We know what we'd like to do but we don't have all the tools to do it. We don't have a cure for pain.

Do other pain doctors think they are doing a great job and don't need to reflect all the time?

One problem might be that the majority of pain doctors have emerged from anaesthesia, where you have a job with defined ends and satisfactions – why indeed some of us still do anaesthetics. A lot transfer this to the pain world where they will spend their time doing facet joint injections and things – job done! Then there are others who get sucked in to exploring the deeper ramifications...

Palliative care also came out of anaesthesia. Palliative care is now palliative medicine, and you can be specialist in palliative medicine. We now have a faculty of pain medicine and the sooner that stops being anaesthesia based the better. I've been in pain medicine for 40 years and in Canada where I practice it still isn't recognised as a speciality and every time I have to establish my credentials – we start with "you're an anaesthetist, aren't you doc..." and we have to spend ages breaking that down. If I were able to say no I'm not, I'm a specialist in pain medicine it would solve a lot of problems and help to prevent these hang-ups we're stuck in now.

A lot of other specialties regard us as anaesthetists. Our new young palliative care doctor regards us as helpers who treat pain by sticking needles in.

In the US the American Academy of Pain Medicine started from anaesthesia. Twenty years after it started only 40 per cent of the members are anaesthesiologists.

After coming to these meetings for the last two years I am more and more convinced that what you are saying is true. We need to pay more attention to the meaning of words. In the old days the job of a physician, pharmacist or nurse was to optimize the restorative processes through appropriate intervention. It's a process. Diabetes is a pathophysiological process; it's not a disease – it's not a noun. What we've missed in medicine is that life is a process, not a noun and we have to start addressing those processes. There is no such thing as pain – it's a made-up word; there is unnecessary hurting and suffering. Until we use our words to address what's really going on we're not going to fix the problem. We're just going to be arguing over controlling pain. You can't control pain – we don't know what it is. You can't manage pain. We can have interventions to deal with nociception but by objectifying things we damage our patients because we give them unrealistic expectations. We don't know what we're talking about so how can we fix it?

The heart of the identity crisis is the divorce between the concept of medicine as a healing vocation, which involves enabling, and medicine which has become preoccupied with control. This is where we've got lost.

