



THE BRITISH PAIN SOCIETY

Special Interest Group for Philosophy and Ethics

Compassion in Modern Healthcare: A Community of Care:

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Introduction

The concerns we have addressed in recent years seem to have diverged progressively from those involved in pain medicine outwards into the ethical problems facing the whole of medicine and healthcare. One theme in particular has dominated our discussions: reconciliation of the demand for effective science-driven medicine with recognition of the total needs of individual suffering human beings. Two words have come up time and time again: care and compassion.

The recent appalling stories of failure of care in hospitals and care homes which have so horrified us all seem to involve a complete lack of compassion. Are these just the tip of the iceberg? – is compassion in danger of being squeezed out of healthcare practiced in a huge, impersonal and increasingly target and profit-driven health service? Compassion and empathy are natural human instincts but is it becoming more difficult for overworked and stressed healthcare practitioners to exercise them?

At our 2013 meeting the Philosophy and Ethics SIG resolved to try to set in motion a movement to change the culture of pain medicine. Our vision this year, and an even more ambitious target, was no less than the restoration of compassion to the culture of all healthcare.

Professionalism versus managerialism in modern healthcare – Where is Compassion?

Mike Platt

I'm going to define what professionalism means in its original sense and what we mean by professional. And I want to make a distinction between managerialism and *management*. Managerialism is an ethos which managers use to manage. I'm not anti- or pro-manager; managers have a place. By modern healthcare I mean principally the NHS, although I suspect Private healthcare is developing similar fault lines and seems to be moving in the same direction.

The key question is 'what has happened to compassion?' Mid Staffs... South Wales... and I hear about other hospitals, which demonstrate that by no means is Mid Staffs unique, and I wonder what has happened to compassion in those who care for those who need it.

Professionalism

The word comes from the monastic calling. Monks had various jobs in monasteries and had callings – vocations - to do different things. So they *professed* a vocation. Most professions have strict rules of conduct, or an ethic. We have the traditional Hippocratic oath, and some medical schools in America have modified versions. Although this has been largely abandoned we have codes of conduct for doctors and nurses for how we address patients, how we behave compassionately towards them, and how we seek the best for them.

The original professions were the clergy, the law, teaching and medicine. Some monks were *physicians*; they had *physic* gardens where they would grow medicinal herbs. The original hospitals were monasteries and called hospices. There was also of course accountancy.

These were the original five professions but managerialism came into being with the industrial revolution, when it became necessary to develop systems whereby complex industrial systems could be managed, and in the 1920's in America Mayo (who was in fact Australian) evolved this idea of managerialism as: "the ideological principle that says that societies are equivalent to the sum of the transactions made by the managements of organizations. (Some of you will perhaps recognise parallels in the NHS.) The managerialist society responds to whatever the managers in various organisations can gain in their various transactions with each other rather than between individuals." He evolved this concept because he felt that democracy was failing in justice towards individuals.

Compassion

There is some debate about the difference between compassion and empathy. I think it's a pretty thin line. Recent research has shown that there are neurones in our brains which respond to the emotions of others. It has been said that if you empathise too much with your patients you will burn yourself out, because you are taking on their emotions. I'm not sure if you can be compassionate (*suffering with*) without empathy, but the important thing is *being there for the patient*.

There is a lot of talk in industry about philanthropic companies, and it is being said that within the next ten years the most successful companies will be those that are most philanthropic towards their workers as well as their clients. A theory goes that if you are philanthropic to your workers they will be philanthropic to your clients. So

how do we get to this point in the NHS? Mrs Thatcher wanted more managers. There is a story that when she was being interviewed live on TV without any advisors and was being asked detailed questions about the NHS about which she had no idea, so off the top of her head she said we need more managers, and allegedly that was how it started. The then CEO of M&S, Griffiths, was brought in to oversee this process. Blair carried this on, and Brown brought in Darzi who brought in the next generation of polyclinics etc. I don't know how the CEO of the NHS works but my impression is that he is surrounded by managers but, I don't think, any clinicians. I do wonder if he and his predecessor, now retired, who was also CEO of Mid-Staffs when it happened are divorced from clinical reality, and really understand the clinical imperatives of the NHS. When Lansley came in he completely destroyed the structure of the NHS and now we have this dog's breakfast. But where is the patient in all this?

Now we have to reach targets, zero MRSA... the latest thing is zero tolerance for non-clinical cancellation of surgical procedures. Zero tolerance! - it just doesn't make sense. But the language is remarkable. You have to abide by a set of rules which bear no relation to your clinical activity. Then we have guidelines which were originally supposed to help you to manage difficult patients. Every patient is different but increasingly guidelines are becoming *de rigueur*. We have lost control of the way we deal with patients, how we run our clinics, and all this is because of managerialism.

So what happened? The first thing was that we lost control of our teaching. It went away from the Colleges and the professions to things called deaneries. We lost control of the profession with the development things like Monitor; the colleges are still there but they don't seem to count any more (I am talking about medics but I imagine this may be the same for nursing and other professions) Numbers are more important – numbers of patients treated, costs etc. Lean nursing – supposed to increase efficiency and allow nurses more time to spend with patients, but tends to be interpreted as the least number of nurses needed to run a ward or theatre.

Where is leadership in all this? We had a major merger of three big teaching hospitals in West London in 2007 and have had no leadership from the top since then whatsoever, at least until now but it's taken seven years. We've had lots of management but people confuse management with leadership.

Where is accountability in all this?

Managerialism doesn't seem to involve accountability.

We have too many patients with complex needs, but we have an increasingly fragmented NHS so it takes them months to be seen by different specialities. This is further complicated by increasing hyperspecialisation of professionals (We have surgeons who only do hernias or varicose veins) Managerialism manages clinical contracts with no specialist involvements. I am told what my contract will be for the Pain Clinic for the next year without any consultation or involvement; if I want to change the way it is run I can't. Professionals no longer have a voice that is heard, patients are no longer properly assessed in timely manner, leading to more problems. All of this frustration with our inability to do what we know we need to do stresses the professional. We get compassion fatigue, we lose our empathy with patients and stop caring; they suffer because of the system but we just shrug our shoulders. We become inured to suffering and patients get punished because of that. They become too afraid to speak up lest they get punished more.

The solution?

For a start, let's get rid of targets. Let's stop focussing on financial goals. Denning was an interesting character: he was an engineer who went to Japan after WW2 and almost single-handedly turned Toyota around. Some of his sayings are coming into healthcare. One of these was "If you focus too much on cost you will never save any

money. If you focus on improving quality you will save money” These things skew the priorities of patient care.

Professionals need time to reflect on their practice, and to be able to share their thoughts on how to deal with different types of patients – and how to look after ourselves. At the moment very few of us have time for any of this. We have so-called audit days but no time for reflection.

We need to improve time with and for patients to allow adequate time for care and diagnostics, so that patients don't just get put on another waiting list each time they get seen. We need to develop proper team working between professionals in the same or different disciplines. We can use techniques that have been developed for continuous quality control (by the King's Fund and the American Institute of Health Innovation among others) and allow you to have a continuous quality improvement cycle. We need to ensure the happiness and fulfilment of staff and professionals but I can't get our trust to take these on. Our vascular surgeons whose practice varies widely from varicose veins only to the most advance aortic procedures using robots are exploring how they can work together as a team.

An interesting report came out from Business Innovations and Skills about an 'emotional resilience toolkit'. They did a study of big companies like Astra Zeneca and BT, giving them freedom to create something to improve the wellbeing of their staff. Initial reactions were "rubbish, waste of time...we need to make them work, why worry about their wellbeing". But they all created totally different programmes: one was getting people to go for walks at lunchtime, another was making therapy quickly available for people who were getting wobbly, and they found that everybody was feeling better and profits went up as well!. But I don't know if they persevered with it or whether managerialism ...

...I think managerialism, if it's done in the right way, can be harmless

A recent survey of hospice patients provided a good illustration of how patients suffer. Pain was only one of several issues which combined to create a perception of suffering. Among these, communication between professionals emerged as of major importance: patients get very worried if they feel that the people looking after them aren't talking to each other.

Poor communication from health professionals is a very common problem in general practice. Patients don't understand the letters they have had from consultants and are often acutely aware that they haven't had the information they need

Another problem for patients is staff overload. Nurses have to be hurrying all the time and there is a level of overload beyond which people start to suffer...

...many patients will sit in a ward bed in severe pain because they don't want to bother the busy nurse.

All these kinds of distress – social, family, financial etc., all bounce off each other

These things get forgotten in the managerial way of running a hospital – you've got to get patients home so you discharge them at 2.00 a.m.

That's part of it but the challenge that we have is that within the NHS we have normalisation of deviance. We realise that we shouldn't be living in that situation; however because it's become 'normal' and we're all in the same boat, and then you couple that with diffusion of responsibility, we all have this problem but it's nobody's individual responsibility to account for it or to do anything... and that's the perfect storm...

You could argue that managerialism is an offshoot of utilitarianism... if a few do badly it's bad luck but most people are all right ...

So, in summary: compassion is essential. Only by maintaining attention to good working practices and time allowed for reflection will there be excellence in patient care.

Discussion

I used to be cynical about targets and I rather selfishly thank Heaven that targets have only become so much more all-pervasive and dominating since I retired. But we did have a talk a few years ago from Graham Sutton (Diana Brighthouse's husband) who is a vascular surgeon very much involved in administration, when he made a very good case for the necessity for targets and what they had actually achieved. Are they a necessary evil?

No – they are drifting away in most hospitals

I think they did change things in general practice, for instance when the management of diabetes was downloaded onto primary care. Most practices were doing it well, but some were really sloppy and didn't check blood pressures ...

That's because they did it wrong – it was supposed to break down the barriers between primary and secondary care. But it was never done properly; they built a brand new centre for diabetes in west London and it never worked.

We set the target for [inaudible] far too low with no age adjustment.

From a sociologist's point of view, professionals are not about expertise, they're about power, and the rise of the profession was about carving out a sphere of autonomy – saying that others are not a professional or less of a professional (like the obstetricians saying midwives don't know what they are doing) and so the idea that is implicit in your talk that if only professionals were in charge and had more autonomy things would be better but ...

... that's not what I was saying – I was talking more about teamwork ...

... but clinical governance came in because of these things – there was a vast variety of factors. There were abuses, there were doctors who did terrible things and were not spotted ...

... they were in a minority – we heard so much about them because they were so rare ... the majority of doctors are doctors because they profess that vocation of care...

... absolutely, and I'm not criticising doctors, but the Royal Colleges, medical training and all of these things were not producing good outcomes. I'm not saying the solution may not have been worse than the disease but I'm trying to highlight why it was felt that there was evidence that there was some very bad practice there – perhaps rare, but generalise not necessarily the best practice ... so it's having more patients and more lay people in the governance of the Royal Colleges and the GMC; . I'm sure you are right that some of these things led to unintended consequences or didn't work out as was planned, but there was a problem and this was an effort to try to solve it.

I don't think there was a problem, and this was blown out of all proportion. The Royal Colleges could have been better placed to improve their relations with

government and the population. The majority of professionals did a very good job. The NHS has declined significantly since we became trusts. The quality of medical care... I'm not talking about nurses here ... medics are less experienced. Some surgeons, when they become consultants, cannot do an anterior resection on their own. There is a huge problem with training medics now. That is a direct result of the profession losing control. I don't mean control in an iron-tight way; there are ways of controlling, interacting and managing. I'm not against managerialism as such but the problem is that there is a fault line between the professions and managerialism and we must find some means of crossing it.

Can't the professions self-regulate by giving people evidence. I am thinking of the huge variation in procedures which are done: for instance there is evidence of massive variation for minor procedures in orthopaedics or back surgery across the country, and huge variation between private and NHS interventions which is not driven by clinical need.

By brining in teams you can make a whole institution more responsible. At the moment you have too much solo working. Individual surgeons work on their own and think they are the best thing since sliced bread and need far more teamwork. In a team you improve each other and make things better for patients.

We kind of run the NHS as a kind of business but it can't have unlimited financial expenditure. A business needs good managers that can communicate and needs to work under some kind of financial constraint. But a good business only succeeds if it puts its customers at the centre of attention. The NHS's customers are its patients and that isn't happening.

What I have seen in years of nursing is that there are some medics who use the NHS as a showcase for their own egos, which has been a real problem and that probably was why mechanisms have been put in place - less so for OT's physios and nurses, but it happens sometimes that people have used their power not for the benefit of all. Most people in the clinical professions have not recognised that they have power at all, and have not been able to use that power for their patients and have not been empowered. It is absolutely my experience from nursing that if nurses recognised how much power they actually had, and were able to use it effectively we would have a very different NHS.

My second point is that using business language is a real problem for something that should be a not-for-profit organisation. We should be - we are - a charity but we don't use appropriate language. Instead we talk about purchasers and providers, customers etc which implies that making a profit is good, that providing services is about financial gain and some of those things that we all know are not true .. that's not what we are trying to do; we are trying to care for people which is much more a charitable aim.

The problem for professionals is that generally speaking they do profess a vocation, and this is why they go into medicine or nursing ..

...is it?? – always? ... what about status, good money – we're not all innocent! ...

There have been some studies done about nursing and why people choose a nursing career, and those things don't figure at all. The vast majority quote desire to help, a meaningful career and profession.

That is true of most medical students. But what happens when you become a doctor is that you get totally frustrated because you can't do what you want to do and think best for your patients.

You mentioned that the CEO's don't necessarily have an idea of what actually goes on at the coal face. But I think it's beginning to change a little. My husband is a senior

civil servant in the DOH and they are made twice a year to go out into clinical areas to make them more aware.

My other point is about the historical context. In her book The Story of Pain Joanna Bourke addresses the issue of sympathy and points out that historically getting the balance right required medical students to apply more detachment and less concern early on in their training, but that was in 1964. But now things are changing. A few pages further on she writes:"The sympathetic nervous system in the 18th century which proposed a mechanism for actions *between* as well as within bodies-in-pain came full circle, albeit in a very different register. Neuroscientists in the 20th century have speculated about another reason why witnessing another's pain might be painful for the observer: empathy involves neural processes." *[fMRI studies showing activity in brain areas involved in pain processing]*

When my daughter went for her interview at medical school she was told: under no circumstances say you want to go into medicine to care for people or they will say you should become a nurse. You should talk about lifelong learning and stimulation and the academic things... But there is absolutely no way in which they are taught to put down compassion. I would say she is far more compassionate at the end of her training than she was at the beginning.

But I wanted to ask you as a senior consultant: what things have you put in place to ensure that you are looking after the wellbeing and happiness of your team?

I have put in place a series of decisions that our pain clinic is trying to make happen to make it a team. My problem is that there are various people within my team who don't want to be in a team...

... so there is a failure of leadership? ...

A failure, anyway. I inherited this, I didn't create it. And I am frustrated in not being able to change my staff, and my managers won't either. They don't want to work *with* me.

But I would have to say that at we have recently appointed a chief executive who is a doctor. And we are already seeing a change in attitudes at the top and hope this will percolate down. And we have a new medical director – an oncologist – to whom you can actually talk and get reasonable responses.

One of the challenges is that clinical practice is quite easy and simple once you stop doing it! And if you've never done it you will never be able to appreciate what a mess it is. It is a mess and therefore variation will always be inevitable, and sometimes completely desirable. And that is why you need quality loops to make sure that variation isn't deviant and that it is a good variation. The problem for some managers who have never experienced a clinical path is that it is difficult to appreciate why you can't have a completely homogeneous path, or that there isn't one good way to achieve a good outcome. It doesn't mean to say we shouldn't be always striving for the best outcome every time, but the best outcome isn't the same outcome every time.

I agree with your general direction of travel but I'm not fully convinced that managerialism is the pollutant. Managerialism can be useful, if you are looking at a total pain model, to provide someone looking with a wider perspective. Sometimes we can all be guilty of having a narrow perspective, whether we are medics, physios, nurses or managers. So managerialism can do very well if you've got someone with a wide perspective; because it's messy, you want someone with a wider picture in charge and that's what I want from managers.

No-one goes to work to be malevolent but the philosophy of managers who want to be good at what they do will do what they think best in any situation as they see it. But what we need is closer cooperation, not just between professionals and managers, but everyone involved in the patient pathway who need to work better

together to improve the outcome for the patient. My problem is that I have a lot of managers who come from industry, with no health background, who don't really understand my problems, and don't have the patience to listen to my frustrations about how we can take things forward.

Patients need to be involved as well.

When we were talking about ethos it reminded me of a passage in the NHS constitution (2009) which might strike as ironic: "... the NHS constitution commits the workforce to respond with humanity and kindness to each person's pain, distress or anxiety or need. To search for the things we can do, however small, to give comfort and relieve suffering; to find time for those we serve and work alongside. We do not wait to be asked, because we care". Did anyone know that?

I am reminded of a consultant I heard the other day telling his juniors "I find the ward round goes much quicker if you don't talk to the patients". That is the hidden curriculum ... of course medical students are put in situations where they have to exercise compassion and empathy and I'm sure you are right that that collaboration is what we should be aiming for but what I am worried about is this hidden curriculum, that they learn from people like that consultant, or from orthopods who don't see patients before and after surgery, they just do the operation and bugger off to their private practice and they learn from that.

Most medical students I talk to are aware of the faults of their consultants, and do recognise poor role models.

And yet it is reproduced generation after generation.

I come from palliative care where interdisciplinary working is the norm. We have meetings, case conferences; everything is done as a group. I came to it as an older nurse conditioned to a system where the doctor is at the top of the tree and the nurses somewhere near the bottom, but this isn't the case in palliative care. Everybody is empowered and we all learn from each other.

This does happen a lot in hospitals - there are some very good examples.

Picking up on Tom's remark: I have recently been introduced to the work of Margaret Heffernan who has written a book called Wilful Blindness, which is all about how people shrug their shoulders and turn a blind eye to things they know to be bad and wrong. In her research, for which she surveyed a wide variety of institutions and organisations, she found that, consistently, if asked the question: are the things going on in your organisation which you know to be wrong but you would not say anything about, 85% say yes.

I want to contribute a political theory/sociology perspective. You mentioned Margaret Thatcher; she was of course a politician. You will all have heard of the sociologists Max Weber and Habermas. What I have been hearing from you all for the last couple of days is that the logic of the market is overtaking the logic of medicine – the syntax, the grammar and the logic of the market has colonised these other dimensions of human life which Jürgen Habermas, the greatest political philosopher of the 20th and 21st centuries refers to (from Weber) as these domains of human life. Ironically the political took over this, but it really wasn't, it was the managerial dimension of Mrs Thatcher: the business person in her political advisors wasn't there .. so that logic took over and the only way to take it back is through politics. What has happened in the neoliberal state is that politics and the political have been subsumed under the logic of the market. Politics has too – we're not supposed to be political any more, we're not supposed to organise. That's why my last slide was about organising. Politics is a blood sport and people don't want that to happen any more; they want there to be this managerial veneer over everything but really everything underneath

is politics. The only antidote to that is politics. You can't solve the managerial problem unless you have political power.

I think it's a shame, though – we are all quite vehement about it – but as you were saying yesterday that it has a corrupting influence on an awful lot of the people who work in it. They join the enemy by administering the bad system, and being cruel and bullying and uncaring – it's the Stockholm syndrome all over again. Have people come across the boiling frog experiment? If you throw a frog in boiling water it will jump straight out but if you put it in cold water and heat it very slowly it will boil to death. So people are just dealing with it, pushing down their own sense of right...

We are all capable of doing evil things but most of us want to be good. If the system drives us into doing bad things ... you may not even be aware it's happening. I was talking about professionals in the traditional sense of professing a vocation and I still think that the majority of people go into the healing professions because of a vocation to help their fellow man. Most of them are in the top 10% of the IQ of population; if they want to make money they will go into the city. Fewer people are going into medicine because it's not as well thought of as it used to be.

In terms of cultures our environment when we are training is bound to have an influence, and this will be different for a nurse and for a physio. Maybe if we had a wider training with more generic things in common it would be easier to communicate.

Restoring humanity in health and social care – Some suggestions

Raanon Gillon

The ethics of this are very simple and the real problems are with implementing the conclusions of ethical analysis into practice. I only have suggestions

I am a retired GP from a peculiar practice as it was once called on television. It started as a student health practice and then became a general practice in the area of South Kensington and included the Imperial College Health Service. You might think that the lots of patients we had from South Kensington were a very high class group, but in our case they certainly weren't. They were the servants, and in one case the slaves, of the people that owned the houses. It was a very instructive experience. As we have heard, it is a tremendous privilege to share peoples' experiences one after another, day after day, and to some extent become part of it. One particular patient who had been beaten up by her mistress was referred for me to check that no real damage had been done. I said "you don't have to tolerate this sort of stuff ... there are refugees' organisations and are ways you can get away from it" and she replied "Doctor, for goodness' sake don't start meddling, This is quite manageable; she gets drunk from time to time and beats me up, but she is out of the country most of the time and I have a nice flat and we get on quite well when she isn't drunk. If you were to report it I would probably be deported back to the country I came from where God knows what would happen to me". A very important lesson for me.

Ethical Principles

As well as working as a GP I did a degree in philosophy and medical ethics. Although I loved philosophy and it was a wonderful addition to my life experience it didn't seem all that helpful with practical problems of ethics. But when I had finished my degree I came across a book by an American philosopher and an American theologian called *Principles of Biomedical Ethics* (Beauchamp and Childress) which is probably the best selling and most widely read on the subject in the universe. I started teaching the subject and thought this is a load of rubbish: they are proposing four principles that we can all accept. So being a good 'Popperian' by then, I set about destroying this claim; except that I couldn't. It actually became increasingly clear to me that these rather simple prima facie principles were very useful and could indeed be accepted by any by any moral agent who purported to espouse some sort of universalisable ethic. It's not, therefore, compatible with any approaches to ethics which are not universalisable; but most ethical structures claim to be universalisable.

As you all know those principles are, in no particular order of priority: respect for autonomy, beneficence, non-maleficence and justice. And that is an approach I have been working with ever since. It went through a period of being quite popular and then a period of denigration because it was all simplistic and useless, and then other approaches came forward which were thought to be in opposition to this. I never quite understand the hostility which some people manifest to pretty obvious moral claims. Moral agents want to benefit some people – not everybody. There are two problems with the approach, one of which is that the scope of applications to each of these principles - to whom or to what they apply – is open to philosophical, theological and political debate and discussion. The second more important problem and lacuna is that they can and often do conflict, particularly when derivations of some combination of these principles arrive and conflict with each other in a practical type of example.

The two issues of scope and conflict - the conflict of specifications of these principles in practice - require judgement. No-one gives one a rule for a way of judging; as Emmanuel Kant pointed out you can't have a rule for judgment because judgment is all about subsuming under rules and you would have an infinite regress if you tried to have a rule for judgement. It's mysterious – we don't really know what's going on but we know that it's very important. But it seems to me - and I always challenge people to disagree with this – that that doesn't undermine any one of these prima facie principles. You have some obligation to benefit others; you have some obligation not to harm others; and some obligation to respect people's deliberated choices for themselves and their autonomy, insofar as is compatible with equal respect for everyone else potentially affected. And we have a principle of justice in which equality is clearly a component but by no means the be-all and end all of justice: you can treat people equally and very unjustly, and indeed in order to treat people justly you may have to treat them unequally, as we in the NHS know perfectly well.

It seemed to me that this was a very useful structure and I should be very interested to hear if anyone here if anyone here says "no, I don't believe in any one of these four principles" or to hear what additional principle is necessary which can't be derived from some combination of these four. This approach is entirely compatible, and indeed is designed to be compatible with other approaches, especially the theoretical approaches which you have discussed in your previous conferences, viz. the deontological approach concerning duties and rights, the utilitarian approach to do with good consequences, and the virtue based - and I would subsume in that the care based - approach to ethics. These main categories of ethics are entirely compatible with the four principles and there is no need to choose between them. One of the advantages of the four principles approach is that it is for practical people like doctors and health care workers to try to help them make decisions in practice without having to agree to start with about what their basic moral approach is.

Compassion

Compassion is currently one of the great zeitgeists everybody is talking about, but I personally don't like the term because it has too many connotations of lady bountiful. I prefer the ordinary term humanity which is much less specific but includes the whole cluster of issues that compassion tends to encompass: empathy, respect, dignity, care, responsiveness, kindness, spiritual and emotional comfort, solace and so on.

All humanity recognises that suffering is bad and harmful and seeks to relieve and prevent it. These are ordinary common human tendencies. We have already heard about the dichotomy between those for whom medicine is a wonderful caring profession and those who think it is a conspiracy against the laity. I am on the side of those who believe that most of us who go into health care are indeed motivated by humanity and compassion. Sometimes it's driven out of us and we may have to learn to temper it in ways that are actually beneficial. When I was young and applying for medical school we were told not to dare to mention that you are there to care for people or anything like that, but I think that's gone out of the window. I was teaching on a course for intending medical students and a recurrent theme that came up was "for goodness sake don't fail to recognise that this is a very important part of why you want to go into medicine if indeed it is. And if you don't want to for that reason perhaps you should be thinking about some more profitable activity."

So far as the ethics is concerned let me briefly point out that the ethics are not rocket science. One of the contributors to the conference at which this all started, Ann Gallagher, talks about 'slow' ethics and the need for complex analysis. It's very true that many aspects of ethics do need complex analysis, but others just need 'fast' ethics. It doesn't take a great deal of effort to see that compassion and humanity are good things and should be encouraged. And if I do a fast version of the four principles approach it is pretty obvious that delivering healthcare with compassion and humanity tend to be more beneficial and less harmful than delivering it without them. There can't be many autonomous people who actually prefer their healthcare

to be delivered without compassion and humanity. And compassion and humanity are very rarely in conflict with justice. That is not to say that there are not some pretty awful resource allocation problems in distributive justice that have to be faced, but if you face and deliver them with compassion and humanity you'll do a better job than without them. So it doesn't need much more than that to defend humanity and compassion. If you take a Virtue Ethics approach – the fast version - compassion and humanity, as well as caring, are of course widely accepted as part of Virtue Ethics.

Ethics in practice

So that is really all I wanted to say about the ethical analysis of this issue, but the paper¹ [on which this talk was based] was an attempt to come up with some suggestions about how to get them into everyday practice.

The first is to get rid of what I call 'biomedical machismo', which is the notion that science is what it is all about, and that we must get rid of all these touchy feely things that spoil it, and concentrate on the important part of medicine and healthcare. It seems to me that this is to put the cart before the horse. The importance of science to medicine is instrumental because science helps us to do it better, i.e. to help people more and harm them less. It is a means to an end. I think the ethos of medicine has swung too far towards not just reifying the scientific component but turning it into a god. So the first bit of my suggestion is to try and sit on the biomedical machismo as part of the requirement for getting humanity back into medicine as not just a constituent part of medicine but its driving force. (And I think it is 'back'; perhaps one of the reasons why humanity functioned much more in earlier times in medicine was that there wasn't much science –or managerialism - available). Most of us have it; maybe I've got rose-coloured glasses but in my experience most doctors, most nurses and healthcare workers are very benevolent and oriented towards being beneficial. But I have come across some counterexamples who seem to have lost their humanity and who are concerned with numbers and targets, and getting things done with efficiency, at the expense of ordinary humanity. When they get into positions of power, which alas they seem to do disproportionately, they can have a very malign influence. So trying to remind people that humanity underlies the practice of healthcare is an important target. I think there is already considerable hope that humanity is now increasingly emphasized in the literature of various sorts concerning medicine. That has been given a wonderful kick up the backside by the Stafford inquiry which, it is my impression, has started to get people moving towards trying to change things. It has been a long process: the NHS Confederation and the Local Government Association and Age UK, had a dignity commission and they reported on delivering dignity and provided an impressive start on the humanity agenda. Then the Dignity in Care Network, hosted the Social Care Institute for Excellence. The Royal College of Nursing urges the importance of humane and dignity respecting behaviour. The government's chief nursing officer categorises compassion as one of the six fundamental values in her vision of the future of nursing. (The others are care, competence, communication, courage and commitment.) The GMC, the Royal College of Physicians and the BMA all manifest humanity oriented concerns in their literature. The King's fund has a section in their Point of Care programme devoted to these issues. The Human Values in Healthcare Forum, with which I am associated, is focussing on the issue of compassion. Incidentally it invites membership, and so does the Institute of Medical Ethics. Perhaps most importantly, the recently revised version of the NHS Constitution¹⁹ – revised partly in response to the Francis Report – has taken up the theme of compassion. Perhaps most importantly, the recently revised version of the NHS Constitution – revised partly in response to the Francis Report – has taken up the theme of compassion, telling all NHS staff that they 'should aim to maintain the highest standards of care and service, treating every individual with compassion, dignity and respect, taking responsibility not only for the care you personally provide, but also for your wider contribution to the aims of your team and the NHS as a whole'. And it tells everyone that 'Patients come first in

everything we do', that (under the heading of 'Respect and Dignity') 'We value every person ... as an individual, respect their aspirations and commitments in life, and seek to understand their priorities, needs, abilities and limits. We are honest and open about our point of view and what we can and cannot do'. Under the heading of 'Compassion' the NHS Constitution pledges 'We ensure that compassion is central to the care we provide and respond with humanity and kindness to each person's pain, distress, anxiety or need. We search for the things we can do, however small, to give comfort and relieve suffering. We find time for patients, their families and carers, as well as those we work alongside. We do not wait to be asked, because we care'. And these values are accompanied by a statement of the right of all 'to be treated with dignity and respect, in accordance with your human rights'. Furthermore, the Secretary of State for Health has now sent a 'mandate' to Health Education England which has replaced the previous strategic health authorities in England and taken over their budget – outlining his four priorities of 'preventable mortality, long term conditions, "being caring", and dementia', and requiring an extremely wide range of 'deliverables' including the requirement 'that recruitment, education, training and development results in patients, carers and the public reporting a positive experience of services consistent with the values and behaviours identified in the NHS Constitution'.

You may well say that's a lot of hot air – just words but what about the action, but what is important about the words is they are now built in to the very constitution of the NHS, and people can be held up, as it were, to meet these obligations. Everyone 'from ward to ward' is required to implement that constitution.

Delivering Humanity

So what about the ways in which it might be done? My first suggestion is to create a high-level task force, a bit like the Delivering Dignity team, to try to monitor and propose practical ways of implementing the humanity objectives in that constitution. If there isn't such a group constantly looking at the implementation of that aspect of healthcare I fear that it will rapidly disappear as it is squeezed out by the other more 'scientific' objectives.

High on the list of structural proposals that I think should be developed is provision of more time: time to interact with patients, clients and colleagues in an unhurried, unharassed, friendly and human way. I don't know how this is to be done but it seems very clear that it should be done. I don't think it's beyond the wit of managerialism, informed by the NHS constitution, to work out ways that can actually produce more time. A simple example from my own practice is appointment time. Some people consult very quickly and some very slowly (I was a very slow consulter) We could devise a method that would reduce the importance of that, partly by letting people choose who they were going to consult, depending on whether they didn't want to queue or were prepared to wait longer for a longer consultation. This sort of variability could be built in, and you could also build in 'buffers', so that a couple of appointments are there to take up extra time.

Good communication skills are obviously a tremendously important part of bringing humanity to healthcare, and these can actually be taught. There are lots of courses on these in medical education and people do get better at it. A simple example is the use of scenarios and actors playing the parts of patients or doctors. I certainly found this very helpful with medical ethics to help people become involved in the assessment of a particularly difficult issue. I wonder whether there might be an 'improve your interpersonal skills' module introduced into such teaching; it might be a bit threatening to say 'how to make yourself a nicer doctor or social worker' but that would be the objective. I have found lots of advice and courses and books and so on about this on the internet. This seems to be an area where it's worth doing some research into what methods actually improve communication with patients and they find helpful. Part of the same thing is to build in the notion of self-assessment. There is no doubt in my mind that structural and institutional changes are essential to bring in a more humane approach to healthcare, but it is also important to remember personal responsibility. We are all moral agents; we can all look at our own behaviour

to see how we can improve it. This is not to advocate the blame game or the threat culture; this is the responsibility game. We can look at our own behaviour and apply a little checklist: 'Does my practice manifest a human face?'. Am I friendly, helpful, kind, considerate? Do I listen enough, do I talk too much? Or too little? Do I interrupt too much? Do I smile enough? Do I make eye contact, or at least appropriate eye contact? Of course some people are shy and avoid eye contact, and in some cultures it is discouraged, but in general it is a very helpful component of communication. Do I 'blank' people out? There is a horrible tendency in the NHS to do this especially if people have been critical and we feel under threat. Am I perceived as (for few of us can admit that we actually are) arrogant or patronising or overbearing or frightening? Do I shout or even scream at people? Do I ask my patients or clients about their concerns and if I do, do I wait for answers? Can I be trusted? And if I have a managerial role what can I do to encourage this human face in the people that I manage? I wonder if this should be included in assessments and appraisals for revalidation or even 360-degree feedback*.

All this needs to be researched. There are ways of finding out what methods of showing a human face can actually help patients. In order to get it into research it seems to me that it is important to point out that humanity, caring and compassion are part of the very concept of health care, in both of the concepts of health and of care. Without it the sort of research that sort of research which purports to be about health or social care is simply scientific research. Any funding agency, researcher or research body which purports to be about health or social care should commit itself to health and to care. Integral to the notion of health is wellbeing. You might not accept the WHO's rather grandiose definition of health as 'a state of *complete* physical mental and social wellbeing', but (as I once suggested at a WHO meeting and it didn't go down very well) you could change the word 'complete' to 'adequate'. So the definition of health as a state of *adequate* physical mental and social wellbeing seems quite a good one, and expressly builds in an evaluative component.

*In human resources or industrial psychology, 360-degree feedback, also known as multi-rater feedback, multi source feedback, or multi source assessment, is feedback that comes from members of an employee's immediate work circle. Most often, 360-degree feedback will include direct feedback from an employee's subordinates, peers (colleagues), and supervisor(s), as well as a self-evaluation. (Wikipedia)

Once you accept the notion that wellbeing is part of the concept of healthcare then you have a stick to beat with - or at least an argument to convince the providers of health funding that actually they ought to be funding humanity and care research as part of their commitment. It might be difficult to get them to admit it and even the big funders like Wellcome who finally, in the 70's or 80's got round to recognising ethics, could be persuaded that research including an element of wellbeing is something they could give money to and encourage; and even to suggest that when any scientific proposal in the area of healthcare is made, there ought to be an added question about how much does this add to wellbeing and of whom. There might be an explicit statement that in the event of a tie between equally meritorious applications for funding those which improve wellbeing would get preference over those that don't.

One could on to wider research themes such as what sort of component in assessing applicants for healthcare jobs are likely to improve patient care. That would be a huge project but it could be done. For instance an Australian research project showed that students who had studied the humanities as well as sciences before entering medical school performed better as interns than those who did not. It's a very interesting correlative finding; whether it is causal or not is another issue but at any rate it is the sort of thing worth studying. My own suspicion is that later entry into medical, nursing and social care schools might be an improvement as far as patient care is concerned and this is something else that could be studied. I may be wrong but we could at least look into the possibility that a broader life experience before going into these caring professions may be better for patients when you grow up, as it were.

Can the studies of humanities: literature, drama and poetry be shown to improve the humanity of healthcare? Macmanus had an interesting article in the Lancet a few years ago that said we should research it. The sort of research this would involve would be different from the controlled clinical trial, but you could, for example, imagine ways in which you could discover whether people with humanities in their background are better appreciated by their patients. I came across a wonderful example of empathy training comparing a group of doctors that had received this with another who hadn't and assessed by how patients responded to them and apparently the first group were preferred.

The overall message is that the healthcare experience, as the NHS constitution now says, should be compassionate, kind, supportive, respectful and humane, but at the moment it isn't.

Discussion

There is a lovely story about a group of NHS managers on some course who were asked to bring a picture of someone they really cared about. They were put in a circle facing away from each other. Someone read out the NHS constitution while they looked at their pictures and within 10 minutes they were all in tears.

I'm not sure about separating science from humanity and compassion because if you show humanity and compassion it can have a positive effect on neuroplasticity in that person. As clinicians we can display humanity and compassion while holding that science in the background. It's really valuable if a clinician can combine the compassionate approach with the ability to explain the science in a simple way. There is a middle ground between the two that we need to work on.

Absolutely – I hate the idea that I might have suggested that I might have suggested that I wanted to separate them off. I want to bring them together more. Medicine is a wonderful culture that combines the two. What I think I was suggesting was at the moment there is this separation because increasingly, science devoid of the care and humanity is taking precedence especially in the way that people run the medical operation and fund research. The balance needs to be restored, even at some cost to fundamental science.

Can I suggest the example of statins which have been in the press – there was a lovely article in the BMJ suggesting we should be thinking about numbers needed to harm numbers as well as needed to treat. This is something that has been going on for more than ten years but you still don't see it very often. This is a way to show clinicians and patients how good a medicine is and how many you need to treat to get the benefit but also how many don't get any benefit and also about the significant number who may be harmed, and you may not want to risk this happening to you. A week after the BMJ was published they had to back paddle vigorously. I have found as a GP that people are harmed by these medicines. When I was a younger doctor I would have been more inclined to follow the science and prescribe something "because it's good for you!" but now I have learnt to think more about harm and not push things too hard. But this sometimes puts me in a very difficult position as I find myself falling between two chairs.

The way I would combine these positions is to point out that when you are talking about benefitting an autonomous patient you need to take into account his or her own view of what counts as benefit. So even if you are only concerned with the Hippocratic concerns about benefit or harm you had better find out from an autonomous patient what they consider beneficial or harmful. Most of us would find a life-saving blood transfusion very helpful but if you are a Jehovah's Witness you certainly don't. It's a hugely important component of benefit to assess the patient's own view of what constitutes it.

Every single patient has an individual risk/benefit ratio for everything you do to them

I wanted to pick an argument about communication skills training which is an unmitigated disaster in many ways. I hate the idea that it is a set of skills that you can add on and that it is not the fundamental human skill of listening, thinking and speaking. You see young doctors doing practicing for their clinical skills assessment and it's like the driving test – you have to ask standard questions about ideas, concerns and expectations and it just becomes a mechanistic rote. You have to get this question in like putting the mirror in your car in a slightly awkward position so they can see you are looking in it. It distorts the humanity in a way that I find very disturbing. I think all we need to do is to teach them to shut up! – to sit with your hand over your mouth!

I suppose one of the problems is that people vary so much as to how good they are to start with. There are some medical students who are not very good to start with and I'm thinking in this context of actors and scenarios where the student has to be the doctor or the patient and the other students are sitting around. I think some students do improve as a result of this.

But whose metric are they improving to?

The metric by which they took more account of what the 'patient' was concerned about. ...

... you can have excellent communication skills and be totally uninterested in the person ...

... but you can't be a good doctor without good communication skills ...

... we hear about brilliant surgeons who are hopeless communicators ...

... why can't they be both? You have to work jolly hard right from the start. Once people can be got onboard to recognize that there is a problem they change. I'm quite hopeful.

I would like to agree and at the same time profoundly disagree with Iona. One thing young doctors say is that they don't want more communication skills training because they have had so much of that at medical school. But we also know that the most complaints about doctors are to do with communication. So there is a dichotomy. I agree that the one thing that is important about communication skill training is teaching them to shut up and in fact you can teach people to listen and to explain to a young doctor that his role is to listen and not rush to explanation. Young doctors tend to believe that their role is to explain, and if you can explain to them that it is also to listen that is fantastic.

Communication is two-way.

One of the difficulties is that the language of communication 'skills' suggests that communication is only a skill, rather than an attitude of mind. And a problem for teachers is that the models and theories that you are basing your teaching on tend to be about information delivery and getting your message across, and being able to understand what you are saying and say it. What we don't have as much of is courses that are around purely listening with no message delivery and no agenda.

Several years ago I did my basic training for the Samaritans. A lot of this was about active listening and involved a lot of role playing. The thing that made the biggest impression on me was when I sat opposite someone who had been told not to actively listen: in a multitude of ways he showed me that he didn't give a damn about

my miserable story. That is something I have never forgotten and more than anything else altered my practice. I was already a palliative care nurse. Nobody in nursing had ever taught me anything about communication skills, but I had picked up those along the way and thought I was quite a good communicator, but in that session I learnt what it feels like to be not listened to. A very powerful lesson.

It may sound a little old-fashioned, but I like the notion of good manners. People can be good communicators and have dreadful manners, but good ones are very appealing to a patient, and it is something I appreciate when I am one.

You mentioned putting together a board to enact ... is there one in existence?

No, as far as I know. I was just suggesting that given that it is in Health England's mandate, and there are sub-groups dealing with other aspects of the mandate, it would be a jolly good idea to get a group together to deal with issues around humanity.

There could be boards within trusts which ensured that these things would be attended to locally.

I'm very interested in the idea of people being referred to a wellbeing clinic and working in a department of wellbeing sounds a great idea.

I went to see the after sales service doctor at our VW garage because my car was poorly and despite all the technology at their disposal they couldn't do anything for me. I noticed on the wall a very large board which said "If you were your customer, would you be completely satisfied with the service you have received today?"

One thing we have talked about a lot in this group in the past has been the importance of role models, negative as well as positive. John Loeser said last year that you can teach medical students communication skills till you're blue in the face and they start out with good intentions to use them, but when they qualify there is a culture, particularly within surgery, where they are exposed to negative role models who behave as if the technology is everything and communication is of no importance. And then it all goes out of the window.

I find that a very difficult one, having not always been a very good role model in my time. It seems to me that one wants to avoid stopping people actually undermining good medicine by demonstration, but I'm also quite keen that people should be allowed to do their own thing. I was upset by the notion that doctors ought not to be fat which I read recently! When advising patients about healthy living it's not 'you ought to be doing ...' but 'if you want to live longer or avoid this or that, then currently these are the ways you are advised to do it, and it's up to you...'

Can you feel my pain? The role of empathy and compassion in health and social care

Tom Shakespeare

It would be better to die once and for all than to suffer pain for all of one's life. *Aeschylus, Prometheus bound.*

I think you invited me because you heard me on the radio talking about compassion and empathy and whether we could teach these things to medical students, but I feel I'm here under slightly false pretences as I am no expert on these subjects. I'm no expert on pain except that I have experienced it a lot. So I am hazarding a few thoughts in front of a group of people who know more professionally than I do in the hope that you will educate me, but if along the way you are enlightened or amused – or infuriated - that's great.

I am going to start with some musings about individuals and their pain and then widen out into the health worker response to pain and then a bit about systems and how they respond or not in a compassionate way.

I did another radio talk this year about disability. It was about the way that people think that people with disability have a poor quality of life and how miserable it would be to be disabled, and yet when you look at the evidence disabled people report a quality of life which is as good or better than non-disabled people. But I qualified that with the exception of disabled children or adults who are in chronic pain. Because you can adjust to almost anything: to being paralysed, to a missing limb or whatever,. Your quality of life plummets and then over time it goes back to pretty much what it was before. But what people find it difficult to accommodate themselves to is chronic pain. They can get used to almost any form of life other than pain. In her book *The Body in Pain* Elaine Scarry describes how everything else besides the pain becomes secondary, even invisible. You narrow down, so pain and suffering threaten our composure, our integrity – everything goes by the board.

And yet we have this paradox that for the person in pain it is world-destroying but it is extraordinarily difficult to feel the pain of others. Nothing is as absorbing as pain but nothing is as boring as pain – to be with someone else in pain is boring. Part of this is because we cannot fully understand the other's pain. It is always going to be remote to us. As Elaine Scarry says, the nature of pain is resistant to language, and Wittgenstein gave pain as an example of why private language is impossible. We know everybody suffers pain, we know about our own pain, but it's like a beetle in a box. We each carry around a beetle in a box; we can't see other people's beetle. We can't know about other people's pain; all we have is a social agreement about when we can use the word pain.

Maybe that's too negative – we can all feel pain so we can have some intuition into what other peoples' pain states are like but it does point to the fact that it's very difficult to *know*. If I say I'm having a terrible day of pain I may have a low pain threshold or may be complaining a lot. It's hard to be sure: you can be certain about your own pain but not about someone else's. There is a tendency to scepticism: 'they're just a winger and can't know what severe pain is *really* like'. We don't know how seriously to take other people's complaints (an interesting word, complaint: what you say is wrong with you)

We know that pain breaks down the mind-body dualism. The effect of psychological factors on pain sensation was known centuries ago to Lucretius who remarked that warriors don't feel pain in the heat of battle, reaffirmed by Beecher's studies in WW2 in Italy. People perceive pain in the same way but express it and respond to it differently. We know that being distracted from pain means that we feel it less. We know that different cultures display pain in different ways.

So it becomes harder to interpret other people's manifestations of pain and get to the true underlying pain, and yet we're here today talking about empathy and compassion, and pain present us with a particular problem in this context. As Joanna

Bourke says in her book *The Story of Pain* that over the eons medical experts, generally white male, have expressed doubts as to whether slaves, women, children or animals could suffer pain. This is the idea of the hierarchy of sentience. This is really a monstrous lack of empathy; a refusal to accept that the way people are behaving means that they are really in pain if they are socially inferior to you. From a book written in 1907 about pain and empathy: "The higher the life, the keener is the sense of pain." So as we become more civilised it is truly the most civilised people who are the most sensitised to pain. American neurologist Silas Weir Mitchell, writing in 1892: "In the process of becoming civilised we have intensified the capacity to suffer". Savages don't really feel pain, but they complain about it a lot; but civilised people not only feel more pain but they keep a stiffer upper lip. That lack of empathy about pain means that folks didn't get anaesthesia even when it was available. One third of amputations in late 19th century Pennsylvania were conducted without anaesthetic. In the early 20th century children were operated on without adequate anaesthesia. There are 5.5 billion people living in countries where there is little or no access to opiate analgesia, so if you are in end-stage AIDS or end-stage cancer or recovering from surgery you aren't going to receive adequate pain relief. That's really shocking.

But we live in more enlightened times and wouldn't commit the errors of the past, (of course not! ...?) but we still have difficulty in evaluating and communicating pain states. What would Wittgenstein think about the Magill Pain Questionnaire? How can we reconcile it to Scarry's comment about pain language? It's a good effort, and it's really important that we can begin to break down different sorts of pain and refining and understanding it.

"The pain you have is unique, it can't be compared with another person's, only you can know how much pain you have and when you have it."

Melzack and Rogers

But then they do go on to compare it to other peoples'! Which is kind of weird! A big question about the MPQ is were people in pain involved? The words came from the clinical literature and then those words were classified by experts like doctors and university graduates and then ranked by clinicians, students and finally patients. But are these words individuals use about their pain? Some are, but I think a lot aren't, because a lot of the time if you're in pain you probably groan, yelp or cry; it's not so often you use discrete words about pain, but at least not that range. People use some of those words but certainly not all of them. The MPQ use the categories sensory, affective evaluative and miscellaneous. But they are not the ways we would intuitively respond to pain. And we are talking about how to be intuitive in our response to other peoples' pain.

If I were doing it I would ask people in pain, and I think what you would get is less of the words and more of the metaphor. People generally talk about pain metaphorically - I know I do. I would say "it feels like someone is cutting off my foot" or "someone is stapling my ankles with a staple gun". Metaphor has more richness than individual words.

As well as communicating about pain we've got doing something about it. It still seems to me to be really hard to medicate pain. This is your expertise and maybe I've been unlucky but as well as back pain I have suffered constant neuropathic pain since I became paralysed in 2008, so I have an understanding of what constant and debilitating pain is like and how hard it is to medicate. To quote from a paper about neuropathic pain in people with spinal cord injury by Henwood and Ellis "there were no participants that achieved acceptable relief as a result of taking prescribed medication". It seems to me we're not very good at dealing with pain - at least not in general medicine and practice although you as experts may be better. We're

certainly not good at teaching medical students about pain. In preparing of this talk I discovered that in the US med students got 10 hours...

It's about the same here. Vet students get more.

The Medical Response to Pain

So what are people in pain looking for from their health professionals? Are we looking for compassion or empathy and is there a difference? The top rated topics in a US survey were compassion and empathy, so these issues are intertwined.

When I interview medical students for Norwich Medical School I ask them what empathy is and almost all of them give the 'right' answer: the ability to put yourself in other peoples' shoes – to feel what they feel. But how reliable is empathy? How do we know that we are feeling what other people feel? Iona talked this morning about imagination. I think this is wonderful and important and should be part of medical training. But it's also very dangerous. We imagine we know what someone else is feeling. There is a wonderful paper by McKenzie and Scully in which they say it is very dangerous for non-disabled people to think they know what it is like to be disabled. Go back to what I said about quality of life at the start, and how non-disabled people imagine it must be dreadful to become disabled. "If I became disabled I would be miserable". But we have discovered that this is not the case. So there is a danger in imagination if it's not rooted in an appreciation, maybe from literature, maybe from talking to people about what their lives are really like. If we think we know what it's like to be somebody else it might be as well to check with them.

Turning to compassion, we have already had it defined as to experience with, similar to empathy. Pequita de Zulueta suggests that compassion combines both emotional (feel with) and cognitive (feel for) dimensions and that "compassion is a positive motivation to act" so empathy is a precursor to compassion; perhaps you can't be compassionate without empathy but compassion takes it further. I was ironic when I called this talk "I feel your pain" because when people say this we know they don't. it's glib, they are just saying it. Empathy is not a substitute for compassion. Raanon Gillon quotes Gilbert and Firth-Cozens' definition : "Compassion is a sensitivity to the suffering of self and others and a deep need to try and relieve and prevent it."

If I were a real disability radical I would be suspicious. When I was one about 20 years ago I had a tee-shirt which said "piss on pity" - disabled people are sick of bloody pity – they don't want compassion, they want equality, they want rights. Compassion is a personal individual feeling accompanied by a motivation to do something individual, charitable and good. But actually if the problems of this group of people are systemic, political or involve rights violations, then how is compassion going to help them? It probably will but it's not a substitute. Disabled people say they want rights, not charity. But I think we need both. There is this distinction between the ethic of rights and the ethic of care, but we need both, not one as the substitute for the other. I can live in the most progressive, civil rights place imaginable, but I will get a puncture in my wheelchair tyre, or I may fall out of it or need a push up the hill.

So what do we do with pain? What is the compassionate response to pain? Obviously things like analgesia, care with handling, being solicitous and sympathetic and so on. But the evidence from a report about spinal injury is that *people with more solicitous relatives report more pain*. I find that fascinating! The more people say how-are-you- how's-your-pain-oh-that-must-be-awful the worse you feel. Paying attention to pain can actually exacerbate it and sometimes the best thing to do is to ignore it.

It could be that the more people say that the less they feel you have to hide it?

It could be, but I'll tell you what, after an hour talking to you about pain I will be in a lot of pain. And when I go round to see my friend Bill and we both moan about our

pain our pain goes up because attention makes our pain worse. Of course the evidence doesn't prove causality either way. But my hunch is that if you're always talking about someone's pain they will feel worse. So there's a paradox! We want to be empathetic and compassionate and people end up in more pain because we've been kind. So really – we don't want to be brusque and say shut up. But it's very difficult; we need to be supportive but not dwell on it, because the more the individual dwells on it the worse it will feel. Soldiers in battle didn't feel pain because they were distracted. I feel worse pain in bed at night whereas if I'm busy I don't feel it.

I also want to say something about scientific evidence. We have this evidence of evidence based medicine which is very important and we are becoming more specialised. We are becoming more rational and we don't do things because we've always done them. There is a great sociology paper by Nick Jewson called "The disappearance of the sick man from medical cosmology". It's about the history of medicine and how to start with, you only had symptoms – all you had was a person telling you their story. You might have sniffed their urine or looked at their turds or taken their pulse but otherwise you had to go on what the person said. But as we proceed through the history of medicine we've had better and better science but we have moved away from listening to the patient – first the thermometer, then the stethoscope – and now you have scientific investigation. But what has gone is the person. We don't just trust what the person says; what the body is saying is what their bloods results and their X-Rays say, not what they say. So the sick person had disappeared because of this objectification. Their testimony is not evidence.

I supported a guy with AIDS who used to see the doctor every month, and he would look at his T-cell count and so on and say "you're great! You're doing really well, Ian." And Ian said "if I'm doing so well why do I feel shit?" So who was right?

So doctors are persuaded by signs, not symptoms. But certain clusters of symptoms are credible; my students can tell you about these. For instance this cluster of symptoms means you're having a heart attack, and this means you're having a stroke. There is evidence that these are attached to an underlying pathology. But when it comes to symptoms that don't have an obvious aetiology the doctor is frustrated. The heartsink patients have lots of symptoms but no aetiology. We have talked today about medically unexplained symptoms or borderline diagnoses like chronic fatigue syndrome or fibromyalgia. Low back pain is the commonest presenting symptom in the world. The progression from acute to chronic back pain is a complex, part psychological process. We're discounting the person in pain and explaining that they have become habituated to an invalid role or whatever. When I talk to doctors – my dad was a doctor and I have many doctor friends whom I respect and love dearly – they tell me that in their experience when doctors encounter symptoms beyond their knowledge and interest compassion takes a nose-dive. It's complex, uncertain and outside their comfort zone. Doctors are often unsympathetic to pain that doesn't have an obvious cause. When there is a lack of specific treatment they can give physicians feel frustrated. (Not you guys – you usually end up with these folks.)

These problems are general but they become really acute in relation to certain groups of patients who are at the most distance and inferiority vis-à-vis medical professionals: disabled people, older people, chaotic people, often women; people at the margins, mentally ill people, I/V drug users, people with intellectual disabilities. (Such as the people in Winterbourne View) A lot of this crisis of compassion is about those people.

So these are areas where compassion may be difficult unreliable or fail. We've said wonderful things about it but we need to drill down a bit closer to look for what goes wrong. I don't think doctors are bad people but to be a professional involves being exposed to suffering all the time and possibly to become inured to it. You need psychological defence mechanisms. Perhaps to survive you need to have a gap – an armour – a degree of callousness even. Part of the difficulty of living with others' suffering is that it raises fears about your own vulnerability. How can anyone deal

with something, for instance, as frightening and horrible as epidermolysis bullosa? One response to this existential challenge is a certain amount of denial, emotional repression, distancing – even trivialisation. Perhaps this is why a lot of doctors make good comedians – if you don't laugh you cry.

Systemic Failings

But we need to go beyond the individual. The doctors at the Mid-Staffordshire were unable to act compassionately and were morally distressed by that – they felt terrible about the situation they were in. And the situation was a systemic problem. In response to this systemic failure we think we have to do better at picking the right individuals. (Cameron: “we must hire and promote nurses on basis of compassionateness etc.”) Systemic failure: better individuals – that doesn't figure. It's the ‘bad apple’ explanation. Today we have blamed managers, we've blamed politicians, we've blamed medical schools in our search to do something about it. But Mid-Staffordshire wasn't about the aggregate of lots of cruel individuals any more than good hospitals are the aggregate of nice compassionate individuals. It's about the way health systems and health and social care organisations can be set up in ways that help or undermine compassion. Compassion is contextual like in our croquet game – a bunch of the kindest people you could find treating each other with sheer nastiness because that's what croquet demands: if you're going to win at croquet you've got to be a bastard. So situations create compassion or lack of it. We're feeling compassionate today because we're a small group of friends in a lovely situation. But faced with lots of patients who are shouting at us, or situations like the Milgram experiments, we could all find ourselves in situations where we would not behave well. Doctors are admittedly overworked but are well paid and have a reasonable amount of control over their situation – but some of them behaved badly at Mid-Staffs. And then you take people who are poorly paid, undervalued and barely trained at all and we wonder why some of them got it wrong? Mary Beard said on Radio 4 the other day “you can't expect sainthood on the minimum wage.” If NHS staff are exploited they won't provide effective care. If they are on the lowest rung of the ladder they are not going to treat people who aren't even on the ladder well. The gap in social valuation between people who work with learning disabled groups and the people in those groups, in places like Winterbourne View, is very slim. I have just read a paper by Winn Tadd and colleagues from Cardiff who say that if staff feel alienated they aren't going to provide effective care; if there aren't enough of them things will go wrong. Where there is anxiety, stress or competition, compassion is squeezed out. This has been shown in chimpanzees. Stress and fear prevents people from being other-directed. Where you are desperate for survival yourself you're not going to be other-directed. Tadd found that a combination of poor staffing, high bed occupancy, blame culture, local ward culture and demoralisation militated against good treatment of old people in acute hospital wards and led to bad outcomes. So they recommended that ward staff should be treated with respect, with better ward management and in a better environment.

What can we do about it?

How can we avoid these abuses? Is it realistic to expect more money and more time for patients? We have rising ill-health, mortality is falling but morbidity is rising and we are living longer. The demands are not going away and the cost of healthcare is rising inexorably, so it's a very hard circle to square. Healthcare is so complex, there is so much political and public pressure that it's going to be really difficult. If it was simple we'd have done it, wouldn't we? I couldn't disagree with a word Raanon said but are those things going to be enough? There have been lots of inquiries, and there are loads of organisations promoting compassion. I don't think we are now dealing with problems we didn't recognize before. We have had repeated scandals – and responses - for generations. And yet we still have recurrent problems. That's not

saying that we should be totally pessimistic and there is nothing we can do about it. But it is a very complex problem in a very big complex healthcare system.

Maybe we can improve the ethos. I read a very interesting paper by Penny Campling about organisations having a virtuous circle of 'intelligent kindness'. Ann Gallagher has written about 'slow ethics', something going deeper than value statements, calling for dialogue rather than rapid response. Slow ethics is great but there is so much pressure in the NHS environment. Things go wrong when there isn't time. We can change the rules. Anna Smajdor thinks it is dangerous to rely on compassion:

"Reminders, routines and checklists are alternative and effective ways of ensuring that crucial healthcare tasks are undertaken without relying on compassion or other feelings to motivate the staff involved".

She talks about etiquette: it doesn't really matter what people think, it's what they do. When we go to the US and everyone says "have a nice day" we think that's false but it's also good and reassuring. Days do go better when people smile at you, even if it's on their customer care protocol, even when you know that, but it does oil the wheels of social interaction. So maybe I am wrong to resist Anna Smajdor's approach. George Burns famously said "sincerity is the most important thing: if you can fake that you've got it made!" Maybe that's all we want from a doctor. We expect doctors at least to be courteous but I'm not sure that it's feasible to expect more and for them to be equally interested in every patient. But I'm resistant to that idea. Stock phrases and gestures only carry you so far. Patients want health workers to give of themselves and not just follow a script. Anna Smajdor says it's about the tasks, but when I was in hospital for 10 weeks in spinal rehabilitation it was the way the tasks were done that mattered. Manual evacuation is a task that you can do effectively or not, or painfully or not. But you can also do it in a way that demeans someone and makes them feel terrible or a way that means that people are able to survive it, and look you in the eye afterwards. It's the same with catheterisation you can do it well or badly but it's whether or not it is done with compassion that makes all the difference. Often patients require you to give of yourself and not just follow a script. 'Attunement' as described by de Zulueta is an interesting concept: a lightness of touch, sometimes distant, some times close, sometimes informal, sometimes formal. It's not a rule and sometimes depends on the task and sometimes on the person. It's about attunement to a person and what they expect or are hoping from you. Some people like you to look them in the eye and some don't. It's a really difficult balancing act. We are asking our clinicians to be wise as well as wishing for an environment in which they can practice that wisdom.

A friend of mine who is in pain has scribbled on my script: "relief from pain! – buggar compassion – buggar empathy" What he wants is relief. People in pain expect advice from a skilled professional with an expert knowledge of drug classes and the rest of it. But they do want recognition and *validation* of the pain they are suffering. They want connection with the people who provide support. Compassion and competence are not in opposition, we need both. There may be a problem with a few brilliant but asocial clinicians – mostly surgeons - and we can only hope there is someone in their team who can supply the compassion.

Conclusion

Pain generates an existential crisis for the person. Victor Frankl asks: "What is the meaning of my life of which suffering is now an inescapable part? Suffering makes huge demands on the individual concerned, and very significant demands on people who want to help them, but cannot fully remove the pain and indignity and can only help them endure it better." And pain, as we know, makes people impatient, intolerant, bad tempered and querulous. Selma Sevenhuijsen talks about caring solidarity in generational terms: we received care as children and will probably

receive it when we are old, and now we are giving it as mid-life adults. Caring solidarity involves taking a wider view of the life-course. We can apply it to compassion for people in pain. You can't fully feel my pain but you either have had pain or have it one day. So don't run away – don't shun me because I remind you of your own pain. Be prepared for your pain and walk side by side with me in mine.

Discussion

You queried at the beginning if pain doctors were any better - or at least less bad - at treating pain than anyone else. It was actually the realisation that a great deal of the time we're actually bloody useless that was one of the main reasons why this group came into existence in the first place.

I'm sure you're better at treating pain than anyone else but what I am interested in personally, as someone who has struggled with pain for many years, is: is it that there is an effective solution and I just haven't found it or is it that there are no truly effective solutions? Are we asking too much of pain relief? When I looked at the evidence it seemed that ... well, in one of the trials I saw nobody got fully effective relief from pain. And yet we don't teach people about pain, I don't know how much we research pain, most people don't get relief at all - why does it get so low a priority when it's the thing that has the most capability to undermine the quality of life. Why are we not doing better?

There's a huge amount of research! ...

Care comes into it. When you are dying in a lot of pain in a hospital situation everyone leaves you but when you move into a hospice everyone gathers round you and you feel valued and you feel better already. One of the problems of modern medical science is that it has separated us from the patient in a number of ways. Care costs nothing – are we losing that because we are looking too hard for the cure? Have we forgotten the adage about curing sometimes, relieving often and comforting always?

It's not just about pain. This may have been part of the problem in Mid-Staffs. An awful lot of the care givers, once you have got into long-term care, are actually not the professionals, they are actually care assistants nowadays. In the past it was females who went into the caring professions but now women have many options so don't go into those professions, so we now have male carers as well and people coming from all over the world caring for relatives – brothers, sisters, elderly parents. Also on top of that we have almost abdicated the care of our families; not many have given up their job to care for their other half or a brother or a sister. Things have changed; people who are ill, disabled, with severe learning difficulties or whatever are not at home with their families. Things have changed. When I worked in the Pacific there was a psychiatric hospital in the capital and they moved it to a province with more population but there were only eight patients in this whole hospital because people were cared for at home.

We can over-romanticise that – sometimes people are cared for by being locked in a shed or chaining them to their beds. I'm just examining a PhD on disabled women in (?) and some of the stories are heartbreaking. It's good if there is a family solution but it can be both the best and the worst. Even in Sweden with the biggest welfare state in the world 80% of the care given is informal.

I was wondering if we were looking at the wrong things and whether what really is lacking is respect and if it is lack of respect that undermines compassion. It ties up with what I was saying this morning about the logic of the market overtaking the logic of healthcare and the logic of human relationships; it's dominating, it's hegemonic in the world of healthcare. It's that lack of respect: not necessarily for one another on

an individual basis but more for the marginalised groups you named when you said that when compassion takes a nose-dive the first ones to go are the intellectually disabled and drug users etc., and when you were talking about the lack of anaesthesia and people thinking that black people and children etc don't feel pain. So it's not a lack of empathy that's the problem, it's a lack of respect that precedes lack of empathy. You can't have empathy if you don't have respect. I think that comes from the culture of the market being the dominant mediator of relationships between people. So there is this lack of respect for staff in hospitals that translates throughout a hospital and becomes a systemic problem. And then compassion has fallen out way before that.

One of the difficulties is that we are at risk of hollowing out the concept of compassion so that it becomes a sort of Kum-Ba-Yah pity, ["someone's crying, Lord"] rather than an aggressive need to make a difference, and an urge to make better for someone the situation you see, more than an urgent need to provide solace. When we talk about compassion some of us are talking about a real fight to provide justice and mercy and others about making sure we can feel people's pain...

...That was my last point about humanity rather than compassion...

...It's the language. When I reflect about Stafford, for example: that's a very close-knit community. From a nursing point of view, with smaller hospitals most of the workforce tend to come from a very small area around the hospital. So the people they are caring for may well be family members. But they still felt powerless to act. So it's something about the narrative of parity: how we take the concept of compassion to be something that could be passive and pitying to something that could be a real act and a force for good.

What you were saying about the way that compassion can be unhelpful and unwelcome made me think about the difference between compassion and empathy, and more confident that there is an important difference. I think empathy goes somewhere beyond compassion. It involves an additional kind of insight. It is a feeling response but not necessarily an overtly emotional response. It can be expressed in complete silence; it can be expressed by a quality of presence with the person you are with. I suppose it's more of a kind of psychic communication between two people rather than emotional expression between them. Whatever goes on at that level can be profoundly helpful and healing. I remember a story about a young man whose wife died and the ward sister just took her into her office and they just sat there for quite a long time and neither said anything at all, after which the man got up and said "I've never felt quite so consoled in my life". I think that was an exchange of empathy rather than compassion.

I was thinking on the same lines about an Iranian patient with little English who came in with her husband and two young children, walking with two sticks, with a low back pain problem. As she sat down I was aware of an overwhelming aura of extreme sorrow about her. I just sat there and absorbed what I could see and I suspect I was absorbing her emotion. After a while I asked, not about her pain, but what she was worried about. She said she was worried about when she was going to get paralysed, which she was convinced was inevitable. So I spent the whole consultation – nearly an hour – just explaining to her what was going on, and she left a happy woman. I realised that what we do is we don't just listen to voice if we are listening intelligently. I think we sense the whole patient and what is going on, and out of our compassion we engage with that to find out what is going on and what the issues are – it's no just about pain.

It's that sense that moves us to compassion.

But you wouldn't have guessed that that was what was going on, would you? You might have thought there were any number of things that provided an explanation - you might have been surprised ...

... I wasn't surprised as I have come across this sort of scenario several times, but my point was that we have to have sensitivity to our patients, and never prejudge them. I think that's why patients trust me.

That's the attentiveness thing. I still feel worried about empathy. I'm not sure about humanity. That seems to be too broad for me. We're searching for words here...

The word 'attunement' caught my imagination. Often when I am teaching nursing undergraduates a phrase I use time and time again is 'are we sensing a tone here?' - if something has gone wrong do you not sense the tone? We need to help and teach people to pick up the tone...

That's what you meant by the ward sister sitting in silence - and perhaps you were attuned to ask the Iranian lady that question. It's a word that brings less baggage with it. I worry about the word compassion and I'm not sure how possible empathy is. How can I expect my 25-year-old white middle-class medical student to have empathy with someone who is a different age, a different gender and a different ethnicity - a totally different life experience, and say "oh, I feel your pain ..."? I know you're not saying that, but empathy is hard to actualise.

It's not a matter of pretending that you actually know...

You can 'have a go' at empathy - you can't say 'I know exactly how you feel' -that's patronising - but you can have a go.

But you don't need to. I had a cancer patient who died. She sensed my compassion for her although she knew I couldn't do much for her pain and she accepted that, but thanked me for caring.

We're talking about ourselves being attuned but our patients are also attuned to us. In one of the studies I carried out in elderly people on the social response to pain, one elderly lady talked to me about looking good and feeling good. She said: "if I go out into the street and meet a friend and I haven't got make-up on my friend will say 'oh, you don't look well'. So when I go out I always put lipply on and people say 'you do look well' and that makes me feel so much better." So emotional perception is a two-sided thing.

I'm a patient, not a doctor, and I'm seeing quite a lot of healthcare professionals at the moment, and I can tell you that if the one I was talking to was trying to empathise with me my rationality would say "I don't know this person - they can't possibly really care about me because I might never see them again - it's just not true". I'm not looking for that, I'm looking for validation of my pain and I'm looking for competence. When I go to see my rheumatologist he looks at me very sympathetically; he holds my hand so carefully I know it's because he understands that my hand is hurting, but he doesn't attempt to feel my pain, and if he did I would think - God, creepy stalker! When I go to get my bloods taken there is one particular phlebotomist and she's a flipping nightmare; there are always two things she says: one [in a very solicitous voice] "are you in much pain today?" and the other is "you're looking very well today - your looks don't do you any favours"! I just want to shout "SHUT UP!!"

She's trying to be empathetic.

To return to the Mid Staffs issue: there is a situation brewing in South and West Wales at the moment which is going to be even bigger than that as it involves more

than one hospital. A couple of years ago my mother got caught up in that and regrettably died as a result of a lot of failures, and as part of that I have been having meetings with a panel of experts who are looking into that case. In the last meeting the medical director of the hospital had his head in his hands and was almost weeping and saying "I am trying my best here but there is very little I can do because there are so many vacancies in the hospital – they can't get people to work in the area. About 90% of the staff are foreign so there is a huge problem with language and different cultures and although they may be competent physicians they don't connect with the patients".

It's the same in this part of the world (West Cumbria) Most of the staff are overseas locums who find it very difficult to connect.

It's apparent that we can all mean different things when we talk about compassion and empathy but for me, in terms of empathy, it's not a feeling. It's more like walking alongside someone in the understanding that you can never walk in that person's shoes. In terms of judgement, I am conscious of the fact that whatever I do I must try to be aware of the judgements I make about the person I'm with and be reflexive.

Speaking as a patient I want my clinicians to judge the evidence I am putting forward – I want my testimony to be equally valid. When I went into A&E with what I said I was sure was a broken ankle I had to hop everywhere until they saw an X-ray which proved that my ankle was broken and they allowed me to have a wheelchair! I want people to judge but I don't want them to be judgemental, because that's prejudging and deciding on the basis of their experience of other people how you will be in that situation.

They ignored your pain until they had 'scientific proof' that there was something wrong with you

I suppose you can define - or at least recognize compassion by its absence. We have talked a lot about people's experiences of lack of compassion in their carers. It struck me that a very common one involves the doctor's attitude when he has failed to help you: "there's nothing more we can do - you'll have to go away and learn to live with it". Most patients who come to pain clinics have heard that – some many times. We can't say that to our patients but one of the most difficult things in the pain business is learning what to say in that situation. Does the fact that you are at least trying constitute some sort of compassion?

We have to educate doctors

As I said, when doctors are faced with symptoms they can't explain or relieve they don't respond well. Are you confirming that?

Oh I am – and it's terribly tempting at the end of a long clinic and you're tired and you're faced with a 'heartsick' patient you've been seeing for months or years

...you've got all your degrees and your training and someone comes to see you and you can't help them, then either you're at fault or they're at fault. But doctors – medicine – don't know everything. I like it when a doctor says I don't know. It's fine if he says I'm not sure but we'll try this – walk with me hand in hand ... but if they can't even admit that they don't know and imply that it's me ... that's where there is a problem.

I don't know if you've ever used hypnosis? If you are using hypnosis for pain you have to really connect with the patient and find out what the metaphors are that they are suffering with, and then you can start to share their experience of their pain. If they think the pain is red or hot or sharp or rough or whatever you can start to say "I wonder what it would be like if it softened up a bit... blue rather than red ... so you

are drilling down into ... You mentioned someone talking of their pain as 'like a stone found their neck'; that's a great one as you can say "let's see how would it be different if the stone got a bit smaller or lighter or changed colour or got a bit warmer ... people come up with the most brilliant treatments, such as "I would like it to be blue liquid floating over my painful limb. I think that's underused...

Can I recount an experience of the occasional difficulty of using metaphors? I was speaking about some work around neuropathic pain to a European audience and I described the frequently used metaphor of the red hot poker. A question made me wonder if we were talking at cross purposes and it transpired that I was thinking of fire but they were thinking of a particularly exciting game of cards!

Compassion fundamental to nursing care? Or too fatigued to care?

Michelle Briggs

First a few words about where I coming from. I am Professor of Nursing at Leeds Metropolitan University and I am also a university chaplain having been ordained about four years ago and serve in this way in a voluntary capacity. I started my NHS career as a cleaner in a hospital for people with learning disabilities moving on to nurse assistant while I did my undergraduate degree in chemistry. I found that I enjoyed and got more meaning in my life from the caring role than from my studies so I did a postgraduate qualification in nursing in 1987, and I have been in the profession for nearly thirty years. What I am going to say is a reflection of my journey through nursing, and my present position teaching undergraduates and preparing the next generation of nurses.

So is compassion fundamental to nursing? Are nurses too fatigued to care? If the latter is indeed the case, an alternative title might be 'How do we lose our compassion in practice?' Compassion has a very high profile within nursing. Jane Cummins (the Chief Nursing Officer) in '*Using the NHS Change Model to support the 6 C's of Nursing*' enumerates these as:

- Care
- Compassion
- Competence
- Communication
- Courage
- Commitment

She defines compassion as 'intelligent kindness'; and the product of that compassion as treating people with empathy, dignity and respect.

But from a nursing point of view, when I am a patient I don't just want my nurses to have compassion but I want my doctors - and my physio's, OT's ... and the porters! - to demonstrate all those things and to be competent and communicate clearly with me.

But if we're just talking about intelligent kindness, what we take out of that definition is the other person and the accompaniment aspect of compassion, and I prefer Anne Bradshaw's definition:

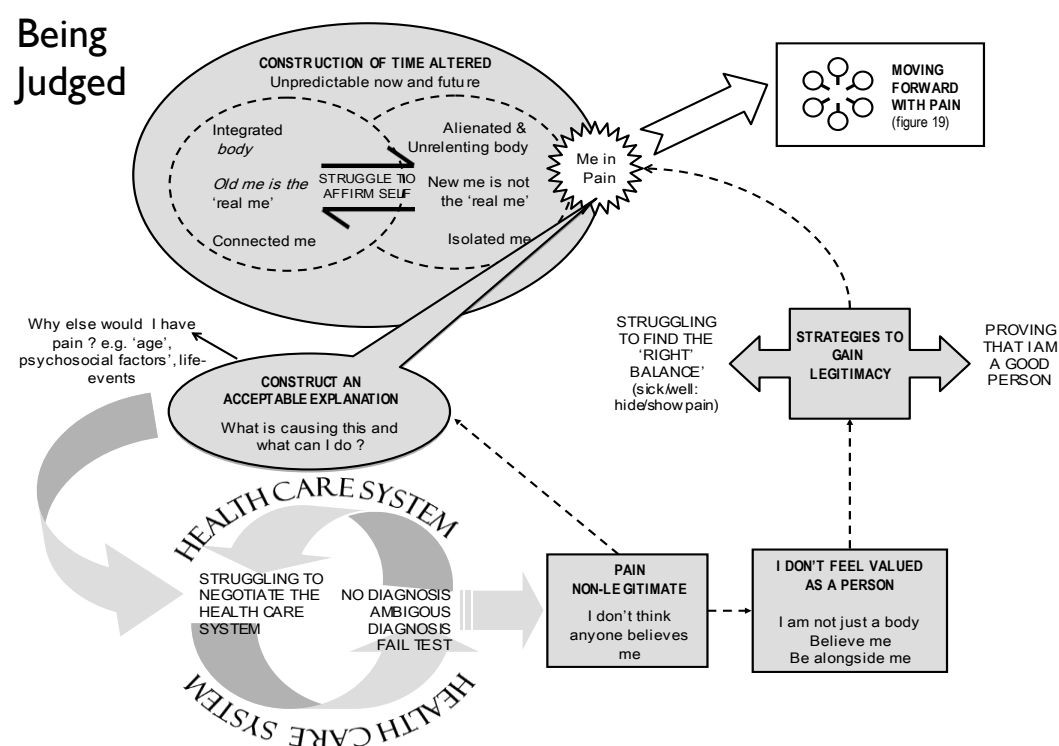
Compassion is the suffering together with another..... A virtue that an individual cultivates..... It involves a strengthening of virtuous intention and practices and a deepening of the disposition to do the right thing even when no one is watching"

Measuring Nursing Care and Compassion: The McDonaldised Nurse?
Bradshaw J Med Ethics 2009 **35** 465-468

Are patients saying that that is what they see? Clearly when we look at Francis and so on there isn't a default setting in the NHS for the ability of people to hold their own and do the right thing even when no-one is watching and we've got a lot of examples recently of that not happening.

Research

So first I want to talk about a project I took part in for meta-ethnography of qualitative research into what it feels like to be in chronic non-malignant pain. Meta-ethnography is a method of drawing together qualitative research analogous to meta-analysis of quantitative data. It involves reading the research, looking at the findings and recurrent themes, and developing a 'meta-synthesis'. When we are using qualitative research it is very often to raise the patient's voice, but often studies don't get pulled together in the same way that systematic reviews of trials do, and meta-ethnography is a methodology for doing this. It involves reading the qualitative research, looking at the findings and recurrent themes, and making a 'metasynthesis' analogous to meta-analysis of quantitative data. We included 77 papers reporting 60 individual studies. 49 papers (37 individual studies) explored the experience of people with chronic musculoskeletal pain, and 28 papers (23 individual studies) explored the experience of people with Fibromyalgia (FM). We looked at all the qualitative data, themes and findings presented by the authors presented and pulled it all together into a model illustrated by fig 1:



What all of those qualitative studies show is that the most important thing, if you *are a patient in pain*, is the struggle to affirm self – to hold your own in the midst of this pain. What you are trying to do is to integrate this new unrelenting body; this thing that won't let you be the person you want to be, with the old you. What you want healthcare to do is to help construct an explanation of why this is happening – not necessarily a thing that can be fixed - and help me work out why I am where I am. This includes struggling to negotiate the healthcare system. Patients find that this involves tests and if they 'pass' those tests, there is no diagnosis and their pain is not 'legitimate'. So if I am a patient I want you, as the pain practitioner, to believe me as no-one else does, to stand alongside me and to *validate* my experience. Where you come in is in trying to help to understand my pain and to achieve a balance between hiding and showing it.

But you are also stuck in this system that does nothing to meet these needs. The quote below was one of the themes confirmed by other qualitative studies, and I think speaks of compassion:

A person needs their doctors to bear witness to their pain experience. This has a profound effect on their functioning as individuals. Expectations are not met..... Their lack of time to listen and understand patients' conditions; disbelief of patients' descriptions and lack of concern; not being taken seriously.

Harding 2005

Time to listen has been a core theme of our discussions.

What a pity it says doctors rather than health professionals.

You are absolutely right but in this work we don't alter the words of researchers; but in our final model we do include all healthcare professionals.

Another factor is the life experience of health professionals. I see many patients who have been totally disbelieved by their GP or other health professionals because they don't fit their own expectations... it's all in my head ...

I hear this and tell patients that it is because that's where your brain is!

Patients tell me that the most liberating thing is being listened to and believed, that that is itself pain- relieving, and sometimes is all they need. When I am locked into the system, especially where this involves incapacity benefits, I need something that society will recognize as a serious problem, even if I am managing alone with no hospital appointments or serious medication, and prevents me from working.

The listening must be non-judgemental...

... and not reinforce that adversarial sense of being guilty before you are proved innocent.

The next project I want to refer to, (*Active listening in hospital staff and patient perspective, Briggs and Manzano*) explores that sense of non-judgemental listening. I have been involved with the Acorn Christian Healing Foundation which is a charitable trust, among many other things involved in training in Active Listening, including for hospital chaplaincies. They asked us to try to provide evidence for the acceptability of Active Listening in a hospital environment, bearing in mind what we were saying about spiritual care interventions and being able to deliver this through an overtly Christian charity, and whether that would be regarded as of value. In the first phase we undertook to explore the acceptability of an intervention for use with hospital volunteers using active listening training through focus groups. Would volunteers want to do this and if it were offered on wards – mainly cancer wards – would staff and patients welcome it? If the answer to this was yes, then in phase 2 we would explore the feasibility of delivering the intervention and develop methods to measure the therapeutic value of active listening and to obtain initial indicators of efficacy. This has been working so well on the wards that the Trust has asked us to develop it in an outpatient setting.

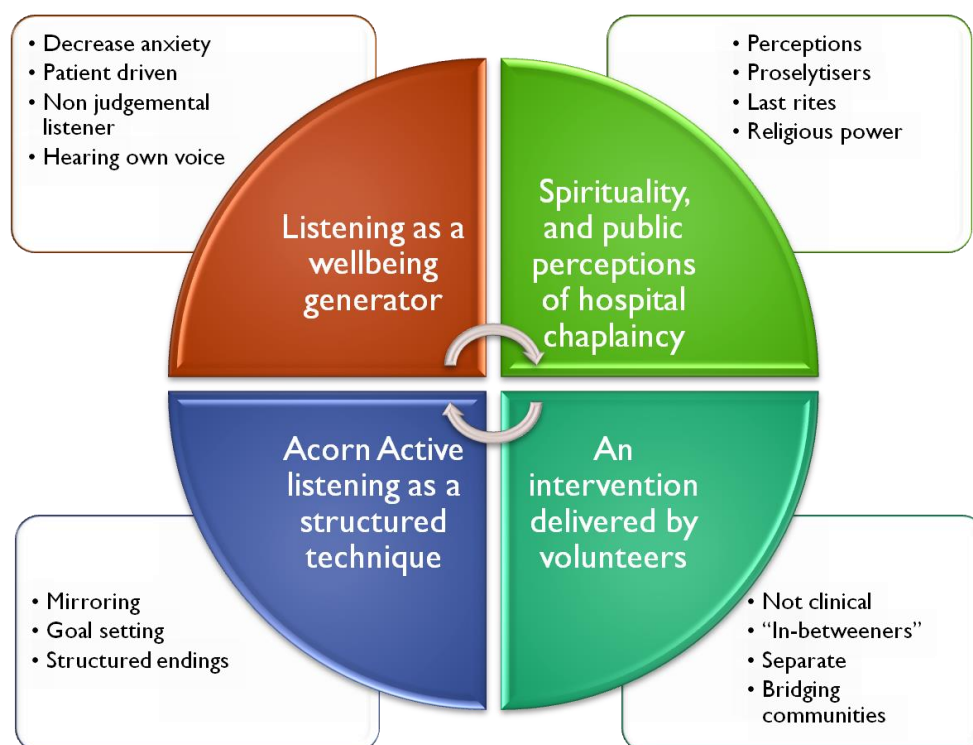
We did a series of seven focus groups for the first phase of this study, purposefully sampling key stakeholders who we identified as: healthcare academics (researchers and lecturers), postgraduate nursing staff, hospital chaplaincy volunteers, trained active listeners, active listening tutors and patients.

FOCUS GROUP CATEGORY	NUMBER OF PARTICIPANTS	GENERAL AREAS OF EXPERTISE
Health Lecturers	4	Physician, , communication skills lecturer, nursing lecturer, psychologist expert in measuring patient outcomes
Health Researchers	3	Social anthropologist, clinical psychologist and health psychologist expert in patient reported outcomes
Nurses	6	Oncology, intensive care, high dependency unit, liver transplant, women's health, primary care
Acorn Tutors	12	Various degrees of listening expertise and years of tutoring: bereavement, GP practices, churches, hospital visiting, etc
Acorn Trained Listeners	8	Various contexts of listening expertise: A&E, street work , bereavement, church, hospital chaplaincy, etc
Hospital Chaplaincy Volunteers	6	Various degrees of visiting experience and specialities: neuro-rehabilitation, oncology, haematology, mental health, transplants, care of the elderly
Patients /service user Group	4	Oncology, rheumatoid arthritis, multiple sclerosis, mental health
TOTAL NUMBER OF PARTICIPANTS	43	--

We used a DVD example of active listening – it is as very structured technique - and described how it was delivered within the Acorn healing model, and something about the Foundation, and then asked the questions like: “As a patient, or a member of staff, if somebody offered you this, do you think it would be valuable, and if you do, what would be the likely impact on your ward area?”

We analysed the responses qualitatively and fig 2 illustrates the results:

Results



There were four elements that people saw as key active ingredients, the first being that listening in itself was a wellbeing generator, and decreased anxiety and vulnerability. There were however real difficulties around spirituality and the public perceptions of hospital chaplaincy and spiritual care providers, and that was a real challenge. But there was a unique benefit from having intervention delivered by volunteers because they were not seen as part of the 'system', but solely there for the benefit of the patients. Staff found the Acorn active listening that linked and had within it clinical supervision, monitoring and recognized training carried a whole sense of being useful and important.

Listening

I want to focus on listening as a wellbeing generator which seems most relevant to our theme of compassion. These are direct quotes from participants:

....our biggest limitation as health professionals is that we don't spend enough time talking to patients

I think it's in stark contrast to the rest of hospitalisation and process in that you're having someone coming to you who doesn't have an agenda at all. Whereas everyone else that has an interaction wants a certain piece of information from you when you're in hospital, so that's what it offers for patients [G1].

Because someone makes you feel important not just a number, not just a bed "we need some paracetamol at 34 So now you have become 34. But unfortunately they are so incredibly busy I can see why that happens . So someone who has time, they're not pushed for time

Sometimes talking to someone, it gives you space to listen to yourself as well.And just knowing that someone is actually listening and heard what you were saying. Because in hospital you can be in a number of days and feel that nobody's really listened to what you've said [...].

When you talk to someone who can be a reflection of your thoughts and bounce them back it helps a lot of people to think more clearly.

The transformational power attributed to being listened to was acknowledged across all participants and all groups. Our biggest limitation as health professionals is that we don't spend enough time talking to patients. It is in stark contrast to the rest of the experience of hospitalisation to have someone coming to you who doesn't have an agenda at all, whereas everyone else wants a certain piece of information from you. So this is what it offers: communication without tasks.

I used to work as a hospice volunteer in the US and I used to see as part of a palliative care team that while the task of every member of the team is obviously important, in some ways the volunteer can do everything the other members who are so task oriented don't do – they are often the person the patient will talk to; that the patient will allow to be present with them. Everyone else has to record information (you see people taking laptops to home visits) whereas the volunteer can do anything that's needed.

What about confidentiality?

There is a real perception regarding hospital and hospice volunteers that they are not caught up in the system and don't have to be part of that bureaucracy. But they do have honorary contracts with the staff, they have to go through an induction and receive annual training and supervision; the hospital chaplain is probably one of the biggest providers of volunteers because they manage them. They are tied to the same confidentiality as everybody else.

The thing that time gives is space: providing a safe space to be the person you want to be.

For doctors and nurses burnout can be a problem. Our biggest limitation as health professionals is that we don't spend enough time talking to patients, but it's also a matter of quality time – not only for the patients but time for feedback and checking what you have been doing because rush around for 10 or 12 hours a day and you go home and feel you have achieved nothing. You're missing out on the stuff the volunteers get which is feedback and human contact. It's not just the patient ... you have to look on both sides.

The tension in that is not just one-sided When we spoke to nurses about active listening intervention they said please, yes. When I asked if it mattered I fit was coming from a Christian organisation, they said: "no, just be honest about who you are, and if you're going to listen to my patients when I can't ... there is one quote that sticks in my head along with other heartfelt pleas: "sometimes I am discharging patients when I have yet to know their names". That was not what she came into nursing to do. Having the support of somebody able to offer to fill the need she knew she wasn't was incredibly valuable.

We concluded from the study that there is a real value in communicating without task or target. And there I think is the link with our problem with compassion.

You may be aware of the theological experiment at Princeton theological seminary in the 70's where involving two groups of clergy; first they gave them a questionnaire about what motivated them to become clergy, about their values whether they felt

motivated to help people and considered themselves to be compassionate. And then they asked one group to write a sermon focussing on the Good Samaritan. The other group were asked to write something around their experiences of theological training. On the way to the place where they were to deliver the sermon they stationed a dishevelled actor who collapsed coughing and groaning in front of them. They wanted to see if their claimed predisposition to being compassionate made a difference, and if the knowledge gained from studying the story of the Good Samaritan changed anything. One group were told that they had plenty of time so they were unhurried; the other that time was short so they were hurried. They found that predisposition to compassion made no difference at all to whether someone stopped. Studying the Good Samaritan story likewise made no difference. 63% of the people who felt unhurried stopped and helped, and only 10% of those who were hurried stopped. Some people who had said they were called to the ministry because they wanted to help people were in the 'Good Samaritan' group actually stepped over the person.

The Challenge: maintaining compassion in a hurried profession

The challenge that I see in my practice is how I am to help my nurses in a hurry; how do I help people to *stop* being in a hurry. That comes back to the sense of being able to put aspects into the system that allow you to feel unhurried and hold your own in the environment of modern UK nursing, which is, as Ann Bradshaw writes:

... increasingly subject to the utilitarian model of healthcare in the UK. A market-driven and bureaucratised approach has overtaken the values of care. *Outcomes, measurement and technical rationality predominate.*
[editorial italics]

We seem to be at risk of trying to measure a nurse's smile! Patients will know if the care I am giving is heartfelt or of the 'have a nice day' superficiality.

So we talk about compassion as if it is something that you are: some people are naturally compassionate and others aren't, or if it is something to be prized. But actually, to repeat Ann Bradshaw's definition, if compassion is 'the suffering together with another (as the derivation of the word implies) it is a virtue that an individual cultivates and involves a strengthening of virtuous intention and practices and a deepening of the disposition to do the right thing even when no one is watching' then it can be cultivated and can grow. It can be encouraged, watered and nurtured but it can also be crushed like a weed or ignored.

There are said to be three levels of burn-out: the first is dehumanising; not seeing people in a human way. This may lead to a place where, because you are recognising that you are dehumanising people, you get to a point where you are emotionally burnt out and you too are dehumanised. Although I am in no way condoning or trying to understand the way the nurses who were in the system who didn't speak out, if you are in a system that allows you to dehumanise others and then become dehumanised yourself, the next stage of that is that the institution is burn out and the people in it suffer. What we need to recognise and learn from a nursing point of view is that the key factor is to be in a place where we value being unhurried. That is not saying we need more time; but we need to not feel hurried – that is the difference.

Discussion

We are all conscious of the way we are driven to work harder and see more patients and so on. This dehumanises us and leads to burnout. This is something the NHS

needs to address; 'lean' working and reducing numbers of nurses must affect care and we as professionals must speak out against it.

One word in your title which intrigued me, but which I don't think I heard you use in your presentation although you implied it a lot, was fatigue. It is an interesting word and implies a lot more than sheer physical and mental tiredness.

Fatigue is what I am seeing in nurses coming for CPD and education and in conferences ... I am seeing a general sense of fatigue. There is a huge literature on compassion fatigue, and I want to see how we can help nurses regarding this. I wonder if when we talk about burnout what we are really seeing is compassion fatigue and that this would be a better word for this sort of thing. We need to be seriously thinking that it's not just about proposals about what we need to do ... There are two strands in this debate that concern me a little. One is that if we just get people who are more compassionate at the beginning we'll be OK - I'm not convinced by that and it goes against the evidence – and the other is 'that it all went wrong when nurses started going to university' This has never been said of a doctor! It implies that being intelligent and educated is incompatible with being caring. I like the concept of 'intelligent kindness'.

We do have the literature that purports to show that medical students have compassion beaten out of them during their training... that seems to be related.

A system that values targets, speed, and being lean and efficient, is counter to valuing compassion. These two things are dialectically in constant tension, and if you live in that tension the pressure may get to you. Maybe that is sometimes why people may get compassion beaten out of them.

But although tiredness is not the same as fatigue it is clearly a major element in it, and I was wondering to what extent the problem of understaffing and too much paperwork etc that nurses are struggling with was a significant factor?

What I see most of the time is that we are so focussed on the target that we completely miss the point. I had a recent experience when I was sitting with a relative in A&E. (ER) . There was a directive that you had to be seen within four hours. We were first taken to a holding area which looked like A&E. We first arrived in something called the ambulance handover station where we waited for about an hour and a half, then moved to A&E which looked exactly the same and then at three hours and 50 minutes moved to another area which also looked exactly the same but we were no longer in the clinical decision making unit. At which point three members of staff had to get to know the patient with three different handovers as she wasn't allowed to stay in the same area for more than four hours ...

There must be a cut-off point in respect of numbers of patients that a nurse can be caring for. Say you've got ten you're hurrying along trying to do the tasks these ten require but if I gave you another ten you couldn't do it. So there must be a point where you have to say "sorry guys, that's a managerial issue and I'm not going to hurry myself any more" You are going to get it in the neck if something goes wrong – so are you – or the RCN – going to set limits?

It's an incredibly difficult challenge to work out – there are clearly different levels of nursing need. Now there is so much focus on delivering care in the community. 20 years ago when I was nursing on the ward you had some very sick people on the ward who needed a lot of your attention but you were aware that there were other people who needed a little help but they were also helping you. They were still part of the community of this ward. That doesn't happen any more. It appears now that if you can breath independently and vaguely stand up you are for home! There are some clear studies that show if the ratio of qualified nurses to care assistants in a ward makes a difference to how you survive. And there is also a lot of evidence that

degree nursing education makes a difference to health outcomes, but you don't hear about that.

It needs to be seen in a cultural context. There is some North American literature about laziness in nurses, and from Scandinavia and Holland about time. And I remember when I was in a ward in Amsterdam when I was looking at how nurses were helping people in pain, and the nurses were playing chess with patients. I have never seen that in this country.

All the older nurses tell me that the discipline has gone.

There is a difference between being managed and being led, and between clear strong nursing leadership as opposed to efficiently managing the activity and resources. I think that applies to medical care. I'm not sure that that leadership is as strong now as it used to be.

I am sometimes shocked ... I walk onto wards at lunchtime to see who is able to feed themselves and who needs to be fed and I have actually sat down and helped a frail elderly person to eat... that shocked them but it changed things on that ward.

I once asked our nursing director if she realised that nurses have completely separate ward rounds from doctors – when I was a houseman we and the nurses relied on each other to benefit the patients better. She changed the practice on three wards ... a lot of these things need to be pointed out as people just aren't seeing them.

This kind of 'invisibility' of both people and problems is a corollary of lack of compassion. So you need role models who can help people to imagine how things can be different - and give them the sense of paradigm changing - and 'take them out' metaphorically.

I work on an honorary contract with a pain clinic. Our knitting group in this gives us the opportunity to listen to peoples' stories in the two hours we spend every week with them. That's a really good way of doing this and feeding back without using clinicians' time. But about a year ago they said "we might have a little bit of funding to pay you for four hours, but if we do that you will have to justify the time you spend with patients. So that gives you about twelve minutes per patient." So I said no thank you.

Which comes back to that real sense of the unique place that volunteers have within an organisation with the flexibility and freedom they can bring...

...having an honorary contract allows me to work outside the rules.

When I was working on the ward [as a palliative care nurse] even when we were quite senior we did one week in five on nights, which was a wonderful opportunity to spend more time with patients. During the day there are pressures even in a hospice – you can't stop to talk in the middle of a drug round. But you could go back after this at night time and sit with them and listen. There was a lady in one of our four bedded bays with advanced motor neurone disease who could no longer talk but was still conscious. On this night we had finished caring for her but there was something in her eyes which told me she needed something else. I sat with her holding her hand and wondering rather desperately how I could communicate with her. After a while I noticed a book of poetry by her bedside. I asked if she would like me to read some and she seemed to indicate by her eyes that she would. I didn't know what she liked and read her a selection. Eventually she dropped off to sleep. The next night when I went into her room one of the other patients asked if that had been me in the night talking to the lady in the next bed. I apologised for disturbing her but she said: "I'm OK this time and I'm going home but the next time I come in it will probably be for the last time. I can't tell you how what you were doing last night reassured me that when

I come in to die, I will know that people will care enough. And that is very important to the rest of us."

So you just never know - and that seemed important not just for our patients to make them feel they are in a secure environment, but also as a lesson for nurses and students to make them understand that they have to reach out to find ways of communicating.

There was another patient on that ward, a Reading University student from Africa with AIDS who became a sort of resident in one of our side wards. We all became very fond of him, but apart from a few student friends he had no visitors as his family were all in Africa. He was an accountant, as was my late husband. But he was also a Scrabble player. My mother-in-law was the unbeaten Scrabble champion of West Berkshire, and all of 90 at that stage, but also an outpatient at the hospice with multiple myeloma. So every Sunday if I was on a late shift I would bring her in after lunch and they would play Scrabble. She struggled a bit at first as in her early life she had been definitely racist but they soon built up a wonderful relationship. Then my husband would come to pick her up and stop for tea and start talking with Idi about accountancy and they also became friends. So there are all sorts of ways of engaging!

I always hold on to something one of my nursing mentors said to me right at the start of my career:

"People don't care how much you know if they know how much you care"

Attention: those little peering efforts of imagination which have such important cumulative results

Iona Heath

In *The Secret Scripture* Sebastian Barry writes of “that strange responsibility we feel towards others when they speak, to offer them the solace of an answer.” We cannot possibly offer the solace of an answer until we have first listened – really listened with attention to the other who is speaking.

Compassion

The Victorian novelist and poet Dinah Craik wrote: “Oh, the comfort—the inexpressible comfort of feeling *safe* with a person—having neither to weigh thoughts nor measure words, but pouring them all right out, just as they are, chaff and grain together; certain that a faithful hand will take and sift them, keep what is worth keeping, and then with the breath of kindness blow the rest away.” That quotation has just been republished in *Tools of the Trade, Poems for new doctors* published by the Scottish Poetry Library and which is going to be distributed to all students graduating from Scottish medical schools. It seems to me that that is just how we want our patients to feel when we are listening to them.

William Carlos Williams, poet and family doctor, writes: “It is actually there, in the life before us, every minute that we are listening, a rarest element - not in our imaginations but there, there in fact. It is that essence which is hidden in the very words which are going in at our ears and from which we must recover underlying meaning as realistically as we recover metal out of ore.” He describes this essence as the nearest most patients come to speaking the poetry of their lives as they struggle to give expression to their deepest feelings and fears in the quiet privacy of the doctor’s consulting room. In another of his novels Sebastian Barry also touches on the power of words: “...and wondered in her private mind at the power of mere words, the mere things you rolled in your mouth, the power of them strung on the penny string of a song, how they seemed to call up a hundred vanished scenes, gone faces, lost instances of human love” – how words can catch and hold the story of a life, the story that, in the consulting room, will prove fundamentally important to both patient and doctor. The patient is talking and the doctor is listening. Simone Weil writes repeatedly about the importance of moral concentration – about what she called attention: “No true effort of attention is ever wasted even though it may never have any visible result, either direct or indirect”, and in a world increasingly obsessed with measurement and recording, this remains absolutely true. In his novel *Chance*, Joseph Conrad describes the transient fashion for certain words: “You know the power of words. We pass through periods dominated by this or that word - it may be development, or it may be competition, or education, or purity or efficiency or even sanctity. It is the word of the time. Well just then it was the word Thrift which was out in the streets walking arm in arm with righteousness ...” Today, more than 100 years later, in the context of the least compassionate government I ever remember, the word is of course *compassion*. And if not compassion, it is kindness. And when words are used in this way, they are very often part of the exercise of power and control. And of course David Cameron used the word when responding to the Francis Report in February last year and said: “There are some simple but profound things that need to happen. Nurses should be hired and promoted on the basis of having compassion as a vocation and not just academic qualifications.” Yet, if we really intend to follow David Cameron’s rhetoric we must attempt to reify compassion and risk damaging it much further.

Attention

As Anna Smajdor writes: “we must commodify compassion: we must control and manage it, and parcel it out in equal portions. Compassion cannot be allowed to be wayward or variable: it must be made to fit into our evidence-based, scientific, efficiency-driven healthcare system.” I am arguing that it is difficult if not impossible to demand compassion. Setting out to support simple kindness would be easier and promoting attention – the foundation of both - may be possible. Weil again: “Those who are unhappy have no need for anything in this world but people capable of giving them their attention. The capacity to give one’s attention to a sufferer is a very rare and difficult thing; it is almost a miracle; it is a miracle. Nearly all those who think they have this capacity do not possess it. Warmth of heart, impulsiveness, pity are not enough” – it is all much more difficult than that. Yet I think that attention, genuine attention, brings kindness and maybe compassion in its wake.

The wonderful Scottish poet Kathleen Jamie thinks, like Simone Weil, that the commitment and concentration required for listening and noticing come close to the idea of prayer: “Isn’t that a kind of prayer? The care and maintenance of the web of our noticing, the paying heed.” And when she describes her experience of bird-watching it sounds so close to the kind of receptiveness that we need in healthcare: “This is what I want to learn: to notice, but not to analyse. To still the part of the brain that’s yammering, ‘My god, what’s that? A stork, a crane, an ibis? ... don’t be silly, it’s just a weird heron.’ Sometimes we have to hush the frantic inner voice that says ‘Don’t be stupid,’ and learn again to look, to listen. You can do the organising and redrafting, the diagnosing and identifying later, but right now, just be open to it, see how it’s tilting nervously into the wind, try to see the colour, the unchancy shape - hold it in your head, bring it home intact.” Right now, do nothing. Just be open to the patient; notice them and hold them in your head. Don’t start to analyse – to diagnose or even to answer - too soon.

Simone Weil again: “Attention consists of suspending our thought, leaving it detached, empty and ready to be penetrated by the object. It means holding in our minds, within reach of this thought, but on a lower level and not in contact with it, the diverse knowledge we have acquired which we are forced to make use of”. This seems to me to be about not applying simplistic labels to people too readily. It is about maintaining Keats’s ‘negative capability.’ The philosopher Iris Murdoch follows on from Weil: “I have used the word ‘attention’, which I borrow from Simone Weil, to express the idea of a just and loving gaze directed upon an individual reality. I believe this to be the characteristic and proper mark of the active moral agent.”

And another philosopher, Stephen Toulmin, reminds us that doctors are inescapably moral agents: “... the proper application of general medical knowledge to individual human beings demands an accurate appreciation of their particular needs and conditions; so that the task of medicine - however “scientific” it may become - remains fully ethical.” Murdoch again: “if we consider what the work of attention is like, how continuously it goes on, and how imperceptibly it builds up structures of value round about us, we shall not be surprised that at crucial moments of choice most of the business of choosing is already over”. Decisions and choices turn out not to be the discrete events so beloved of politicians and healthcare policy-makers – they evolve within the relationship between doctor and patient provided that relationship is informed by sufficient attention ... The task of attention goes on all the time and at apparently empty and everyday moments we are ‘looking’, making those little peering efforts of imagination which have such important cumulative results.” (The source of my title). I think every clinician will recognise ‘those little peering efforts of imagination’ and how much they help. Yet this is all very difficult and perhaps increasingly difficult to sustain. Arthur Kleinman, professor of both psychiatry and anthropology at Harvard, offers the beginnings of an explanation as to why this should be so: “One unintended outcome of the modern transformation of the medical care system is that it does just about everything to drive the practitioner’s attention away from the experience of illness ... The system thereby contributes importantly to the alienation of the chronically ill from their professional care givers and, paradoxically, to the relinquishment by the practitioner of that aspect of the healer’s art that is most ancient, most powerful, and most existentially rewarding. ... the priorities of the practitioner lead to selective attention to the patient’s account, so

that some aspects are carefully listened for and heard (sometimes when they are not spoken), while other things that are said, and even repeated, are literally not heard.”

The eminent medical historian Charles Rosenberg, also from Harvard, agrees: “This modern history of diagnosis is inextricably related to disease specificity, to the notion that diseases can and should be thought of as entities existing outside the unique manifestations of illness in particular men and women.”

Biology and Biography

This takes us straight into the world of guidelines and Evidence Based Medicine and P4P, all of which are disease- rather than person- focussed, and the reaction of discomfort among clinicians which managers and some non-clinical researchers sometimes find so hard to understand: the way we struggle to shoehorn the enormous diversity of human experience into the world of standardised protocols, and the discounting of significant chunks of the patient’s narrative to fit the diagnostic criteria (so nicely demonstrated by Gene Feder’s work in rapid access chest pain clinics).

Ignoring part of a patient’s story is not only dangerous, it also betrays a lack of interest. Simone Weil again: “ ‘You do not interest me’. No man can say these words to another without committing a cruelty and offending against justice.” Yet we have so little time. We are hemmed in by diktats, threats and incentives, both direct and perverse. Weil writes from her experience of factory work: “None of the conditions under which she and the other employees worked allowed for the essential conditions she believed indispensable for dignity in labour. Among these prerequisites was the possibility for thought, for invention and for the exercise of judgement.” Yet now even for doctors these prerequisites are being eroded. Sebastian Barry describes the process in another context: “But it was all in the manuals, and a sergeant-major must be faithful to such things, like an agnostic priest. And God knows, when reason and mercy had fled out of the world, there was nothing like a manual”. And sometimes we feel that reason and mercy have fled out of our world too and certainly out of the worlds of our patients, and we too take comfort in the manual, the protocols and the guidelines.

The German artist Anselm Kiefer writes about his work: “If there is too much order, it is dead; if there is too much chaos, it doesn’t cohere. I’m continually negotiating a path between these two extremes”. And so are we as clinicians.

The contemporary Dutch philosopher Annemarie Mol writes in her magnificent book *The Logic of Care*: “good professionals need to ask patients about their experiences and attend carefully to what they are told, even if there is nothing about it in the clinical trial literature. There won’t be. The unexpected is not included in the design of trials.” I find myself both challenged and comforted by this. “If doctors and nurses want to learn about the unexpected effects of interventions, they should treat every single intervention as yet another experiment. They should, again and again, be attentive to whatever it is that emerges” [because] “care is bad when the measurement of a few discrete parameters displaces attention from the sometimes painful and always complicated intricacies of day-to-day life with a disease.”

Day-to-day life with a disease is just on aspect of the powerful intersection between biology and biography. Medicine has one leg firmly grounded in biology but the one that should be grounded in biography is largely missing. And it is perhaps doctors in general practice who have the greatest need of this other leg. In a wonderful article that helps us to unravel the connections the Norwegian microbiologist Elling Ulvestad writes: “as culture is shaped as a cooperative effort along the generations, the human organism is always and without exception a lived body in which history and biography are woven together with interpersonal meaning as well as individual purpose.” He emphasises the importance of paying attention not only to the patient in the present, but also to their history and biography.

Adverse experiences early in childhood include physical, emotional, or sexual abuse; witnessing domestic violence; growing up with household substance abuse, mental illness, parental divorce, or an incarcerated household member. Such

experiences have been shown to predict future premature mortality to the extent that people with six or more adverse childhood experiences died nearly 20 years earlier on average than those without any. In the context of a damaging childhood, all too often marred by minimal kindness and less attention, the developing brain is cumulatively exposed to repeated stress responses with resulting impairment in multiple brain structures and functions. Each patient is unique in terms of their values, aspirations and context but, even more fundamentally, each life's history and experience alters the way the body works through a multiplicity of mechanisms which include effects on the functioning of the nervous and endocrine systems and epigenetic effects on gene function. These processes have the greatest effects in response to early life experience, and they serve to accelerate or decelerate the natural ageing of body cells. Socioeconomic inequality and the directly consequent unequal distribution of hope and opportunity play out in premature disease and death for those on the losing side. Yet the damage is not irremediable and there is now evidence that if lives can be invested with respect, dignity and meaning, outcomes improve. Remarkably, Goethe understood this perfectly more than two centuries ago: "When we take people merely the way they are we make them worse than they are; when we treat them as if they were already what they should be, then we make them everything they could be". This seems to me to be precisely the role of kindness and attention in healthcare, both for staff and patients.

The Solace of an Answer

This brings me back to Irish writing and the marvellous Seamus Heaney who writes of "that whole creative effort of the mind's and body's resources to bring the meaning of experience within the jurisdiction of form." He is of course talking about the form of a poem, but his words apply equally well to the form of a diagnosis, especially one that incorporates both biology and biography. In his autobiographical memoir, the writer Edmund Gosse describes learning "to concentrate my attention, to define the nature of distinctions, to see accurately, and to name what I saw." This is what doctors are required to do when they try to provide the solace of an answer: to name what they see, hear and feel. The wise old man John Berger recognises the importance and power of naming: "They know too that what they have been subjected to in their lives is intolerable. And the naming of the intolerable is itself the hope. When something is termed intolerable, actions must follow. These actions are subject to all the vicissitudes of life. But the pure hope resides first and mysteriously in the capacity to name the intolerable as such. Simone Weil also touches on the enduring presence of hope in terrible circumstances: "At the bottom of the heart of every human being, from earliest infancy until the tomb, there is something that goes on indomitably expecting, in the teeth of all experience of crimes committed, suffered, and witnessed, that good and not evil will be done to him. It is this above all that is sacred in every human being." The harm suffered becomes imprinted on the body through neuroplasticity but this is not a one-way process and the brain's capacity for adaptation can also be a means of making people better. Each of us constructs a more or less coherent autobiographical narrative which is constantly reviewed and refined. It is through the story of a life that we make sense of what is happening to us and begin to make sense of the world. The freedom and the delight is that the stories can be changed, and if doctors, by listening and by investing in their solacing answers the experience and perspectives of patients with respect and dignity, they can help to shift stories that have become damaging and stuck. A story of failure and suffering can be recast as one of courage and endurance in the face of impossible odds; one of inability to cope at work can become one of exploitation and seeking solutions in forming alliances and activism.

So let me end where I started, with Sebastian Barry: "It is always worth itemising happiness; there is so much of the other thing in a life, you had better put down the markers for happiness while you can."

Discussion

I think I probably speak for all of us when I say that that was one of the most inspiring talks we've ever had, and I look forward enormously to listening to the recording and treasuring all the beautiful quotations. But... how do we get from where we are to where we want to be? At our meeting last year on changing the culture of pain medicine we discussed the means of spreading this gospel. And although we are mostly a group of pain clinicians, for the last two or three years we have been talking more and more about medicine as a whole ... So we are inspired ... but frustrated!

You have to be ...

"midwives to a paradigm?"

Yes, and "be the change that you want to see in the world" . But it is so depressing and we have to make sure that we make young doctors understand that that great moment of peace when you shut the consulting room door, although you may not realise it when you begin your career, that is where you are and you have the freedom and creativity and if you can just understand that uncertainty is your friend and not your enemy that is your room for manoeuvre and adjustment for a sensitive response – a solacing response, then it works and that's what keeps people going – that it is so bloody rewarding and such a privilege to sit there and ... In Kentish Town, for 35 years I saw people from every country in the world and every social and cultural background imaginable and yet I was able to have a one-to-one conversation with them. You'd die for that sort of experience in any other field. It's that magic and wonder that we have to hold on to communicate and ... and keep going.

Taking part in these meetings for the last ten years has changed me both as a human being and as a doctor. At the lowest level you are doing something for yourself... you can say what you like without fear of being taken apart and learn to mean what you want to say and say what you want to mean. But it also carries into the way we work and onto the doctors and nurses we work with, and I hope my patients benefit. Looking at the bigger picture we are doing ourselves more harm than good if we pay too much attention to the negatives ... this is what we have started to do recently looking at why the culture of the NHS is not moving and pushing so hard ... but there is so much beauty and life stuff going on and .. and if you focus on that and just treat the NHS as you would treat the patients and keep chipping away at it and keep your chin up and look at the positive ...

This doesn't mean you shouldn't organise in response to political outrage. Jeremy Hunt, our revered leader thinks it's a good idea to name and shame GP's who miss a cancer ... if you treat other individuals for whom you have a responsibility like this ... Jeremy Hunt should have my Goethe quotation *'When we take people merely the way they are we make them worse than they are; when we treat them as if they were already what they should be, then we make them everything they could be'* pinned up on his wall. 28

What I was really taken with was the power of naming – both negatively as in naming and shaming, but also the power of having what you are living with named and being the first point at which you can become better than you are because you know what you are dealing with, and being acknowledged. And the real challenge that we work with in pain clinics is the drive to have things like unexplained pain being something that is OK to live with.

... a fantastic paper about things like medically unexplained symptoms in which they wish to emphasise *medically*... and saying that the problem surely is the [biomedical] analysis because you were trying to analyse in terms of organs and symptoms but this needs to be explained at the point of the whole person.

[Brief break in recording]

... fantastic book on child sexual abuse by Norwegian writer. Of the many case studies in it there is one that sticks in my mind about a woman with intractable pain in one arm. After a lot of listening it eventually emerged that that was the arm that was trapped when her abuser was lying on her - her problem had to be interpreted at the level of a person's biography.

... body memory ...

"The pathos always comes before the pathology"

It is possible to shift stories. The basis of the explain pain model is that you can actually change ... you can explain the neuroscience in a very easy way to show how you can actually change things in the body. People come to me who have had no positive experiences whatever and are completely hopeless; they don't have anything in life they can be successful at, but if you can take that first small step and give them one positive experience you can then shift their story. If you sit down with them and listen to them and acknowledge that what has happened to them is pretty awful and has made them the person they are it is possible actually shift that ...

I want to keep pushing on this body politic analysis as well. You are talking about individual cases but as was said earlier said we are all suffering with frustration and I have heard many times from many of you in the last few days about how the body of medicine is suffering too. And if you can apply the same method and attention and diagnostic practice to the situation that we are all undergoing now, and 'being the change you want to see' I think you have the seeds of a solution. ... it's macrocosm as well as microcosm approach

I really like the thought of two worlds coming together: when I did a humanities course in Glasgow I was introduced to the ideas of C.P. Snow and the two cultures. I am reasonably positive that we are at a stage in history where we can join science and the arts and work at the interface between narrative and neuroscience. We live in a science-based world but this interface does exist. You described positive neuroplasticity and there are simple things we can do as clinicians to engage people in that process ... like Kathleen Jamie's poetical works and the idea that you can immerse yourself and notice without naming. My working life involves that; I don't articulate it well but I do feel it. And other people can reach this non-verbally, through art, music, movement ... it doesn't have to be an academic, linguistic method of transformation.

Isn't there a paradox in this quotation? Maybe I don't understand attentiveness, but for me this is saying 'don't attend to the way people are, imagine what they could be like and help them to get to there ...'

You can only imagine what they could be like if you attend to what they are.

I just want to give you three examples of when attentiveness to what we are might not be the right thing to do. As I'm going to mention in my talk later, where relatives of people with spinal cord injury are attentive to and solicitous about their neuropathic pain, the person reports more pain – attentiveness to pain makes it worse. The second example is when I was in spinal injury rehab I had manual evacuation which is horrible and degrading. The nurses were fantastic because they didn't attend to what they were doing – obviously they were using their skill to do it as gently and efficiently as possible at a mechanical level but they distracted you and made you feel as if they were doing nothing – like they were not attending, and it was the fact that they could be as it were not present that enabled you to be distracted from and made it possible for you to carry on being a dignified human being. And then

presumably you get some people who are so trapped in their mess of pain and distress they are locked in to a very bad place with a self-reinforcing narrative, and if you follow them into that place you help reinforce that. In all these situations it seems to me, maybe I'm wrong, it is the Goethe thing: you are almost saying I'm not going to go there, I'm not going to follow you down that path, I'm going to enable you to be in a different place almost by wilfully ignoring where you are at and enabling you to be somewhere else.

I do see what you mean and it is messy. But what I think I'm talking about is that it's absolutely hopeless to get bogged down in specific symptoms. I'm tempted to tell you about my most dysfunctional consultation ever. It's about the tangential question about trying to broaden the attention. The patient in question who was well known to the practice was not mine but belonged to one of my partners who happened to be away on three months sabbatical leave. This 70-year old woman decided she wanted to see me and came once a week. She was the sort of old lady who wore a knitted tea-cosy on her head; she had once had a mental hospital admission in her early twenties which was probably something to do with some sexual indiscretion for which she had been punished, and then punished for the rest of her life by her mother who had totally dominated her and had only died within the last few years in her 90's. She was not my problem so I spent most of her 10 minutes trying to get her out of the room, and then on her way out she would go to the receptionist and say there was something she had forgotten to tell me. We were in this recurring dysfunctional pattern for quite a few weeks, and then, I kid you not, I'm sitting there and she gets up, turns round and sits on my knee! This was not how things were meant to happen! I asked her to go and sit back in her chair which she eventually did. So I asked her a few questions about her past and quickly found out that she lived two streets away from where she was born – this is Kentish Town with huge population mobility - but she had only once in her 70-odd years been out of London, on a day trip to Margate before the war. And suddenly I realised that all she needed from me was to see her life in a much broader context. And I suddenly got such huge respect for this life which was invested with such geographical endurance. She stopped coming every week because I had acknowledged her as a person.

I wonder what you think about people who express their pain in metaphor? When I was working in a pain clinic in Jerusalem we had a patient who said that "the pain is like a stone round my neck" and the clinician didn't know what to do. So they sent her to a psychiatrist who immediately knew what she meant and how to deal with her problem. The stone was to do with the way pain was expressed in her particular culture – I think she was Moroccan. (Another patient announced that her pain was "zere, zere and zere"!)

You talked about 'medically unexplained symptoms'; do you find as I do that a lot of patients GP's and specialists don't accept the patients symptoms or even that they are ill because there is no medical explanation? There is one well-known surgeon who often refers patients to me with the words "I've got another mad one for you". They are often quite explainable.

Medically unexplained symptoms – MUS - is a fantastic example of reification of diagnosis; it's become a thing that people have - three initials that mean nothing! It's just one extreme of diagnostic reification that goes pretty much the whole way towards broken bones – pretty unequivocal! There is a wonderful Norwegian GP researcher, Kirsti Malterud, who has done a huge amount of work on MUS. One of her papers which changed my practice suggests the question 'what did you want me to do when you were coming here?' Often if you only ask the right question ... the question pitched at the right level, the patient will tell you what the problem is ... like their son is in prison.

Another classic patient of mine was a young girl from Morocco who arrived in the UK having married a British citizen – an arranged marriage – a bright girl but with no

English. When she got here she discovered that although she had been told he'd never been married before this was not true and all his previous children were living in Kentish Town and also on our list. She had such a sense of betrayal and shame; but as if that were not enough she had two children one of whom was severely disabled. And her whole body just screwed up in pain – whose wouldn't in those circumstances?

I wanted to reinforce that point: that you can explain symptoms when you know a person's whole story. But the doctor may not have time to listen to it all and there are affordable, accessible ways of doing that without taking clinician time by perhaps having the patient tell their story to someone else in the team and sharing it with the team.

I wouldn't want to live in that world - I think every member of the team can contribute to hearing the story but taking away hearing the story from the clinician ... what makes it rewarding ... the stories are the privilege. We must also remember ... we mustn't claim to know the story, because every other is essentially unknowable. We may only know a bit of the story but we know more than we did before. It's important we don't annex the patients life story to our knowledge base - not the whole thing.

One of the difficulties is that we don't help people to tell their stories. Patient support groups tend to be about people telling each other their stories. I have been working within a research programme, where the Patient Public Involvement officer came from a drama background and spent a lot of time trying to help people to work out what part of their story they would like to share. One key thing for me was that sense of when you talk to a doctor about your story you are actually handing your story over, which they then translate into a medical history which is no longer the patient's story. They then no longer have power over what happens to that medical history: it's a medical history but it's not the patient. They have handed over the things that have allowed the doctor to create it. It's that transformation and the interface between the story and the history ...

A patient came to see me with pain in her wrist. It turned out that about six weeks previously she had injured her shoulder. That had sorted itself out with no pain in her shoulder but intense pain in her wrist. I asked her if she had ever had a pain like this before and she said yes, when I was eleven I fractured my wrist and had severe pain. When she injured her shoulder it had reawakened the pain. No-one had asked her this.

[Not clearly audible] ... what's interesting now is that letters get sent to patients. I'm not sure that that is totally good. Most patients ignore them, as significant proportion think the letter was sent by mistake, and a significant proportion are very upset by them because they see exactly what... "that was not what I said, doctor" ... they go back and say what they said but nobody ever listens to them. This is particularly true in psychiatric letters ... very helpful ...

...It's understanding that difference between my story, my patient journey and the medical history...

In general practice I always wrote the letter with the patient sitting there. I often found when I did it afterwards I hadn't asked half the stuff I should have asked but doing it then and there I remembered the questions I had forgotten and did a much better letter. Another benefit of this is was the patient knowing what you had told the consultant. When I worked in a pain clinic for three years I started to do the letters with the patient sitting there and if they were nodding I knew I was getting the story how it was. But everybody in the clinic said you can't do this. I couldn't understand it but had to change my practice as it was causing so much upheaval. This seemed a beautiful example of the importance of getting patient narrative right.

It's very helpful to have to spend less time dealing with people saying that's not what I meant. But I did once write that CRPS is an ill-understood syndrome and when the patient got the letter she said I would like to see someone who does understand it!

I'm a patient at the moment and I'm seeing three different specialists and I'm overwhelmed by the number of letters and I have to say that when you get a copy of the letter it's quite horrifying to see that a chance remark you made is put down there as if it were absolutely central to your whole way of being. And you think, yes, I did say that but it's not what I meant – not that it's untrue but it doesn't inform my whole life. But it is nice to get the letters as the next time you see them you can correct that misconception you get letters saying 'this very pleasant patient' and you immediately think WHAT DOES THAT MEAN! So when you write your letters don't use adjectives because we always think it's the secret code of doctors ...

... we used to write extremely difficult patient!

Pay attention! Intention, context and healing.

Jeremy Swayne

Many of you know Paul Dieppe, who is usually a regular at these conferences and very much regrets that he can't be here this year. Our paths have increasingly converged since I was invited to give a talk here 5 years ago, when we were reunited after our first encounter many years previously in a pub in Bristol, when he was Dean of the Medical School and I was looking for an opportunity to do some research on the use of homeopathy in rheumatoid arthritis.

Paul, in his time, has been a pillar of the biomedical establishment, and is still widely respected as such and as an academic; and has been healthily sceptical of unorthodoxy. While I, despite my conventional background in general practice, have always been uncomfortable with the hegemony of the biomedical model and the 'paradigm paralysis' that underpins it; and a bit of a maverick - becoming at one time Dean of the Faculty of Homeopathy and more recently a Church of England priest. My challenge to the conventional wisdom first emerged in 1976 in a series of papers likening the relationship between medicine and healing to a broken marriage and culminated in a book, *Remodelling Medicine* a couple of years agoⁱ.

But Paul, for all his orthodox eminence, has never been a died-in-the-wool paradigm paralytic, as his affection for this group of refreshingly iconoclastic 'paradigm pioneers' demonstrates. He even peer-reviewed my book for the publishers, and was immensely helpful in my exploration of what we mean by 'natural medicine' or 'natural healing', and the placebo and contextual effects that underpin it.

In Paul's paper '*The "placebo" response in osteoarthritis and its implications for clinical practice*', written with Michael Doherty in 2009, they report a significant placebo or contextual effect accompanying all forms of treatment; and an effect size in the placebo response that in some instances exceeded the effect size of the active treatment. They say: 'it is obvious . . . that practitioners should capitalise on the impact of context effects to enhance the benefits to their patients as a professional responsibility.' And conclude, 'Practitioners of complementary and alternative medicine (CAM) often do this very well, and seem ahead of us more traditional physicians. . . . We often label (them) as charlatans and explain their success as 'just placebo effect', apparently oblivious of the large effect size of such 'non-treatment' benefits. But if we did learn from the research literature, from practitioners of CAM, and from simple observation, and optimise these meaning responses in our clinical practice, the benefits of such 'contextual healing' to the population of people with osteoarthritis would be huge.'

Paul's refreshing and challenging open mindedness has now reached the point at which some of his biomedical peers might well conclude that his brain has indeed fallen out; because alongside his more respectable academic duties at Exeter University, where he is Professor of Health and Wellbeing, he is researching the nature of 'healing' in its broadest, and in some instances most esoteric forms. And it is here that our paths have now closely converged, because I have the privilege to be part of a small and eclectic group supporting him in this work. There are one or two points of difference in our stance as paradigm pioneers, which I will mention later, but we are of one mind on the matter of the power of compassion in a healing relationship. And I am going to interweave some of Paul's reflections with my own as I explore this theme.

Compassion is essential in medicine and in all healing. The physician or nurse cannot heal, that is make whole again, without feeling and knowing the nuances of a particular patient's predicament

Pellegrino and Thomasma

In the course of Paul's explorations he has encountered a great variety of ordinary, or sometimes eccentric people, medical and non-medical, who have given him insights into the mysterious phenomenon that in one sense or another we call healing. Some of these encounters have been deliberate, sometimes in the course of attending medical meetings, sometimes sheer chance. In the latter category was a Bulgarian taxi driver, who told Paul, "I know a bit about wellbeing". "So what is it about then?", asked Paul. "Well", said the taxi man, "we all need companionship. We need to be able to share our experiences with other people who are like us. That's what makes us well". Quite a good way of describing compassion, or one element of compassion, don't you think? A form of companionship that offers what in the context of the doctor-patient relationship Iona Heath has called an experience of our shared humanity.

The meaning that a patient attaches to illness and suffering, especially in chronic or fatal illness, is critical for the healing process; and that meaning is accessible through the patient's illness story.

James Markum

A very different encounter gave rise to the same insight. Paul was speaking on '*The relationship between joint pain and joint pathology*' at an international meeting in Milan. Although he played the orthodox game by reviewing the literature and so on, he decided to go 'off piste', and talk about his own experience of pain in his arthritic knee. "I detected a feeling of some discomfort amongst the audience," he wrote later. "Were they perhaps thinking 'what is he doing, this is not science; how dare he talk about himself? Scientists do not do personal disclosure or 'experiences'." He explained that the word 'pain' is inappropriate for most of the abnormal sensations that come from his knee, and that all the ways we use to try to assess pain severity (including the ones that he has helped to invent) are now meaningless to him; and how he deals with the symptoms by behavioural change rather than pills. (More discomfort in the audience). And then he 'disses' the whole pharmaceutical approach to pain, with which of course, most of the audience are complicit. (Deep discomfort; even anger). In conclusion he goes even further and tells them that he is now working on caring and healing, as he believes that they are the most important new avenues of research if people like him (as a rheumatologist) are going to be able to help our patients (and ourselves) more. And he laments the lack of *patient-relevant* progress that has come from the extensive investment in biomedical research on pain. "As I stop," he writes, "I wonder if I have gone too far and completely alienated the whole room. There is an embarrassed silence. Then someone in the audience gets up, thanks me profusely, and tells us that she also has pain that she can make no sense of, and that the medications she has been prescribed have not helped. "

A torrent of discussion and questions follows. One or two people try to put him in his place by explaining, for example, that the cure is just around the corner thanks to their ground-breaking work on the molecule 'boringase14', but most are supportive and many are personal. They want to talk about their *experiences*! They want to tell their story.

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

David Misselbrook

Paul has evoked a sense of wellbeing in his surprised biomedical audience through the medium of companionship in shared experience: compassion; the common

human need in adversity, whether we are an immigrant Bulgarian taxi driver, or a medical scientist.

Paul's investigation of healing has embraced a wide variety of context and practice. He has spent time with different individuals and groups of people who call themselves 'healers'. Although there have been some, as in medicine in general, whose activities have been egocentric rather than altruistic, he has been impressed by the majority whose claim to channel healing energy has been motivated by and mediated by what one called 'deep caring', or even explicitly love, for their patient. She talked about the experience of interacting with people when you are just 'in the moment', caring for someone and working intuitively – a state in which you have let go of your ego and you are working with love for the other. Working with your intuition seemed to be an important part of things for her. Her explanation was evocative of things that others have talked about, and of David Reilly's description of the 'moment when the room disappears' – when you are really just *with* another.ⁱⁱ

This capacity to be 'with' another person in a particular way is reflected in another of Paul's encounters. On a visit to Lourdes, he spent time with a severely ill woman whose condition could have deteriorated and become acutely terminal at any moment. In his account of the conversation he relates how she really opened up to him, telling him very personal things about herself and her life, and he wondered why she was doing that to a complete stranger whom she knew nothing about. And then he gives the answer. "I looked her in the eye and above all else she had my full attention – I listened with all my being, nothing else existed in that room for me as Claire told her story."

After discussing his diverse experiences with us in his support group, Paul reflected: "Perhaps the *intention* is the critical thing. Healers talk of unconditional love for another and the importance of intention as a means of allowing the flow of energy to initiate healing; or of some change in internal energy that facilitates innate healing. Doctors intend to help their patients, but perhaps their fascination with reductionist biology and the disease blinds them to the wider dimension of health, wellness, wholeness and the soul. And soul-reintegration," he goes on, "might be achieved in some circumstances through the simple expedient of being with another – a sort of transfusion from one to another; allowing the other person to find new meaning for their dilemma – and the discovery of new meaning allows reintegration." Which recalls the earlier quotation from David Misselbrook.

Intention

These excerpts from the story of Paul's continuing exploration of healing describe features of what we might call the landscape of compassion that is not only necessary for true healing to take place, but also powerfully conducive to the contextual effect that enhances clinical change, as his more formal medical research that I quoted demonstrates.

Amongst the characteristics of these people and these encounters that our small group identified, most of which you would expect, such as truthfulness, absence of ego, and a non-judgemental attitude, were the perhaps less obvious ones of '*intention*' and '*attention*'. So now I want to say something about these; a little about '*intention*', and quite a lot about '*attention*'.

True compassion in our professional role has to be predicated on our intention to heal, to make whole, to make well. True compassion requires not only that we understand and feel for the distress or suffering of the other person, but that we also perceive something of the greater wellbeing or fullness of life that can be available to him or her, and that we intend to do something about it.

Perhaps I can illustrate this by relating an episode from another of Paul's encounters. His companion asked him what he would do if he was God. In an almost transcendental moment Paul replied, 'Wonder, beauty, perfection. That is what I would want if I was God for a day, I would want everyone to experience something wonderful and special, like that rainbow. Something, anything - from art, literature, music, the natural world, whatever; something that spoke to that individual as a

person, allowing them to be uplifted and to feel the joy, beauty and wonder that the world and the humans on it can create. That is what I would do'.

Empathy: Identification with and understanding of another's situation, feelings, and motives.

Harvey Chochinov

In other words, our compassion for another person must embrace something of the good that we passionately desire for them. It is that creative and holistic character of compassion that sets it apart from sympathy, and that is essential for empathy. This intention is probably at the heart of most people's vocation to healthcare. But it is very difficult to fulfil - to find the time, insight and emotional space for in our contemporary medical culture.

Even more difficult to achieve perhaps, but indispensable to true compassion, is the ability to give others our full attention.

I want to tell you about two very remarkable young women; Etty Hillesum, and Simone Weil who has already been introduced to us by Iona Heath. Etty was Dutch and died in Auschwitz in 1942 at the age of 28, and Simone was French, but died in England of TB in 1943 at the age of 34. Both of them achieved extraordinary feats of compassion. And for both of them, the ability to give others their full attention was the well-spring of that compassion.

Etty Hillesum*

Etty was a young Jewish woman, who grew to personal and spiritual maturity from troubled and atheistic beginnings during the Nazi occupation and persecution in Amsterdam. She refused opportunities and the impassioned pleas of her friends to escape deportation and death; partly out of a sense of solidarity with her Jewish community and their common destiny; partly because to go into hiding would mean to live in fear and she absolutely would not allow her soul to be invaded and eviscerated by fear; and partly because of her vocation to use her gifts at the forefront of life where people were hurting; where she could use her skills to relieve some of the pain.

In Auschwitz, surrounded by so many 'bundles of human misery, desperate and unable to face life, she felt she had what was needed for the huge task of giving support: a deep well of compassion in her heart, and skills in the art of listening. At the heart of her vocation to care was her confidence in the inner meaning she had found in her own life; the same quality that Victor Frankl identified as essential to survival in the camps. And once again we see how vital *meaning* is to human identity, integrity and wholeness.

It was Etty's practice of paying deep attention which transformed her. Through the months in the camp, as her contemplative heart attended to *her* inner life more and more, her direction was affirmed; strengthening her sense of solidarity with her people and her longing to care for the weakest and most vulnerable. Ever alert to signs of this life in the faces of those around her and in the natural world beyond the wire, she was determined not to be numbed by the cruelty but to go on seeing.

Listening was the primary mode of her believing.

**Etty Hillesum: a life transformed* Patrick Woodhouse: Bloomsbury 2009

Simone Weil*

Simone Weil trained as a teacher of philosophy, but felt a compelling vocation to identify with the suffering and hardship of the poor and oppressed.

**Simone Weil: Waiting on God - the essence of her thought.* Fontana, 1977

She wanted to experience fully the life of working people; first in the vineyard of the Jura; then, in spite of chronic headaches and delicate health, in a Renault factory where she strove to avoid anything which could make her lot differ in the slightest degree from that of her companions in the workshop; and later in the Republican army in the Spanish civil war, experiencing in the very depths of her being the utter calamity of war.

Her experience taught her, too, the absolute necessity of attention to release compassionate love for others. In her own writing she says:

‘Not only does the love of God have attention for its substance; the love of our neighbour, which we know to be the same love, is made of this same substance. Those who are unhappy have no need for anything in this world but people capable of giving them their attention. The capacity to give one’s attention to a sufferer is a very rare and difficult thing; it is almost a miracle; it *is* a miracle. Nearly all those who think they have this capacity do not possess it. Warmth of heart, impulsiveness, pity, is not enough. The love of our neighbour in all its fullness simply means being able to say to him: “What are you going through?” ‘

It is a recognition that the other exists, not as a unit in a collection, or a specimen from the social category labelled ‘unfortunate’, but as a man exactly like us, who was one day stamped with a special mark of affliction.’ (That experience of shared humanity again.)

‘For this reason’, she says, ‘it is enough, but it is indispensable, to know how to look at him in a certain way. This way of looking is first of all attentive. The soul empties itself of all its contents in order to receive into itself the being it is looking at, just as he is, in all his truth. Only he who is capable of attention can do this.’

I believe these quotations teach us several things: that true compassion is hard and costly; that a vocation to care and a warm heart are essential but not enough; and that the capacity to give another person our full attention, which is the cornerstone of compassion, is a rare attribute, but can be developed. This last point is key to the debate about whether compassion and empathy, which are closely related in this context, can be learned.

American physician Harvey Chochinov has written, ‘For some, compassion may be part of a natural disposition that intuitively informs patient care. For others, it slowly emerges with life experience, clinical practice, and the realisation that, like patients, each of us is vulnerable’.

Eric Cassell insists that the habit of attentive listening can be acquired during medical education, and that the judgement of patients’ values – the characteristics that strongly affect their experience of illness and suffering - that attentive listening based on trained observation permits, is found to be reliable and consistent.

This injunction could, of course, be narrowly applied to the development of clinical acumen, but it is a skill fundamental to the development and expression of compassion. In fact, Simone Weil likens the discipline of giving full attention in the compassionate care of another to the discipline of giving full attention to a task in the classroom.

This quality of attention is essential to Colin Murray Parkes’s description of empathy as the ability ‘to sense accurately and appreciate another person’s reality and to convey that understanding sensitively’. It makes possible the insight and wisdom that help us to discern what is going on in the patient’s body, mind and spirit. It is essential to a proper understanding of the patient’s narrative; and powerfully enhances the contextual aspect of the therapeutic encounter that is so important to the clinical outcome, and to healing.

But we do no one any favours to pretend that this is easy. When, as we should, we see it as our responsibility to be hospitable to the person in need, we must remember Jean Vanier's warning that, 'it is always risky to welcome anyone... To welcome is not primarily to open the doors of our house. It is to open the doors of our hearts and become vulnerable. It is a spirit, and inner attitude. It means accepting the other into ourselves, even if this means insecurity. It is to be concerned for others, attentive towards them and to help them find their place in the community or in life itself.'

And the risk is the same even if we reverse this pattern of hospitality and accept John Swinton's suggestion that as healthcare professionals, rather than see ourselves as the host and the patient as the guest in our consulting room, we should see the patient as the host, and ourselves as the guest in the story of their life.

The bottom line is this: Compassion requires the willingness to allow the pain of others to impinge on ourselves. It requires us to accept the fear and embarrassment of being present to them as they are, and the difficulty, and perhaps the impossibility of understanding it or being able to *do* anything about it. It requires the willingness to be hurt, and to *let* the hurt hurt.

But although the discipline of full attention is hard and costly to achieve - because it requires self-knowledge, which can be painful, and the capacity to love and forgive ourselves, warts and all, in order that we may love our neighbour, warts and all - as well as being a source of compassion and healing for others it is of course a source of healing for ourselves. And there is a reassuring paradox in that the compassionate willingness to allow the pain of others to impinge upon us, which requires such attentiveness, will not crush us if we really do give them our **whole** attention. Because in thus divesting ourselves of our own preoccupations, needs and prejudices, we can be truly compassionate and empathetic, but without becoming so involved and burdened that the milk of human kindness runs dry and compassion fatigue sets in.

When we are *fully aware* of another person in distress, by our presence, attentiveness and absence of self-interest, compassion is the natural response. M T Southgate has written, in words that echo something of Paul's vision of being God for a day:

'Medicine and art have a common goal: to complete what nature cannot bring to a finish . . . to reach the ideal . . . to heal creation. This is done by paying attention. The physician attends to the patient. The artist attends to nature. If we are attentive in looking and in listening and in waiting, then sooner or later something in the depths of us will respond.'ⁱⁱⁱ

That, 'something in the depths of us', is the compassion that is the indispensable context for healing.

That is the essence of what I have to say: if we develop in ourselves and encourage in our colleagues, students and trainees the 'miraculous' capacity to give our attention to a sufferer; and if, a very big *IF*, we can remodel medicine in such a way as to permit it; then empathy and compassion, and their sometimes miraculous power to heal, can be assured.

But there is a corollary or postscript. In his reflection on his visits to Lourdes, Paul pays tribute to the power of hope, and compassion, and immersion in its rituals and ethos of care. But he says that he sees no reason to bring God into it. I have no experience or opinion of what goes on at Lourdes, but when it comes to the healing power of attention, empathy and compassion, I do see a need to bring God into it. But not a God that is often so misrepresented by religious practices and doctrines which some who would label themselves as atheists rightly deplore and disbelieve.

For Etty Hillesum and Simone Weil their compassion and the attention to the sufferer that fuelled it, were inseparable from their experience of a personal relationship with God. But for Etty the Jew this existed outside any framework of religious life or religious affiliation; though she drew deeply upon the spiritual literature of several different traditions. Simone despite her upbringing absolutely refused to adopt formal Christianity, and fiercely resisted the pleading of a priest whom she profoundly respected to be baptised; although she had a real sense of relationship with Christ. For them, and for all of us, I believe Simone Weil's insight is true; that

‘Not only does the love of God have attention for its substance;
the love of our neighbour, which we know to be the same love, is
made of this same substance.’

Discussion

That was a great talk but with regard to the Christocentric point of view presented in the last few minutes I just wanted to remind people that for Tibetan Buddhism the whole of the point of the exercise is to develop compassion through quite specific exercises and practices. And of course Buddhists have no concept whatsoever of a God; the Buddha is a man. So I think having a personal relationship with God is great if that is how you are but is that essential? I am reminded of a song from Les Misérables with the line: to love another person is to see the face of God.

This is where words become a problem; you can use words like transcendental to express something beyond ourselves which beyond words ...

I remember listening to a talk to a pain forum group of about 60 clinicians. On one of his slides the speaker clicked body, and then mind, and there was a little discomfort, and then he put up the word spirit .. and there was a sort of audible intake of breath...! And you could feel people shrinking in their seats! And then he put up asking us to draw on a post-it note what we meant by healing. And I drew two concentric circles with arrows inside coming out from soul and the outer ring was meant to be the whole person and more arrows going everywhere. I noticed that the two doctors on either side of me drew a bone fracture ...!

You could argue that there is God in all of us. I was reading a book by a vicar who had been a Japanese prisoner of war and he said that when he looks in a person's face he looks for Christ whether they believed in Him or not.

I have been struck over the last couple of days by how many of peoples' patient, personal, and family stories have struck a chord. We have heard about compassion for the other person but also compassion for self and the need for a care-giver to have self compassion. I suspect one of the valuable things about giving attention is that it reawakens in the person the ability for having compassion for self. A lot of the people I see have very low levels of self-compassion and give themselves a really hard time, often with guilt, and struggle with what they are going through because of this. So part of the therapeutic value of attention is activating peoples' self compassion.

There is a psychologist in Derby (Paul Gilbert) who does compassionate mind-training in a very practical way.

It's used for anorexia.

I go frequently to Lourdes as a nurse and I've had some amazing experiences. While Jeremy was talking I was reflecting that God is love. And that is what I see happening actively in Lourdes. People are able unashamedly to be themselves. I find there is a great freedom there despite all the ritual and endless services which if you weren't a committed Christian you would find difficult. But if you just absorb it ... I have gone with doctors and nurses of all faiths including Hindus who are attracted because there is something very special about a place that is dedicated to compassion, and healing in its many forms, not at all physical....

I'm very unorthodox in some of my views about Christianity, and very universalist in my perception of what we mean by God. I don't we are helped by the passage where Jesus is reported as saying "I am the way, the truth and the life and no-one comes to the Father but by me." That has been interpreted by Christians to mean unless you wear the T-shirt ... But actually I am convinced that he was referring to something much bigger, much more universal: an essence of life. The 20th century theologian Austin Farrar says: "We should not assume that the Holy Spirit works in none but Christian hearts. There may be, so to speak, a Christ factor where there is no Christ."

Changing Practice, Challenging Systems

Betsan Corkhill

At the very tender age of 17 I moved from a sleepy Welsh town to London where I started my training in physiotherapy at the Middlesex hospital, and as the only Welsh student I was soon known as Jones the Physio! My memory of the Middlesex is of strict discipline and uniforms which were so stiffly starched they stood up by themselves, elaborate nurse's hats and very scary matrons and sisters.

As a physio I was trained to treat body parts: backs, knees and hips. I recognise now I was more of a body mechanic than a true 'therapist' It was a time when clinicians were respected, trusted and believed often without question, I stayed at the Middlesex for a year after qualifying but it had always been my dream to live and work in Switzerland – more from a love of skiing than anything to do with career prospects. So when a job came up in a medical rehabilitation spa I successfully applied, and moved from a Victorian London hospital to five-star luxury, from a tiny rather smelly hydrotherapy pool in a basement to two Olympic-sized pools, one indoor and one outdoor, full of natural spa water. It took me some time to accept some of the treatments on offer because they weren't scientific enough for me. Even the hairdresser and the beauty salon could be prescribed by the doctors. They understood the value of making people feel good. I soon realised that if people feel good about themselves they manage their conditions better, respond better to treatment and heal faster. And so my interest in whole-person healthcare was born, and I started asking myself the question: can we heal when there is no cure?

Whole Person Healthcare

For me whole-person healthcare means considering a person's health within the context of their whole life, environment and relationships. Understanding how the 'little things' add up, how the other things going on in their lives affect their experience of pain and the way they respond to treatment. It takes into account the patient's values – the things that matter to them. All these things influence their pain experience.

What, for instance, is the impact of loneliness and social isolation? What is the quality of their social interaction – does it address the emotional and social aspects of feeling lonely? What is the quality of family relationships? Do they have any opportunity to enjoy fun, play and laughter? Do they have anything in their lives they feel successful at? Is their reward system stimulated on a regular basis? Are they able to be creative? Are they happy exploring or managing change? Is there a balance in their lives between stress and relaxation? To what degree are symptoms intruding or preventing balance? Are they still able to work – if not, do they still have some rewarding occupation or anything that gives them purpose, meaning?

Tim Cocks of the Neuro Orthopaedic Institute (NOI) puts it more succinctly –

Consider one continuous nervous system without arbitrary slash marks separating peripheral from central and one whole human being with an embodied mind embedded in an environment and culture."

We are all familiar with Maslow's Hierarchy but how many of us consider these issues in terms of our patients? After all the experience of pain is heavily dependent on the level of perceived threat and context. With changes in the benefits system and bedroom tax, many patients are struggling to get on the bottom rung of his ladder. As for feeling secure, having a sense of belongingness, sexual relationships, self-

esteem, most don't go near that, let alone reach Maslow's pinnacle – creativity, playfulness, laughter, fun, vitality.

How many of our patients feel comfortable with who they are, feel safe, feel they belong? Should we be aiming to move people up Maslow's ladder alongside prescribing medication? We've shown through our Therapeutic Knitting group at Bath's Royal United Hospital that there are affordable ways of doing this.

Does it matter? Well...yes. Even for those who believe medication is the only way, those 'other things' make a difference. They raise the perceived level of threat and increase sensitivity to change the patient's response.

If a person's brain constructs that there are enough dangers and threats within themselves and society, worthwhile of increasing sensitivity, then a defence against synthetic medication may be mounted. In a biopsychosocial framework, maybe the meds would work better if other drivers of increased sensitivity were dealt with or maybe the meds may not even be needed."

NOI Adelaide – Neuroscience Nuggets series

In the course of running a Therapeutic Knitting group for patients with chronic pain I get the opportunity to hear their stories. They tell me that all those 'little things' add up to increase stress, worry and fear. . These can include the language we use to describe their condition, the tone of our voice. All have the power to increase or lower threat levels. Why are we surprised when the lady with two 'crumbling' knees and now a 'crumbling' spine doesn't move?

Patients notice if we are ticking boxes to reach targets or are genuinely interested in understanding the person behind the pain – truly listening to what they have to say. Finding the department's answer phone on time after time can be a major problem for someone who is stressed, distressed or elderly. When it's answered patients register the tone used and the message that tone conveys. A radio producer once said to me, "You can hear a smile over the radio."

Other problems include lack of communication between departments. Many of our patients have complex problems and will be referred to departments within the same hospital or other hospitals. Is anyone pulling it all together and following the patient's journey right across primary, secondary and social care? Traditionally this was a GP's role but these days people see different GPs so it's become a problem. This is one of the things I find myself doing within the knitting groups.

Hospital letters asking GPs to arrange vital tests may be long delayed from dictation to receipt. My own mother was discharged from her local hospital needing an ECG and died still needing it. Admission letters are often computer-generated, impersonal. Even the letterhead can be worrying. One lady received a request to attend for blood tests but the letter was typed on a letter headed 'Haematology Oncology Department'

Do you communicate with your patients in a way that makes them feel safe and valued?

As part of the research I've been conducting into the therapeutic value of knitting I have collected a large number of narratives from around the world, and have been intrigued by how some people live fulfilled lives despite a huge number of problems and others seem to sink under minor issues. The context within which people suffer ill-health plays a big part in how they manage, how they respond to treatment and how they heal.

I have identified five core themes –

- Loneliness, social isolation
- Low self esteem, feelings of worthlessness
- Stress, fear, worry
- Lack of rewarding occupation
- Change in or loss of identity

These issues feed on each other and cause physical symptoms such as muscle tension, bowel and sleep problems, migraine which feed back into the cycle of stress and worry.

Chronic pain is so complex that we can't treat symptoms alone and expect success. We need to consider the bigger picture because no matter how good the biological treatment is, if we don't address these other issues we are likely to fail over the longer term.

A personal and family perspective

From the age of 19 I had significant spinal pain for three years, which eventually just disappeared. I often ask myself why didn't I go down the chronic pain route?

It is likely that the diagnosis (ankylosing spondylitis) was incorrect but I've put it down to a number of things: I was seen by an 'expert' immediately; I was treated as an equal; there was tangible clinical evidence that there was something wrong so I felt believed; lack of sleep didn't matter at 19 – it was an excuse to party more; I was referred to a research team at the Middlesex who were world experts in ankylosing spondylitis. This gave me access to ground breaking knowledge about my condition; crucially, movement improved my pain, being still made it worse, so I got fitter and didn't get any of the secondary problems associated with not moving; I was encouraged and supported to keep working, not forced to give up to go on benefits; perhaps most importantly, I didn't become my pain and pain didn't become my life. It was something happening to me but not who I was.

The long-term outcome may have been different if I'd had to wait months for appointments and scans, if I'd had to stop working or if movement was painful.

This is so important: a lot of my patients have been deprived of a place in society. You identify who you are by your role and if you lose this that is so bad – almost the worst thing that can happen to any human being ...

Immediate referral to an expert in the field is important too – in the field of [inaudible] there is a real sense of patients spending a lot of time trying to convince a GP that they would like to talk to an expert and not being made to feel that they'd got to the place ...

... where they start ruminating and mulling over issues and that increases their pain levels.

When my mother was ill I found myself constantly fighting to get her the right treatment at the right time. I was the only person pulling it all together both for my mother and my mother-in-law when she was ill. So I really do feel sorry for the people who haven't got families who can help in this sort of way. My mother died as the result of a catalogue of failures across the board in primary, secondary and social care, which was subsequently admitted. There were a couple of major issues but it was mainly a matter of lots of little ones that added up to erode her dignity and self-esteem, so at the end she felt her life had no worth whatsoever and I believe she just switched off. But as a result of my experience with my mother I succeeded in getting my mother-in-law all the treatments she needed, but I had to stand up and challenge clinical decisions, and on one occasion I had to threaten to take her home.

Even as a clinician this took all my courage, so it must be extremely hard as a lay person.

If we as clinicians don't try to change the system, some day someone we love will be caught up in it. The complaints procedures themselves are fraught with the same problems as the system they investigate: poor communication; overstretched resources; stressed-out staff. Everyone involved investigating their particular niche with no one taking an overview of the whole picture or where parts overlap. And it is in the areas of overlap that the problems often arise. Three years down the line we still haven't received the final report on my mother's case and I believe many families don't complete the process to safeguard their own wellbeing.

I did a lot of observing when both my mother and my mother-in-law were in hospital and trying to put my finger on what was actually missing. There were a lot of clues missed along the way by the carers, the nurses and the doctors so I put a list together of the things I think clinicians need:

- Compassion and respect for dignity
- Empathy and respect
- Intuition
- Emotional intelligence
- Interest
- Curiosity
- Competence
- Experience
- Social cognition
- Constantly aware of changing cues, clues and hooks

We should be careful about taking empathy too far because if we really feel what patients feel it could be dangerous for our own health. We shouldn't be afraid to use our intuition and emotional intelligence to guide us alongside our clinical knowledge. We need to show interest in the patient and always be curious; be what I call 'a curious detective', constantly asking why? It struck me that care assistants may be in most need of these attributes because they are the people who are often best placed to pick up little changes and clues yet they are the ones who often only receive two days' training and are paid the least.

. Social cognition is the ability to make sense of people and how they interact with their environment, but also how we think and interact with them.

A lot of my patients are institutionalised so when they come and tell me something I use this by asking why in a funny way, so they have to think about what they have just said - which is often regurgitating what they have been told in hospital. I say why? - I don't understand this. Patients are very often playing a role - they want to be good patients so they haven't asked why or challenged what was said and you have to be curious for them.

We must be constantly on the lookout for the clues patients are giving us about changes and prepared to act on what we pick up.

We should be careful about taking empathy too far because if we really feel what patients feel it could be dangerous for our own health. We shouldn't be afraid to use our intuition and emotional intelligence to guide us alongside our clinical knowledge. We need to show interest in the patient and always be curious; be what I call 'a curious detective', constantly asking why? It struck me that care assistants may be in most need of these attributes because they are the people who are often best placed

to pick up little changes and clues yet they are the ones who often only receive two days' training and are paid the least.

The patient's experience

I am unable to share specific patient details because of patient confidentiality, but over the years of talking to patients and collecting narratives I have listened to numerous stories of complex, often traumatic backgrounds that no one was aware of previously even though the patient may have been in the health system for 20 years or more.

Patients report that the 'attitude' of staff plays a huge part in their experience of pain and it doesn't just extend to clinicians, it covers reception and admin staff too. As I mentioned previously, it matters whether and how someone answers the phone. The language used in hospital letters matters, even the presentation and spelling is important because it all creates an image of competence or incompetence before they even attend an appointment.

One highly anxious lady told me through tears –

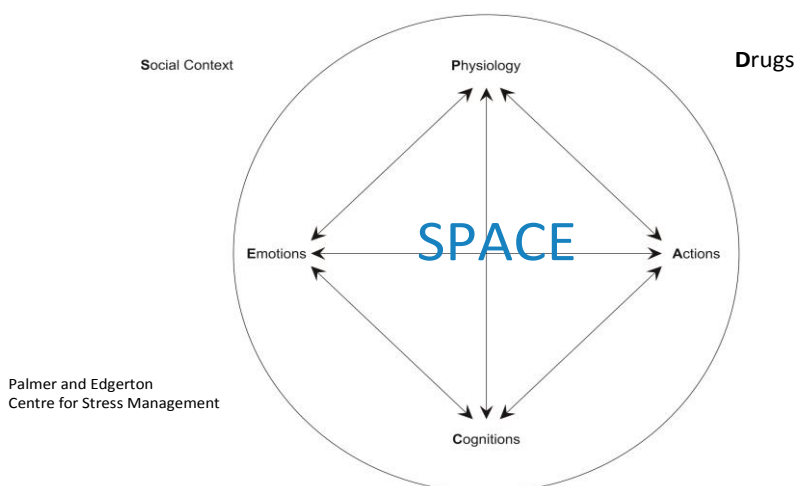
"The hospital letter from the nurse I saw was amazing. It wasn't your usual computer generated stuff. You could tell she'd listened to everything I'd said and picked up on the things I was afraid to mention. I could tell I mattered and I felt safe and confident that they would look after me."

Experience has taught me that taking time to prepare the ground properly prior to treatment, helping the patient to nurture a more positive frame of mind, being a curious detective on the alert for clues and cues, knowing their bigger picture and story saves time, suffering and...yes... money in the longer term.

This 'space' diagram is a useful tool for showing people how your body reacts, how you feel, how you think and your reactions in a social context are all linked together



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Self care and compassion

The relationship between clinician and patient, clinician and other clinicians is vital and the state of our own health is paramount in this. As clinicians we need to look after ourselves too. Our health is critical to our patients' health.

Earlier I listed the qualities needed as a clinician. It is difficult enough to maintain these at the best of times. When we are stressed, I would argue it is impossible.

At a time when clinicians are coping with high caseloads, clinical and administrative shortages, stress amongst healthcare workers has reached a critical level. This is compounded by the fact there is little managerial recognition for the need for 'time out' to reflect, liaise or discuss caseloads with colleagues. Tight targets leave insufficient time for proper patient consultation or communication within or between departments.

Stress affects our performance, our relationships with patients and other clinicians. It increases the chance of all those 'little things' going wrong that affect patient care. The chance of major events happening rises. It will affect your quality of life, your relationships out of work and increase the risk of burn-out or compassion fatigue.

I took this from a modern version of the Hippocratic Oath:

I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.

I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick.

Does this conflict with the values of your organisation? Are conflicting values affecting your performance or your health? How do you measure your performance? – against organisational targets, ticking the boxes to get by, and not allowed to be curious detective? Are you completely happy with what you offer patients? Can you be the clinician you want to be? If there is conflict, how are you managing it?

I realise that I am probably preaching to the converted in this audience but I do think that this is something we need to get across to other clinicians.

It may help you to be 'space aware' (fig ii) yourself, and to learn to identify when your threat levels are rising or perhaps to be aware that you or a colleague are using drugs or alcohol to deal with stress. Follow some of the advice you give patients – make time outside work to relax, replenish your reserves, refuel. Have tools you can call on at work when the going gets tough.

You may remember the story Beatrice told us last year about a grandfather walking on the beach with his grandson. The beach was strewn with stranded starfish and the boy picks one up and throws it into the sea. The grandfather says "there's no point in doing that – look at all these: you can't make a difference." The boy replies "yes, but it can make a big difference to this one." So if enough of us throw back a starfish, can we make a significant difference? Can we change the system? By being the change we wish to see in the world, can we change the practice of others? Can we come together as one voice?

In these challenging times clinicians need to get together to get their voice heard, to share knowledge with and support each other in speaking out – to be midwives to a new paradigm.

"Be the change you wish to see in the world" Ghandi.

Discussion

This bridges a lot of the ideas we have been talking about today. One thing I have been hearing concerns the stress on workers, on professionals. Are we aware of our own stresses in the workplace? My wife tells me I am working too hard but we are driven by our desire to sort patients out, as well as management who want us to see more patients. But I am beginning to put my foot down and set more realistic limits to what I do.

But there's good stress and bad stress, isn't there?

Actually stress management experts have changed the language: there is no longer good stress. They use the word *pressure* as organisations are trying to get away with using 'good' stress to imply that a bit of stress is good for you, and using that to get more work out of people. The health and safety executive are now saying that pressure at a level at which it is under control may be good for you and help you to behave at optimum levels but once it becomes stress its bad for your health.

It's utilitarianism taking over health – the maximum good for the maximum number. But when it begins to affect individual patient care that's when we get into trouble

If we were using tools we would take time out to sharpen the saw or maintain a piece of equipment. I suggest that we look after our equipment better than ourselves. Organisations sometimes don't recognise that people need 'maintenance'. And when we are working in an environment where we are the effective intervention, we need time out too.

Karin related last year that she had wanted to get her team together for an hour every Friday afternoon but had a huge fight with her management to allow that .

There is a sense that you have to justify all your activity and that this has all to be direct patient care and there is no time to ...

They used to say 2 ½ sessions (half-days) for personal development and 7 ½ for direct patient care. Now they want 9 sessions for patient care and 1 for personal development.

I would like to ask Iona what her answer would be to Betsan's question about how we interest other clinicians and persuade them to join us, having been a significant person in a large organisation and having your philosophy and approach to health care. Is it like trying to change the course of a super-tanker? – just so slow?

You have to keep on trying to do the best you can and find ways that are right. I think this will have a 'butterfly wing' effect. I'm not one for starting new organisations to change the world – they will probably rapidly develop a new bureaucracy. It's just a question ... like with the diagnosis thing you seem to reach a tipping point where the majority of people suddenly understand what you have been going on about. I don't think we should beat ourselves up too much ... we should just keep ...

'Be the change you wish to see in the world' is the kind of vision that keeps me going. Whether you want to put it in scriptural terms like 'the vision of the Kingdom' or in terms of evolution ... we have to keep that in our sights. You were talking about visualisation and we could do that on a more macro level.

I should have thought that the clinicians you talked about would have classed the patients you described as 'heartsink' patients, and communication hampered by this and clinicians not talking to each other about them. But as well as that, not everybody has the skills, let alone the time and patience, to talk to people like these with very

difficult backgrounds. A wise GP teacher once said to me "There's no such thing as a heartsink patient; when you think you recognise one you are recognising your own failure to provide adequate care for them." This is a tremendous challenge and I am very lucky in the practice that I work in that 'difficult' patients are recognised and have to be given double appointments. You don't always move very far but at least the problem is acknowledged. There are loads of people out there where nobody knows ... it's good to have examples like these to remind us that there are stories behind these difficult patients that we may never uncover.

What has been surprising is to discover that they are not unusual. These are just two out of several. All the doors close when one patient walks into a clinic because nobody can bear to have any contact because she is so difficult. She does have the additional problem of having a personality disorder but she actually fits into the knitting group and it's the first time in 58 years she has ever been in any social environment, and her problem is intense loneliness.

Do the patients in the knitting group actively support each other?

They don't often know each others' backgrounds; they usually talk to me afterwards and I often hear "I've never told anyone this before ..." I sometimes ask their permission to talk to the doctors and this may enable changing their treatment plans. We have one woman whose stepfather has been sexually abusing her since she was 12 and she's now 44, and we are helping her to deal with that now.

It seems to be a common factor that you have provided a place of safety for people which is not expensive ... it's not rocket science ...

... yes ... finding out about peoples' background can definitely save the NHS money....

It occurred to me that pain clinics should evolve their ethos to provide places of safety. Very often the stories come out if people are given time and space even in a threatening clinical environment. One of the reasons why I couldn't work in a pain clinic any more was that I couldn't single-handedly take those problems on without any support. Pain clinics should evolve to recognise that there are many traumatised people in deep need of complex interactions and need places of safety where they can recover. Those that I have worked in are single-moded services for biomedical intervention and none of this is taken on board.

You've got these complex patients but our clinical psychologist has a year's waiting list. He says he can't bear to think about it.

They could be learning to knit while they are waiting and maybe they wouldn't need the psychologist!

A lot of them just require ... the 'coaching' side of it works nicely as you work with what the patient with what they can do and build on that and quite a few of them just need someone to take an overview of all the different things going on and pull it all together. Patient T, for example, is going to all these different clinics and she doesn't understand the language so she brings me the letters to ask me what they mean. I almost need a personal assistant to help pull things together.

One of the real challenges we have in the pain services is that they are completely divorced from social work. What we have is a biopsychosocial model of pain with interventions which are indeed m bio and psycho, but zero social. You have been describing social interventions which social workers would be using a lot in their practice but we don't have social workers within pain services.

They have started in America and there is a little group of social workers who do work in pain clinics. Some of them are already members of IASP. I think it will evolve but it's going to take ages in this country.

This is very important. In the current climate social services are being hit very hard but there are a number of groups supporting people and the community and not being funded and there is no access. The NHS doesn't see that as part of its role. This is definitely something I would want to encourage. Do you know of any other groups doing anything similar to the knitting group, particularly working with pain patients?

Yes, there are a number starting up with whom I have links.

There are people like, for instance, torture survivors for whom socialisation is a big part of the pain problem and until that is addressed ...

You've hit on a really good point there. There is a big problem with people seeing only their own little environment and not the patient's whole journey ... just push them on ... back to the GP or other services. They don't work together or talk to each other ...

... there are lots of people doing fantastic work ...

GP's need to look at what they can do. Most live in a surgery and you go and see them ... but I think people need some kind of drop-in centre with all the advice patients need similar to what you can get in a hospice; you could have knitting groups and this that and the other ...

There is one in Heywood near Manchester set up by a retired GP, called Recovery Republic. People can drop in there and get all sorts of financial advice, all sorts of groups including knitting, volunteers running a café, an allotment ... it's a fantastic idea.

Also the citizens advice bureau does a lot of work with people with chronic conditions.

I can't imagine getting a man into the knitting group – is it all women?

It is all women and we are thinking of setting up separate all women and all men groups. It's something to do with the automatic movement when the brain is occupied with a task it sets up a certain level of capacity and they seem to talk more freely. They don't talk about their past problems in the group unless people get particularly friendly with one person. The conversation is generally very positive and there is a huge amount of laughter, but they do come and talk to me afterwards.

Lastly, thinking about ourselves: as professionals we always stick together. I am intrigued by the new generation coming up some of whom have only really known shift work and whether they are going to work the same hours as we do. It will be interesting to see how that evolves. But it's important that we stick together and look after ourselves, because unless we do we can't really look after our patients.

Katherine Pettus

Clare Roques and I met in India and she and I spent time together looking at temples and talking about pain medicine. She educated me as I'm not a physician, I'm a political theorist and a policy person, in particular about the difference between chronic pain management and palliative care; and about the use in both of opiates and about the many misapprehensions regarding their use in chronic pain.

My presentation is about opiates in palliative care. And I'm going to put it in an ethical and philosophical frame which is fun to do and I can't do it with many people, but it is apparent that this SIG is about thinking about things in depth.

I'm going to talk about palliative care as a metaphor for the pain of the world writ large: the existential and sort of cosmic pain in the world that we are called to address, whether clinically, pastorally or just as human beings. So if you can, expand into that bigger frame. In the Yoga session this morning we were thinking about energy and this presentation is much about energy: the energy of fear, the energy of healing and the energy of showing up, as much as it is about average daily doses of morphine and historical trauma which I'm also going to address.

Drug control treaties

You presumably know that morphine and Methadone are on the WHO list of essential medicines. I work for an international association for hospice and palliative care on advocacy for improved access to essential medicines with NGO partners throughout the world, mostly in the global south and the former Soviet block countries, but we have many partners in Canada, the US and Australia. The presenting problem is that more than 80% of the people in the world – some 5 billion people – have no access to these drugs. The ICNB (International Narcotics Control Board) which is the group in Vienna that supervises the treaties that control these drugs have identified, through surveys, that fear of addiction is one of the main barriers to use. The first drug control treaty was enacted in 1961, although there was a whole half century of other treaties that were consolidated in this single convention. Most international treaties are not 'self-executing' which means that when a country signs the treaty it doesn't automatically come into law, and each has to make its own laws about opiates. But the single convention gives a framework about what should be punished and a lot of language about opiate availability and the purpose of opiates. The preamble to the international law sets the tone: it talks about how the control of drugs is for the health and welfare of mankind. And we will get into the other language which contextualises and conditions the availability of opiates around the world.

The ICNB controls the movements of narcotics around the planet. In order to prepare their annual report they receive estimates from every country of how much they want to order, and in that way the INCB determines how much licit opium poppy is to be ground. So they really control the movement of licit opioids in this extraordinarily complex way. They also monitor the illicit supply. They comprise 13 unelected people, some pharmacists, some doctors, but no international lawyers or human rights people. They have quite a complicated process of appointment. In essence these 13 people monitor and set the standards throughout the world. The 2010 data suggest that the highest consumption internationally is in the US with nearly 500mg morphine equivalent per person followed by Australia at about 200, compared to the lowest, India, at 0.24 mg/person (It used to be higher in India until they enacted a narcotics control law in 1989; further legislation this year will hopefully make access easier. India, incidentally, grows more opium poppy than anywhere else in the world) So this is an issue of global justice and inequity.

All these opiates used to be legal. You could buy and sell them from itinerant peddlers on the road. One of the reasons for this was that medicine wasn't as developed as it is now and you couldn't cure things that you can now, so pretty much all people could do was to relieve pain. People didn't realise the potential harms although there was a sense of what addiction was, especially in China, where the

British capitalised on their source of opium in India [to the extent of going to war] Britain has been described as the first big drug cartel: the Empire was built on opium and sugar, both addictive substances.

The first prohibition treaties were integrated into the whole frame of international politics and relations during the colonial era of the first part of the 20th century. There were different criminological and clinical contexts. Although the great wave of independence in the global south and the colonies happened in the 40's 50's and 60's after WW2, the first drug control treaties were signed in 1909 in Shanghai. The Americans initiated the process of control after they conquered the Philippines where there was quite a lot of opium usage because of the large Chinese population. The Spanish had had a regulated market there for opium; they accepted the Chinese use of it as part of the culture of the Philippines and taxed it. When the Americans took over their bureaucrats were quite willing to take on that system. But there was – and still is - a very powerful evangelical force in America which refused to accept this and said that if we were going to have this empire and conquer the barbaric people in the Far East we would have to bring American moral standards, and instead of regulating opium use it had to be abolished. So the beginning of drug control came with the American and British missionaries and social reformers, followed by physicians and pharmacists, who wanted to abolish or at least regulate the prodigal use of opiates.

Supply reduction of all illicit crops, i.e. everything except that used for medical and scientific purposes, was considered the only way to go about this. There was no such thing as the sort of evidence-based treatment that we have now – it was just get rid of the stuff. So that was the old paradigm. But the fact was that no-one knew how to calculate the amount needed for medical purposes throughout the world, including the newly independent countries in Africa, India, Laos, Burma - to do this you have to know what your population is, what your morbidity and mortality figures are - and you need trained people to do this. So basically it was just control, control and punishment but no provision. The 1961 Single Convention which brought all the colonial era treaties together was supposedly was about provision and control but the emphasis was on control and punishment. As recently as 1988 the UN Special Session on drugs had the slogan “a drug free world – we can do it” which conditions the attitude that the things they called drugs and physicians call medicines should be avoided if at all possible.

The emotional energy for all this came from the stirred up charge of fear of mass addiction. The early propaganda used photos of Chinese opium dens and the suggestion that Chinese men would lure white women into their dens (The trope of American culture that men of other races – black men on coke and Mexicans on marihuana - would take white women was a sure way of getting laws passed and they used racist narratives all the time). You will all remember how in the Cold War in the 60's and 70's when we had the fear of nuclear annihilation there was also this binary of good and evil. Language creates us, and the drug control laws and conventions constantly use the language of *evil*: drugs were cast as evil and immoral. You also have the fear that surrounds illness, death and vulnerability, and all this creates this charge around morphine. Drug control treaties are the only ones to use the language of evil; none of the really scary stuff, those about slavery or climate change nor even the treaties about nuclear weapons and nuclear annihilation use the word. No evidence or scientific method was used in the evaluation of these substances. Some of my colleagues went back through the WHO records of the 60's, 70's and 80's of the expert committees on drug dependence and found that they hadn't evaluated morphine, cannabis etc in any kind of rigorous way. The 60's were also pre the development of palliative care or pain medicine, and pre the AIDS epidemic and widespread i/v drug use. It was when I was doing this presentation in Rome last week that I learnt what the etymology of addiction is: the Latin word *addictus* means a slave awarded as a debt to a creditor, so an addict is a slave to his habit. In international law around drug control they only use the words addiction and abuse, not the words tolerance and dependence or anything to do with the therapeutic use of morphine.

The preamble to the 1961 Single Convention talks of “recognizing that addiction to narcotic drugs constitutes a serious evil for the individual and is fraught with social and economic danger to mankind” and yet this is the treaty that is supposed to allow the medical use of morphine around the world. The authors are “conscious of their duty to prevent and combat this evil” and “consider that effective measures against abuse of narcotic drugs require co-ordinated and universal action”. There is nothing anywhere in the preamble or the act itself to suggest that they are “conscious” of the need for physicians to relieve serious pain or that morphine is the gold standard for treating it. Wittgenstein said: “the limits of my words are the limits of my world”. I did a word count of the single convention. The word control is used 76 times and abuse 17 times but pain and illness once each and physician never, although the whole point of the treaty was to allow enough for medical and scientific use

When the rest of the world looks at this and becomes conscious of the problem their reaction will be “God, guys, if you can’t get the pain and suffering part right, why do we have these treaties at all?” It’s not like they are working to control illicit drugs, which are pretty easily obtainable as well as incredibly dangerous. We need to fix this but nobody is willing.

Primary Barriers to Access

The CNB, which is where I work a lot in Vienna, is starting to take this seriously and their surveys have identified several factors. As well as fear of addiction to opioids and fear of diversion, there is the problem that one of the paradoxes of international law is that it has the illusion of sovereignty in sovereign countries. All of a sudden in the 60’s you had all of these colonies and dependencies in South America, Africa and Asia becoming independent and sovereign and having to cope with all these things on an equal level. They had to cope with things for which developed democracies have had hundreds of years to develop an infrastructure, so they have totally inadequate healthcare resources, and no national policy or guidelines related to opioids. Many countries, including some advanced democracies, still don’t have such guidelines.

The UN Office for Drugs and Crime has almost no data but has estimated that there are between 16 and 38 million of what they call drug users worldwide. They say the number has been stable for the last 20 years. They say treatment is available for less than 1 in 10, and that’s optimistic. They put the number of injecting drug users at 16 million of whom 3 million are HIV positive. In contrast, there are an estimated 550 billion people with no access to essential opioid medicines for pain, palliative care, or opioid dependency treatment. So the fear of drug abuse – a relatively tiny problem – is being used to justify lack of access to medical opioids for millions.

Reframing the Debate

That’s the old paradigm, but now we have a new one. Palliative care and pain medicine are developed specialties. There is evidence based treatment. Non-communicable diseases are on the rise everywhere especially in the global south as well as the HIV/AIDS epidemic. This is the new morbidity/mortality paradigm. So we can redefine the presenting problem as both a public health issue and a human rights issue. It is an ethical issue in that we have a shared responsibility to dispel fear instead of being a prisoner to the fear that created the problem. So my job is to redefine the problem and present it in a different way to allay this fear. This involves working at multiple levels. I work at a transnational level with the UN Commission for Narcotic Drugs (CND) in Vienna to educate the member states about this problem as many countries – developed as well as less developed – are unaware of it. When I gave a presentation in Vienna to a group of member states in February the delegate from Switzerland came up to me and he was beside himself as he had never heard of it. He has now taken on this advocacy, and we are getting many more member states informed and involved. You can work at the regional and the national level,

with NGO partners, physicians' groups and clinical teams and individuals to keep shifting this paradigm.

There is a need to target different outcomes; for instance to institutionalise palliative care. This is very spotty and random throughout the world. The World Health Assembly recently passed a resolution encouraging member states to integrate palliative care into their public health systems, to really develop primary healthcare, and to allow basic pain medication and better access to Essential Opioid Medicines (EOMs). The WHO works like a silo: WHO is in Geneva, CND is in Vienna and the UN is in New York. They are like parallel universes and don't really communicate so one of my jobs is to act as an interface between them and synergise the three of them. Otherwise CND is all about enforcement and punishment and WHO, which is seriously underfunded, about provision of healthcare. The access to controlled medicine staff has been eviscerated. So it's just not a priority for the international community because many of them don't know about it. There is also a need to institutionalise harm reduction and community based treatment. That to me dispels the fear in a really concrete and institutionalised way. I was in the Vatican last week and I got to have a meeting with some monsignors from the Pontifical Council for Healthcare Workers. The words 'fear not' run through Scripture, and I said to them: "look, the main barrier is fear". And they were like "YEAH!" So the Vatican - the Church - can be the Voice of the voiceless because patients and families who are coping with serious pain and serious illness are not represented in the political world and have no political power. The Church can confront the institutionalised fear that has created the barriers.

Lobbying and organising

I come out of the generation of the other CND! - and when young worked with Physicians for Social Responsibility (PSR) and International Physicians for the Prevention of Nuclear War (IPPNW) which won the Nobel Peace prize in 1985. I now work for the International Association for Hospice and Palliative Care. Other groups involved in advocacy include Human Rights Watch, the International Drug Policy Consortium, the Committee on Ageing in Geneva, Pallium India, Physicians for Human Rights and International Doctors for Healthier Drug Policies (IDHDP)

Would you like to comment on the Drug Enforcement Agency in the US? ... they go after people and sling them in jail for 25 years ...

Yes – it's really nasty - a witch hunt. Morphine is demonised in this theological politics kind of way. DEA is not only out of control it's actually out of alignment with federal policy.

The Morphine Manifesto has been signed by about 60 partner organisations. Neoliberal society tries to fragment us and prevent us from organising. When I give this talk to palliative care physicians I say that you guys can organise and change things for the better. I am also very cognisant that many of them work a 90 to 100 hour week and also have families, so they barely have time to do anything beyond that, let alone take care of themselves.

Change

But things really won't change until we start changing our mentality and our energy around it and start showing up to work with one another below the level of the radar of UN and governmental organisations; doctor to doctor, community to community, sharing knowledge and supporting one another. We can and must midwife this new paradigm into being because the old one is unethical and unsustainable. It really reflects the pain of the world that we have inflicted upon one another through our own historical traumas and our collective shadows. We can change that.

Discussion

It strikes me that we are getting increasingly fearful of prescribing opioids. There is great confusion about addiction and tolerance and we need to clarify our own teaching. I find diamorphine more effective than morphine and I am very conscious of the fact that it is only available in two countries, the UK and Belgium. In the US there are thousands of addicts although it isn't available for lawful use.

At the last meeting we were discussing the means of reaching out. You were saying that we need to bridge all these gaps. We in this group have come a long way since our first meeting in 2001; there is no divide between professions and we have evolved in our understanding of the problems we have faced. I have certainly evolved as a person. So this has given me an insight into the problems you must have in talking to people who haven't learnt as we have...

In Paul Brand's book Pain, the Gift Nobody wants, he describes how his patients in India only required one dose of morphine postoperatively because the families were camped round the beds. I wonder if in our society when patients in hospitals are isolated do we create an atmosphere where people require more analgesia. Do they need more love?

When I think about pain writ large and Cicely Saunders' concept of total – physical, spiritual, emotional and social - pain, and you expand that to the total pain in the world and think of the people who use drugs in a way that we call 'addictively', but are dependent on drugs that make you feel good, I reflect that people don't just get addicted they use them for pleasure and to alleviate these other aspects of pain. In the US where there is a high use of opiates it's not all for physical pain, they are alleviating the spiritual and emotional pain associated, for instance, with being unemployed – or in many cases overprivileged and isolated in that way.

So if you use total pain as a metaphor for the world there are ways that we can use a multidisciplinary palliative approach to that.

[Paraphrase of partially inaudible contribution] Fear of opioids involves worry about an inevitable going up the 'ladder'. This may be associated with trying to resolve the pain without looking at the wider aspects of people's problems. I find myself in the psychology clinic trying to steer people away from strong opioids. People can be very stuck in the mindset that the only way of dealing with their problem is physical. A lot of reluctance is around tolerance. This is not so much a problem in palliative care as in longer term use if we're using that medicine as a way of avoiding interacting with the other things. Some of the push from patients and physicians can be to take away the pain and let them get on with their life, but looking at it the other way round some of the over use of strong opioids is because we haven't made the investment of time in the other side.

To bring us back to the practical aspects of what you were saying, I was wondering if the current campaign to decriminalise drugs for non-medical use and the sort of campaigning that you are involved in are entirely separate issues or whether to some extent they are working in parallel against similar barriers?

I wouldn't say parallel – I think they are synergistic. Some of us were worried that there might be some blowback from the legalisation of cannabis in Washington and Colorado for medical use on the lines of 'because we have legalised cannabis we must really crack down on opioids'. But we've just got to keep pushing through that and educating ...

I loved that comment about letting opioids do the work that we are unwilling to do – the spiritual work.

In my experience in palliative care people brought in to have their pain controlled were often on very high doses but as we got to grips with all the other things – spiritual, emotional and social – by the time they went home (as do 85% of our patients) they were on much lower doses, because by then we had untangled what was the real problem. They came in in pain and that was all they could think about but there was a lot of teasing out because we had time to listen to them.

If you are dying in a hospice you have relations by your bedside, psychological advice, pain control ... everything you need is there, but if you are in pain in the outside world and not dying, no-one wants to know.

I talk to patients in chronic pain and they report that they go to see the doctor to help them to make sense of their lives and how they can live positively with this pain, but he keeps offering them a prescription. That's not what they want – they will take the prescription if it's all that's on offer, but they are not getting the relationship, the social support, the understanding of their belief system ...

... the doctor thinks that by writing a prescription he is getting rid of the patient ...

On the other side of that we have created a passive society who are not taking responsibility for their own health. When they get to the pain clinic they are expecting a quick fix cure. And the doctor doesn't have time to do anything else but write prescriptions.

They come with MRI's and say that's what's causing my pain and if you say no, that's not what your pain is coming from they don't believe you, they believe the MRI.

Has anyone attempted an assay of endogenous opiates in different states of psychological wellbeing – for instance if you are being cared for in a hospice does your endogenous opiate level go up?

The analgesic effect of acupuncture is reversed by naloxone

There was a study published in the BMJ about sex... [and the effect of arousal on pain tolerance]

Willy Notcutt last year showed an fMRI of a brain during orgasm...

...but it was only a female brain...

Bernd told us the story of the lady on the Jumbulance who forgot her medication – she had been trapped in her house with severe RA on strong analgesics ...

... she was on 80mg of oxycodone which was packed in her luggage underneath the bus, but this was the first time she had been out of her bedroom or had any proper company for months. Not only did she not miss her oxycodone, despite having a fall, but she didn't even suffer any withdrawal symptoms.

One thing that physicians don't do other than in hospices is to adjust opiates down – not even in pain clinics. If you try to talk to patients about this it's a no go area.

... opioids may be harmful if they encourage passivity or if patients are unable to engage

I had a young lady in our knitting group, only in her thirties, and she was curled up in a ball with her head on her knees, unable to lift it. When I did manage to get her

head up she had no eyebrows or eyelashes. It transpired that she was taking so much morphine that she could barely stay awake but she was still chain-smoking and had singed off her eyelashes. We couldn't get her to sit up and I tried to get her admitted but there wasn't anywhere that could deal with it.

I am concerned about patients being made dependent on fitting in with the system to get what they need: a secondary need that they subconsciously develop strategies to address. Once you've got the status of acknowledgement that you need morphine then it is also acknowledged that you have severe pain. So if you've been in the pain clinic, particularly if you have a claim pending, for instance you've been injured in a car crash, and your morphine is taken away you are no longer ill. So it's not so much drug dependence but dependence on another level on being acknowledged as someone with something seriously wrong with them.

There is an increasing number of situations where GP's are reluctant to prescribe opioids when they are actually required. I have seen surgeons who don't want me to give proper pain relief because they are worried about something else. They don't worry about pain.

One of your slides showed that some of the more expensive drugs are available in some countries where morphine isn't ... who is deciding that?...

... Fentanyl patches? ...

The pharmaceutical companies. Fentanyl is killing morphine; it doesn't carry all this baggage that morphine has although it has been the gold standard for pain relief. And morphine is cheap so it's not profitable to market and sell. Fentanyl is expensive and doesn't have that name ...

... but governments could choose to ...

... they could, but they don't, because no-one has clue about this stuff.

I loved this discussion about overuse when I had talked about underuse! It so reflects the historical inequities of our planet.

I very much liked the phrase you used "midwives to a new paradigm". That is something I have always regarded as the essence of this group. I am reminded of a similar phrase "paradigm pioneers", which comes from a book called The New Business of Paradigms by Joel Barker. And the opposite to paradigm pioneering is "paradigm paralysis".

Ian Stevens

Louis Gifford was a unique individual whom I am profoundly grateful to have known.

Professionally Louis opened up my mind to new ways of thinking about interacting with those with persisting pain problems. Personally, and on many levels, Louis also helped me keep my faith in the human condition as he was consistently generous, kind and enthusiastic in all his communication with me over the years I knew him. Louis, like many of the influential people who have given talks at these meetings, was charismatic, driven and a real iconoclast. He achieved much in his life and died in 2014 of prostate cancer. He spoke with the gentle distinctive burr of a Cornishman and followed in the footsteps of his physiotherapy parents

Louis was well known in the emerging physiotherapy pain interest world, but he will be probably unknown to most medical practitioners outside the Falmouth region of Cornwall where he lived and practiced. Despite this his influential and critically well-received books have been sold throughout the world.

Louis' idea of compassion involved action and interaction with those he listened and communicated with as patients and the many clinicians he taught when delivering his ground-breaking courses.

Most doctors and physiotherapists are educated in a structurally dominated pathological model. This is appropriate in some circumstances, particularly where acute injury or end stage pathology is concerned. My education was firmly within this structural model of the body and initially I tended to see all problems through this lens. However, very early on in my career I quickly came to realise the limitations of this model, especially when presented with the typical outpatient caseload of on-going pain or unsuccessful post-operative management. As is often the case in physiotherapy practice there is a desire to assist patients with the 'tools' at your disposal: physical assessments, tissue 'treatment techniques', exercise, ergonomic 'adjustments' and the like.

When I met Louis and spent a week with him on a teaching programme I realised that I had become fairly stuck and frustrated in my practice. That week of being exposed to information from pain science, stress biology, motivational psychology and seeing how some patients could be transformed by knowledge, education and extended consultation was a revelation.

I'm going to talk about Louis' influence on my career through his immersion in pain biology, his interactions with pain pioneers like Pat Wall, his interest in memory and his interaction with Steven Rose. My talk is more at the 'micro level', about case management and one-to-one interactions with patients. I want to link that to my experiences in this group, and to illustrate that with a few images.

A case history

At the micro level of pain management we are all dealing with suffering and often profound frustration. The following case history is that of a patient who had an RTA in 1997. A scan two years later suggested that he needed surgery but had to wait a further two years for the operation. During this long period he explored lots of alternative therapies and was also treated by three or four different physiotherapists. The operation was a fusion of the L4 and 5 vertebrae. In his words:

"After six weeks of aerobic rehabilitation I hit a brick wall and my symptoms returned, leaving me in a permanent state of chronic pain for the next 11 years. I underwent lots of treatment and moved to Spain (from Glasgow) for the better weather. I attended the pain clinic in Glasgow where every possible drug and treatment was thrown at me from TENS machines to steroids, none of which helped and some

made me worse. I was finally deemed suitable to go on the pain management programme, having initially refused by the psychologist, as she believed that my understanding and attitude towards my pain was incorrect. I felt that it was the other way round and that they were trying to make me fit into their rigid understanding of what would work rather than assessing my life to see what would be most effective. The psychologist refused point blank to believe me when I said that I wasn't feeling any better from the tasks, which she prescribed, and my experience within the programme was similar. All of my passions in life involved music, art and film, and their pacing system required me to minimise practising in these fields to the extent that I was doing so little I was getting depressed. One of the negative aspects of this programme was that I was with a group all of whom were at least 20 years older with a drastically different life outlook. They were extremely negative, but right from the time of my accident I had always felt that it was up to me to take responsibility. I did get some positive things from it, such as learning mindfulness meditation, and being believed by the other health professionals. After leaving the programme I felt I was only marginally better informed about chronic pain. Shortly afterwards my wife and I had a daughter and I had to become her primary carer. This took its toll on me and increased my pain."

A month later he was bedbound was continuous muscle spasm, and once again he had hit a brick wall. It was at this stage he moved into the area (Callander) where I work. He continues:

"His [I.S.] approach: discussing with me my life and pursuits, and treating me accordingly, was far more encouraging on anything I had had before. I focused on energy and fitness levels, exploring movements and exercise that would feed into my existing attitudes. It took daily commitment and dedication from me as all things do when dealing with chronic pain but it is the first time I have experienced progress as well as increased wellbeing. I was encouraged to do more of the things I loved rather than less, and felt less depressed."

I am not saying that I helped this patient significantly, but the reason I was able to help him was probably due to my knowledge gained from managing some previous complex cases and the resonance and connection I felt with this particular person. As an aspiring musician myself and talking to a real musician I understood where he was coming from. Primarily, I was able to explain his pain in ways that he understood, and to engender by using active strategies to enable him to get a bit better. It was really only by understanding pain physiology and neuroplasticity at a micro level as well as the whole person, and ignoring most of my initial physically dominated education that I was actually able to help him.

We can look for explanations of pain and suffering in many different areas and disciplines; philosophy ethics even global politics. At the local level - the ground and clinical level – I sometimes think that simpler approaches can 'work' and engender great change in people. When I reflect on places that allow me as a person to develop, it seems to me that these are quieter more serene environments, such as this venue, Rydal Hall. Patients, particularly those that are distressed, confused or fearful need environments that facilitate or promote change and reduce threat. However most of the pain clinics that I have worked in or have spent time in tend to do the opposite. I have often been asked to interact with patients in sterile environments where a silver tray for instrumental procedures and a stark couch are the items on view in the consultation room. This does not seem to be an appropriate environment for the promotion of relaxation and confidence.

We talk about the micro evidence in pain about neuroplasticity and maladaptive pain processes, but there is also positive neuroplasticity and things can improve as in

the story I have just related. In retrospect, the postero-lateral fusion of this patient's spine was unnecessary and his problems were possibly largely iatrogenic. He was disabled by the interventional structural approach to pain which led to an unintended negative sequence of events.

I was powerfully influenced by the talk given by John Loeser, former president of IASP, at Launde Abbey in 2013. He described the influential and iconoclastic John Bonica. Bonica was a driven dynamic man who left an indelible mark on Loeser. Bonica worked twenty hours a day. He created the IASP by corralling people into a monastic retreat centre from which they couldn't 'escape'. He started a movement through his own dynamic energy, his forceful attitude and persistent dogged determination. It wasn't through randomised trials and science that the IASP was formed (although science was very much involved and Melzack and Wall were present at the inaugural meeting).

The places where information is gleaned from have had a powerful influence on me, such as the building at Glasgow University where I heard a talk from Ramachandran on 'phantoms in the brain'. The light in that building is absolutely stunning and my memories of that talk are still with me: how Ramachandran treated phantom facial pain with cotton wool buds, and the remarkable parallels between phantom pain and the type of conditions that I see. Physiotherapy, in my experience, is usually a secondary consideration in medicine; often viewed as something to placate patients when nothing else has worked. However many clinicians and patients fail to understand the role that movement has in life and health since, neurophysiologically, much more of the brain is developed to serve movement than to language. 'Language is only a little thing sitting on top of this huge ocean of movement', Oliver Sacks suggests. Movement is more than a little bit of exercise.

The sensation of pain can be changed through perception and attending to movement and sensory experiences. This bodily attention coupled with cognitive evaluation or re-evaluation is perhaps one of the main roles that physiotherapy could offer in clinical encounters, (particularly with the many patients with ongoing undiagnosed musculoskeletal pain).

We hear a lot about limitation of time and resources in pain management but often failure of interaction is the biggest single problem. In order to take a photograph, particularly one that may have some impact, it is sometimes necessary to shift your bodily perspective: at normal height you may miss what you want to feel and you may have to crawl on the ground to look at a different angle. Many writers have described this process better than I can. In this regard I have been influenced by the phenomenological nature writing of Nan Shepherd. Shepherd, a writer who spent her whole life around the Cairngorm mountains, beautifully captured the transformational aspect of the way her bodily processes influenced her thoughts and feelings.

Sometimes analogy is appropriate where a shift in perspective is necessary when interacting with individual patients. There is often a necessity to shift one's vantage point or perspective in order to reach across to another person. I believe this process of guidance, empathic communication and teaching is the main role of a physiotherapist.

Louis on the river



Louis was a driven, interesting and independent thinker. I communicated with him for over 15 years and he has left an indelible memory in me. He spent much of his adult life researching into and communicating about pain. Looking at this picture I think you can see the kindness in his expression and the twinkle in his eye – he was an amusing bloke. Remarkably, he was able to teach complex information to people schooled, drilled and brainwashed into thinking that the structure of the body holds all its secrets. As physiotherapists we have to think and to interact and we have been trained to use our hands. Most people are not averse to being touched if it is done in the right way. Scientifically the justification and relevance of touch in medicine may be understood by considering the work of Robert Sapolsky who is one of the world's foremost stress biology researchers. Sapolsky's primate research emphasises the powerful interaction that baboons derive from touching. The ones that most regularly have nits picked off their backs have the lowest cortisol profiles. Raised oxytocin levels associated with engagement and bonding are developed through touch, not just through words.

Physiotherapy is a structure and movement profession. Sometimes, as Paul Dieppe revealed* fixing the structure, such as replacing a joint, doesn't solve the problem. Some people are made worse by the rehabilitation process itself when this involves forcing the body to do things when it is in a defensive state. Understanding at the micro level why some people report pain, including the understanding of the sensitisation of peripheral tissues really helps in clinical decision-making.

Louis explained, though his research and that of Patrick Wall and others on adaptive and maladaptive plasticity in the nervous system, why some people can be helped by massage and manipulation but in others it causes an amplification of pain. If you are schooled in a physical, structural, mechanistic knowledge base you haven't a clue why that should be happening.

**(What happens if you have the 'fix' for pain and it does not fix you?'* Talk at Rydal SIG meeting in 2010)

Traditional thinking about movement is structural, but largely through Louis' pioneering work we are moving out to encompass culture, physiology and wider

issues.

Emotional suffering is a large and often overlooked aspect of clinical practice. Reasoning philosophically about touch, interaction and bodily processes can help to transform emotion. This is a big under-researched idea in medicine. Louis made sense of many complex presentations. He made me aware of neuroscience and through this enabled me to think about the individual psychosocial factors and broaden the rehab process.

Being the change

We have talked about a paradigm shift and 'being the change'. In order to do that it helps to be unique like John Bonica: very curious and a bit thick-skinned. People like Bonica are the ones that bring about paradigm shifts in medicine rather than those beaver away producing papers in academic institutions.

Developing effective therapy, by linking narrative research with microbiology and looking at the way that trauma and early life experiences can affect people at a cellular level, needs an interaction between art and science. Ethics may also come into it, and education, teaching and modelling at a practical ground level certainly does. Perhaps there is a necessity to consider that the famous art science 'two-cultures' divide described by CP Snow in 1959 is an unnecessary artefact. In our current era there appears to be enough valid theory and evidence to bring the two-worlds a little closer.

I attended a course with Louis Gifford about 15 years ago. The clinic was full of chronic problems: patients who had had 'failed' surgery, nerve root blocks etc. I saw great transformations in about three or four days purely through education, explaining neurophysiology and how severe pain had become maladaptive. Some people were completely transformed through simple understanding and movement-based practice.

My structural training led me to try and find all sorts of complex physical reasons for apparently structurally based pain. However it is unfortunately still the case that the majority of practice appears to be based on dualistic notions of pain rather than more complex models and fluid constructs such as Melzack's neuromatrix theory.

Understanding the trajectory of Louis' career is an illuminating journey of challenging existing paradigms, developing new integrated teaching tools and the realisation that change is never easy, as in the case history.

Like me, and many other young physiotherapists, Louis wanted to get competent at treating physical, musculoskeletal pain and as I did went on traditional orthopaedic-based courses like those that James Cyriax presented (Cyriax was a bone-setting doctor at St. Thomas's in the post-war years [*with his own very aggressive methods of manipulation*] that developed very financially successful courses [*as well as a very lucrative private practice*], which still attract a lot of attention). An Australian physiotherapist called Geoff Maitland, who had attended Cyriax courses in London developed a system of assessment and treatment for physiotherapists in the 1980s that strongly influences physiotherapy musculoskeletal practise even today.

Louis went off to Australia to do the 'Maitland' course and research but he read a very seminal paper by Patrick Wall written in 1991 about central changes involving sensitization in the spinal cord and brain after peripheral nerve injury, and a lot of strange cases of pain sensitivity suddenly started to make sense. Louis immersed himself in pain biology and memory research, and integrated these with Sapolsky's stress biology. He tried to integrate all these into a model, to explain persistent distress and dysfunction. Among the literature he produced was a teaching tool called 'The Mature Organism Model' whereby tissue injury was 'sampled' not only at the periphery but at the spinal cord and multiple different regions in the brain. This processing is influenced not only by cellular processes but also by past experience and the culture a person lives in. Subsequent motor and sympathetic output, the movements that we see and the experiences people tell us about are all part of a

complex interconnected 'sampling' and 'processing' system. Most people manage perfectly well after minor injury with little input from medicine. However, there are, as most clinicians realise small numbers of patients where this is not the case and the pain defence system may become 'maladaptive'. As time moves on and pain outlives its 'usefulness' a person may become increasingly disabled and deconditioned. Treating this type of scenario requires physiological and social knowledge as well as ethical and cultural understanding.

How do I work with this kind of information in practice? I no longer get out my skeleton; I sometimes use my whiteboard to explain about the senses. Sometimes, but admittedly not very often, one can quickly reduce threat.

Following on from Louis's seminal work and the dissemination of knowledge to physiotherapists at national conferences and weekend courses more awareness of pain biology and educational approaches began to grow in physiotherapy practice. The well known Australian educators David Butler and Lorimar Moseley developed the book *Explain Pain* which combined cartoon drawings with up to date science in order to teach these concepts to patients.. Education and interaction, rather than intervention and structural treatments, have helped many people in ongoing pain. An example of how I use some of the information I have learned over the years in practice is in the following brief case history. A lady came to see me the other day that has really arthritic knees. Her knees were particularly sensitive despite having a few unsuccessful steroid injections. I simply doubled up my consultation time on the next visit and went over her case in longer detail. Within a week the temperature in her knee had reduced. Her knee pain was bound up with her husband's mental breakdown; he was a butcher who had lost his business, and she had had to take on two or three jobs. I explained that the load on her body and all the central effects were affecting the output of her nervous system, and that she needed to calm that down. She understood that, and used ice packs, and in order to reduce the load on her body stopped one of her jobs and used a crutch temporarily. She was able to reduce her medication.

Louis introduced me to Benedetti and his book *The Patient's Brain: the science behind the doctor-patient relationship*. Hope and trust - even if you are deeply suspicious of science - have a neurophysiological basis. The physical distance between people can affect them either positively or negatively as the nervous system projects around the body (the 'peripersonal space'). People may become more vigilant and the space around their body 'shrinks' (through body-mapping as personal space neurons in the CNS have been reported to adapt to changing circumstances). Traditional tribal people for example feel linked to distant people - whether that is a metaphor or an actual physiological process is speculative. However in our atomized and often-disconnected culture, where connection with others may be cautious and defensive, touch and clinical encounters may in some situations help to counter this. Perhaps this is one reason why in the right context massage and other body therapies are sought in times of distress? However, one thing that is apparent in the scientific literature is that the nervous system is potentially plastic and adaptable.

I have been helped clinically by the knowledge I have gained through expanding out of 'structuralism' into complex physiology, as well as the literature of philosophy and ethics. Benedetti's work rationalizes and validates what we are trying to do. The room you are working in, the way you approach people and the way you interact have measurable effects. In our science-based world that's a pretty concrete reason for understanding it, and also for me minimizes the need to work with pseudo-scientific explanations.

Louis Gifford was ahead of his time and faced opposition from traditional groups in my own profession, and throughout the mechanistic world of rehabilitation. However Louis persisted; his work and ideas spread and led, particularly in Australia, to dissemination and the research which proved his ideas. He was a great disseminator, he was a great teacher and he modelled effective therapy. Over the years I have become less of a physical therapist and more of a teacher and a

'therapist' through reading, reasoning but primarily through my interaction with Louis Gifford.

It was heartening to me to receive a copy of Louis work, which was posthumously edited and published by Phillipa Tindle, Louis' wife and partner. This trilogy of 1319 words is a fitting tribute to Louis and I know of no other person from the medical or therapy world that could have completed such a comprehensive piece of work. It is unlike so many books relating to pain and rehabilitation, the books are readable, funny, anecdotal and useful! The books reveal the man who wrote them, sceptical, impressively well read, articulate, personable but most of all a flawed human like the rest of us who is able to see the funny side and admit his mistakes too. A review of this important writing and a fitting tribute to Louis is by Professor Paul Watson, to be found at

<http://giffordsachesandpains.com/2015/01/13/a-review-of-louis-gifford-aches-and-pains-by-professor-paul-j-watson-phd-fcsp>

The best paper I have read for many years is Iona Heath's *The art of doing nothing*. Heath characterises the art of doing nothing in medicine as "active, considered, and deliberate. It is an antidote to the pressure to DO and it takes many forms including listening, noticing, and thinking, waiting, witnessing and preventing harm: peach an art in its own right requiring judgment, wisdom and even a sense of beauty".

It is not an exaggeration to suggest that Louis Gifford did an enormous amount practically and academically but the end result of the action in practice would appear quite simple. He taught me to try to understand more and to be creative in getting this information across to the individual but most importantly to try and keep a sense of humour and perspective along the way.

Discussion

I was a bit appalled by this story [of Ian's patient's experience of a pain management programme]. I expect this sort of attitude from an orthopaedic surgeon but a psychologist in a pain management program having this sort of prescriptive 'interventionist' approach – is this common among psychologists these days?

It is and probably reflects the amount of time they have to deal with loads of patients. You see it with physios who just give the patient a piece of paper with loads of exercises.

It's also a failure to differentiate things like artistic processes and music from functional tasks like ironing or cutting the grass... you can't pace art or inspiration ... you can't stop writing a poem after two words because your hand is aching ... you have to complete the creative process. It is often best to have the satisfaction and accomplishment of completing and gaining some brief sense of 'flow' even if this carries with it some 'risk' of a flare up in the sensitivity of the body. This I believe is an important point.

In life as in the clinic it's very easy for things to become prescriptive, such as pacing ... "this is how you should do it." it's important to give people the choice to do whatever works for them ...sometimes to risk a little and to try things afresh even if you are unsure of the outcome

A lot of doctors don't understand how the motor and sensory systems interact ...and a lot of therapists are not educated to see the motor assessments and 'exercises' in

the context of goal directed behaviour .

I'm not here to defend psychologists but I would just like to echo what has been said: the important thing is that we have to work as part of a team. As a psychologist you have to be working with doctors who understand the explanations that have to be given to confer the credibility, the belief and safety of the patient. In New Zealand, I at least understand where the criticism is coming from because of the advent of insurance companies having more said over what happens. Psychologists are seeing patients in isolation and this is not the way to help them. I thought it was a wonderful talk and underlined the importance of having mentors and leaders.

A link to Images that were discussed at the talk and slides I shared with Louis around my interests in Scotland :

<http://s1219.photobucket.com/user/iansdunblane/library/Rydal%20images?sort=6&page=1>

God, Suffering, and the wisdom of Michael Hare Duke

Peter Wemyss-Gorman

I was wondering what I could talk about to fill in the programme and it occurred to me that although we had been quite preoccupied with 'spiritual' aspects of suffering in our earlier meetings (even if some of us were a bit unsure what the word means), for some years now we have only touched on these tangentially. And when I mused about religion and theology my thoughts inevitably turned to Michael Hare Duke*. For those who don't remember Michael, he was the retired Bishop of St. Andrews, Dunkeld and Dunblane and a former chairman of Age Concern Scotland. He came to our very first meeting at Scargill in 2001 and remained as our 'resident theologian', attending nearly every year until his last appearance in 2008 since when he had been kept from us by age and failing health. When in 2011, to mark the 10th anniversary of our first meeting we invited previous speakers chosen by popular vote as the ones whose contributions stood out most in peoples' memories, Michael was the leading contender but he wasn't available. So what I decided to do to make up for this was to prepare a sort of brief compendium of Michael's talks and present them today. It has proved a challenging task – there is at least two hours' worth of material - but a very rewarding one.

A word of reassurance to any atheists among you: although Michael was obviously a Christian his approach was always refreshingly non-sectarian and non-dogmatic, and totally honest in conceding the difficulties inherent in a religious attitude to pain and suffering. One of his most memorable sayings was "This is not an argument to be won in favour of this side or that. It is instead a way of finding the golden thread which runs through the total human history and makes it possible to hold together the contradiction of a loving God and a world of pain". And if you find this contradiction – this theological paradox – an insurmountable barrier to belief, may I suggest another paradox, this time a human one: that the more improbable the existence of such a God may seem the more people seem to need him – if only for someone or something to be angry with.

Indeed, it could be said that the very evolution of religion has come about as a response to suffering and that religions actually begin with suffering rather than being invalidated and ending with it. So in this context, may I draw your attention to the transcript of our 2007 meeting on Suffering and the World's Religions. That year we invited representatives from the five major religions: Judaism, Christianity, Islam, Hinduism and Buddhism to give us an insight into their approaches to suffering, as well as a secular/humanist overview from Michael Bavidge, himself a long-time regular. Except to say that the two non-monotheistic religions faced considerably less difficulty than the three Abrahamic ones, and that Buddhism seemed to be of the most practical value in helping people with chronic pain, there isn't time to go into any of them now, so may I recommend reading the transcripts (or re-reading them if you were there) May I also recommend the book *Problems of Suffering in Religions of the World* by John Bowker. Incidentally the following year we tried to see if science could answer 'why' questions about suffering and you might like to see how successful we were. (See transcript of 'Science and Suffering' 2008)

So that's enough of me and the rest of this is almost entirely in Michael's own words.

*Michael died in December 2104 at the age of 89, so this article has become an in memoriam tribute.

Theology and Pain

In his first talk, at our first meeting at Scargill House in 2001, entitled Theology and Pain, Michael began by acknowledging that in earlier generations the perception of human life was of struggle and pain, a view endorsed by the Bible. As Adam and Eve are driven from the Garden of Eden, the man's condemnation was

'Cursed is the ground for thy sake; in sorrow shalt thou eat of it all the days of thy life.'

For the woman the sentence was

'I will greatly multiply thy sorrow;
in sorrow shalt thou bring forth children.'

In the Book of Job the theme continues

"Man is born to trouble, as the sparks fly upwards"

Previous generations perceived that disaster and death were mixed with beauty and pleasure in the natural world and that human nature veered between love and tenderness on the one hand to violence and tyranny on the other. For the most part however the negative aspects seemed to dominate.

This gave rise to the question: how did a good and gracious God create a world of so much pain? The answer came in terms of human sin which had skewed the original design. But to do theology one needs to discern the underlying question and also the context within which it originates. This is particularly true over the attitude that has been adopted to physical pain and distress. Most of human history has been lived with a sense of the inevitability of suffering, especially that caused by poverty and disease. Where was God in this? Following the Old and New Testament, the Mediaeval Church was led to the assumption that sickness was most often the result of sin, as expressed by the Collect for Times of Common Plague or Sickness:

"O Almighty God who in thy wrath didst send a plague upon thine own people in the wilderness.....Have pity upon us miserable sinners, who now are visited with great sickness and mortality..... that like as thou didst then accept of an atonement and didst command the destroying Angel to cease from punishment, so it may now please thee to withdraw from us this plague and grievous sickness; through Jesus Christ our Lord ."

The questions: why have our bodies failed in health or the weather turned against us, were answered by reference to personal or corporate failure to obey God. The obvious ills of society were Poverty and Pain. There was no way of explaining their incidence and since everything was understood to be in the hands of the Almighty God they must reflect his will.

Jewish spirituality began by seeing the process as one of Sin - Punishment - Repentance - Healing. Then there was interposed the possibility of Vicarious Atonement. The annual Day of Atonement involved enacting the ritual of the scapegoat. Written back into the story of the Israelites in the wilderness escaping from the Egyptians was the idea of Moses standing in for them to make atonement to Yahweh for their sins. In its final form this is part of the Christian understanding of the death of Christ. It needs however to be clear that the image of the Cross as a substitutionary sacrifice is by no means the whole story.

In a world where pain and suffering could only be endured it needed some kind of story to make it bearable. St Francis embraced the pain of the Passion and bore in his body the stigmata or wounds of Christ and identified himself with the poor and the

lepers as representing the poor Christ. The same kind of reasoning lay behind the ascetic practices which characterised the spirituality of some Mediaeval saints, such as Catherine of Sienna, who literally starved herself to death in her pursuit of personal sanctification.

The popular perception of events as divided starkly into good and bad can be seen in the hymns of Mrs Alexander, wife of the Archbishop of Dublin, whose God presided over a moral order that required sacrifice for sin, and for whom everything was aligned on one side or the other in a dualist conflict. She has no room for shades of grey or ambivalence:

“There was no other good enough to pay the price of sin”

She could only see :

“All things bright and beautiful.
All Creatures great and small
All things wise and wonderful
The Lord God made them all.”

It has remained the task of the Monty Python team to provide an alternative and more pervasive perception of a creation where all things are part of the Creative Will :

“All things sick and cancerous
All evil great and small
All things foul and dangerous
The Lord God made them all

All things scabbed and ulcerous
All pox both great and small
Putrid, foul and gangrenous
The Lord God made them all”

We have entered a new phase of human history where in many ways we are more in charge of our lives and therefore less in need of a cosmic dependency. There is no longer an inevitability in the unfolding of history, but rather an understandable pattern of the play of market forces. Medicine and surgery have taken steps to confront the inevitability of disease and pain (and perhaps to try to dominate it by intervention). Popular expectation has outrun the claims of scientific medicine and tends to assume that every problem can be met. We are left with a view of pain as an enemy to be conquered and perhaps for some the same is true of death itself.

Is there inherently something important for each human being in overcoming difficulty and adversity? Is the slogan 'No pain, No gain', simply an attempt to make the best of a bad job or is there an ennobling quality in pain? The answer will depend on our definition of pain. How far does this include emotional distress, the experience of loss and mourning? Here again, increasingly, pharmacological remedies are being sought for psychological ills like depression. How far are pills the remedy for anxieties about old age or the fear, of terminal illness? Just as palliative care seeks to take away the physical hurt, can we accept that the pain of the spirit can also be appropriately alleviated? Or have we a lurking suspicion that people grow by confronting them?

We must ask ourselves: whose side are we on? And does this depend on our perceptions of medicine or a faith position which must be argued at another level?

In his book 'A dignified Dying', Hans Kung addresses the question of how far a patient has the right to say "I have endured enough". In the teeth of a theology which

argues that any embracing of death is unethical, Kung declares that his faith begins with a God who is the gracious Father, not an author of unbearable pain which will prove our trust in Him. He writes that: "Precisely because I am convinced that another new life is intended for me, as a Christian I see myself given freedom by God to have a say about the nature and time of my death ... out of unshakeable trust in God who is not a sadist but the merciful God whose grace proves eternal."

As we grow older or consider our death as a relatively imminent event, we have fears not about today but about tomorrow. Will we be able to cope with worries about how to pay for future care, the threat of future illness and what will happen when a particular point of immobility, dementia, or indignity is reached?

What assurance can be given to such worries? Once it was possible to talk of leaving the future in God's hands. How far have the medical profession taken over? Where does your confidence come from, to operate in this twilight area? What theological stories do you and your patients need to be able to work together with a confidence that all will be well?

It's very tempting to use action as a substitute for listening and thinking, or to put off the evil hour of getting to grips with a patient's real needs - or admitting that action is unlikely to help much and helping the patient to accept this. It can take courage ; (for the therapist as much as for the patient) to give up the struggle - and make the positive choice (*not* the same thing as passive giving up) to abandon the battle against pain , and to learn to accept it, to be still and listen to it.

Almighty Love and Ills Unlimited

In his second talk, Almighty Love and Ills Unlimited, which he gave at Launde Abbey in 2002, Michael acknowledged the apparent bleakness of the prospect, quoting lines from a modern version of the book of Job;

"I heard upon the dry dung heap
that man cry out who could not sleep
'If God is good, he is not good,
if God is good, he is not good'"

God cannot be Almighty Love, if Ills are unlimited. If he were loving how could he let this happen to me? If he is good, he cannot be what we assume by the title 'God'. If on the other hand he has all the power of the Creator, then he is a cosmic sadist.

Michael continued : The same question dogged me when I was I was a hospital chaplain. Patients would contrast their respectability and moderation with the opposite indulgence that they had observed in their neighbours. They themselves were in hospital whereas the others were flourishing. The objection was always 'Where is the justice in this?' or more simply 'It is not fair!'

As pain consultants you are more aware than most of the pressure of suffering in our society and of its random nature. How are you able to hold on to the notion of the love of God for yourselves or what comfort can you offer to sufferers or relatives? Do you see that as part of your role, or is that your cue to send for the chaplain?

Traditionally Christianity has answered the questions about suffering and justice by looking at the suffering of God, seeing Christ crucified as identified with the world in its pain. This, it has been said, is God's action to acknowledge responsibility for the suffering that is inherent in his act of creation, rather as a parent will see how family life is potentially the source of suffering as well as joy and take responsibility for the areas where it has gone wrong.

Long before Leibnitz coined the term Theodicy, people were suffering and asked how the pain could be understood and how it could be combated. One solution was

to find a source of wrongdoing which had incurred God's displeasure and brought punishment on the individual or the community. For instance the search for scapegoats to account for the Black Death led to pogroms against the Jews who were accused of poisoning wells.

The alternative solution involved Dualism: the One God was replaced by two rival forces. The Good Creator was matched by an opponent, responsible for all evil, including pain. The created world was seen as a battlefield between Good and Evil, Dark and Light, God and the Devil.

The healers, enlisted on the side of Life, eventually evolved into two complimentary professions of doctors and priest/pastors. I believe that the time has now come when increasing efforts are required to bring together the two groups of practitioners who have on occasions been seen as rivals. In the worst cases clergy or 'pastors' have wanted to magnify their status by advocating 'spiritual healing' over against the medical remedies, and the medical world has repudiated the 'mumbo jumbo' of religion. This however is to institutionalise the Mind/Body split that characterised the Cartesian world-view. It may rather be argued that for a priest to anoint a patient before an operation or to administer Communion may introduce a positive dimension which makes its own contribution to healing, adding to the surgeon's skills, not vying with them. Unless this partnership is properly acknowledged, there is a danger that when scientific medicine has come to an end of its resources patients or relatives will be tempted to resort to magical remedies 'just in case'.

This however to import the split to the area of the sickbed, pitting the priest/magician against the doctor/scientist. The healthier option is to look again at the make up of the human person as an interacting system of body, mind and spirit; and try to discern which part lies behind any particular set of symptoms and then see what the appropriate response might be.

The diagnosis of bodily pain begins with a search for the physical cause. Then comes the question of the contribution of the mind. At a stage further in this complex is the belief system within which the sufferer lives and uses to interpret experience. Is life for him or her a series of random events which may appear to have a mixture of chance, choice and ability, or is there behind them all either an overall plan or another dimension from which help may be sought or derived? This is a world into which we can make our entry by supernatural or non-scientific means, which can be described as either magical or spiritual. These however are quite distinct ways of operating. Magic is about manipulating objects, events or people by a spell. The spiritual way is primarily through prayer which brings some kind of influence to bear on a person or situation but in a non-prescriptive form. This is not always understood. When we have treated a patient to the best of our ability, when we have thought whether there is resistance to getting well and sought to help him to explore this, then there remains the power of a kind of prayer that does not dictate any specific outcome to an illness, but simply lets the distressful situation come to rest with a Wisdom that is way beyond our own and can discern outcomes that we could never imagine. Rather than prayer on the lines of 'Lord, make her rheumatism better' we should seek simply to 'move her into the light'. What does become important is to have confidence that 'all shall be well'. It comes out of the personal faith of an individual but also from the culture of a religious belief. A propensity towards healing is part of the human condition. Wounds heal, broken bones mend, we grow through some forms of mental illness, forgiveness is an expected outcome of conflict. It does not always work, but there is a bias towards a good outcome. Although the language of prayers to saints and belief in the ministry of angels is not in vogue in a secular environment, it carries a sense that in the struggle with pain we are not alone, and we are on the side of a total system that carries a bias towards restoration. I treasure Jung's remark that he had had 'clinical experience of angels'

The existence of a transcendent world around us was the theme of a book by Peter Berger entitled 'A Rumour of Angels'. In it he draws on the experience of a mother comforting a child crying in the night with "its all right.....it's all right" – suggesting a sense that the universe is on our side, and that beyond her love is lots of other love.

Such examples of transcendence from human experience are the signposts by

which it is possible to discern a bridge between the two poles of a loving God and a world of pain. It is not an argument to be won in favour of this side or that. It is instead a way of finding the golden thread which runs through the total human history and makes it possible to hold together the contradiction. It's not simply an argument to be evaluated intellectually. It is something lived out in the hope, the tenderness and the dedication of all healers of body, mind or spirit. We keep on doing our jobs in spite of tiredness, stress and failure because of the sense that it is worth doing and that we are on the side of something bigger than ourselves. We are the witnesses by our practice, holding on against the temptation to give up, entering into the pain of others, believing in them when they have ceased to believe in themselves. Maybe few of your patients would use the language, but on the ward rounds or in the consulting room you are for others an icon of the supernatural world, concrete messages of the love of God. "If he or she is around, I too can hold on". It is an awesome responsibility.

The Pain that is Shared

In Michael's contribution to our meeting in 2007 about the world's religions, which he called "The Pain that is Shared", he started once again by acknowledging the apparent utter hopelessness involved in some forms of suffering such as the Alzheimer's patient in a psychogeriatric ward who can only endlessly repeat: "I want to go home....I want to go home...." – and there's nothing you can say to this. No religion, no prayer – nothing can resonate; there's just this sad lost person. We go through life and there are tears surrounding our death because it is loss – the letting go of many valued relationships and loss of those who are gathered round them. We start with tears and we end with tears. What sort of faith justifies this sort of existence?

Religion is socially useful partly because people have seen it as a way of dealing with guilt and sin ("we've earned this for ourselves") and partly, because society has been suffering, as a form of social control: whether it's putting people in prison or threatening the pains of hell.

He subtitled his talk "The dangers of singing the wrong hymns" such as Mrs Alexander's "There was no other good enough to pray the price of sin" to express the popular myth of the Cross as satisfying a God whose justice is a demand for recompense. A much better way of looking at the Incarnation was expressed by Irenaeus: "The Son of God became the Son of Man so that the sons of men could become the sons of God – it was a divine exchange; He made His home among us so that we might forever dwell in Him", thus making possible a restored relationship – the broken covenant between man and God is thus restored, but not by paying a price."

Another hymn dating from the 18th century contains the line: "sad were our lot, evil this earth, did not its sorrows prove / the path whereby the sheep may find the fold of Jesus' love": We come back to God through the pain. This perhaps should be seen in the context of the 1755 Lisbon earthquake in which all the churches were destroyed. The same question "where was God?" arises when we think about the slaughter of WW1 or the Holocaust. There is a story of some Jews in Auschwitz who staged a trial of God and eventually pronounced him guilty; then the senior rabbi said "and now it's time for prayer". The worship, the transcendence is there as much as the struggling with the history and the facts.

We need stories to make unbearable things manageable. That seems to be the point about much theology. But then the theory – the story - gets messed up. We take it on board as part of our background thinking and use it as a way of dealing with unbearable things; this applies to much of the content of the Old Testament, and perhaps contributes to the confusions provoked by singing the wrong hymns. [Or as

memorably expressed by another friend of mine in his address at my wife's funeral: "If the stories are allowed to harden into doctrine they lose their illuminative power"]

We're faced with the facts of suffering – they challenge us. We have deployed all sorts of ways of intervening and reducing the suffering and yet we haven't really come to terms with it. Is it something we ought to be seeing as character-building ("no gain without pain") - pushing on through the pain barrier in order that we might learn to live more obediently to God? Or is it something over which we must stand up and wrestle with the creator of this painful world, as Sam Lebens told us was at the root of the Jewish approach? Or is it a way of learning to put aside wrong things and mistakes and instead become more human, more compassionate. It challenges us not to bear but to obviate – to take away.

Poetry and Pain

Michael had a great love of poetry and was a great advocate of poetry, along with storytelling, as a means of trying to communicate when understanding fails. He was a poet himself and has written – in my opinion – some of the best religious poetry since George Herbert. His last, and perhaps his most memorable contribution was a sort of epilogue to the 2008 meeting, on poetry and pain.

Medicine and science, he suggested, were about mastering things, whereas poetry seems to be giving space to the unmasterable emotions. It seems we need both in treating the phenomenon of pain. Looking to poetry as a way in which emotions are expressed he thought of the different kinds of emotion that pain evokes in us and what we need.

First of all there is the protest that comes with pain – the need to complain. That's there in *A Poison Tree* by William Blake, about anger:

I was angry with my friend:
I told my wrath, my wrath did end.
I was angry with my foe
I told it not, my wrath did grow.

And I water'd it in fears,
Night & morning with my tears;
And I sunned it with smiles,
And with soft deceitful wiles.

And it grew both day and night,
Till it bore an apple bright;
And my foe beheld it shine,
And he knew that it was mine,

Arid into my garden stole
When the night had veil'd the pole:
In the morning glad I see
My foe outstretch'd beneath the tree.

Who is the foe? Sometimes it's the physician that doesn't come up with the answer - expecting him to be the scientist who knew exactly what the pain meant and how to cure it. Or sometimes it's the god, as in Elizabeth Barrett Browning's poem *A*

Musical Instrument about the great god Pan, who makes a musical instrument out of a reed, and plays it:

Sweet, sweet, sweet O Pan!
 Piercing sweet by the river!
 Blinding sweet O great god Pan
 The sun on the hill forgot to die,
 And the lilies revived, and the dragon-fly
 Came back to dream on the river.

...and then the question: why does it have to be first the pain, and then the effect – to get the beauty?

Yet half a beast is the great god Pan,
 To laugh as he sits by the river,
 Making a poet out of a man:
 The true gods sigh for the cost and pain
 For the reed which grows nevermore again
 As a reed with the reeds of the river.

It's somehow an understanding of pain that says it's got an outcome – it's a cost you have to pay to get the music. It may be a kind of natural pattern, but why is it made like that? Where is the justice of God who makes beauty out of pain? Why does it have to be this way? When we try to help people in pain or with a terminal illness what can we say to them that actually helps make sense of things and have some kind of story which gives them hope and enables them to cope? There is certainly an ability to be angry about the injustice but also there is the value of compassion.

Blake again, in *On Another's Sorrow*:

Can I see another's woe,
 And not be in sorrow too?
 Can I see another's grief,
 And not seek for kind relief?

He doth give his joy to all;
 He becomes an infant small;
 He becomes a man of woe;
 He doth feel the sorrow too.

Think not thou canst sigh a sigh
 And thy maker is not by;
 Think not thou canst Weep a tear
 And thy maker is not near.

O! he gives to us his joy
 That our grief he may destroy;
 Till our grief is fled & gone
 He doth sit by us and moan.

Here is God suffering human pain and taking it on board; allowing a new relationship to overcome the anger at the injustice – God taking responsibility for the injustice and pain. That's a coping story and all the other religions have their coping stories. For the terminally ill it provides a view that there might be something beyond – a faith statement.

The experience of depression is expressed in the Gerald Manley Hopkins poem /
Wake and Feel the Fell of Dark:

I wake and feel the fell of dark, not day.
 What hours, O what black hoürs we have spent
 This night! what sights you, heart, saw; ways you went!
 And more must, in yet longer light's delay.
 With witness I speak this. But where I say
 Hours I mean years, mean life. And my lament
 Is cries countless, cries like dead letters sent
 To dearest him that lives alas! away

To feel that someone as devout, as caught up in the world of faith, and can also write poetry, who stands alongside you in your depression: it gives you a voice

Here is Hopkins again, reminding us of that sheer awfulness of pain (both mental and physical) in *No Worst, there is None*.

No worst, there is none. Pitched past pitch of grief,
 More pangs will, schooled at forepangs, wilder wring.
 Comforter, where, where is your comforting?

“And so I wanted to look at the pain that needs expression to cope with it: somebody finding words that they can share with me. Not just imagining unspoken things, but finding words that will incarnate them and enable me as a counsellor and priest to work in a world where we no longer have any easy scriptural references.

If we are to connect with a person we have to know what their question is; and I sometimes wonder if we should be more concerned with what the patient is asking because if I'm answering my question I'm not answering theirs. We've got to be communicating well enough to know what the question is, and speak to that condition rather than tell a story whose meaning is beautiful and let the words take over from us, and even become a kind of game, like Humpty Dumpty telling Alice in 'Through the Looking Glass that "words mean what I intend them to mean – I pay them".

Language can be a great blocking off - a way of flight from engagement because if I can say something I don't have to engage nearly so closely. There are lots of ways of blocking people off: when as a young hospital chaplain I was rushing round the wards in time to be back for Evensong, I'd say 'how are you' and they'd begin to tell me – and then I'd realise that this was going to be a long story. And then I'd feel as if I had a kind of stopwatch in my pocket. And I could see the person look very wretched - he asked but he didn't bloody want to know... I used to do it when I ran the diocese and people asked difficult questions which I'd manage to shift on with a bit of theology and they wouldn't be helped and neither was I – but I'd got out of it. Language which blocks is so easy a tool for avoiding the pain of direct clear communication.”

So helping people to cope is first of all giving them a voice, but we can only give them one out of our own understanding. We have got to have some sense of empathy with their feeling – their needs – and then sharing it, working with it - taking it apart so that we don't have to look directly at their pain but at this thing on a side view that they can relate back. For some people it used to be words of Scripture and for some it still is, be it the Qur'an or the Bible.

The sense of searching is expressed in the poem by an anonymous author, *The Rabbit*:

I hear a sudden cry of pain
 There is a rabbit in a snare;
 Now I hear the cry again,
 But I cannot tell from where.

And I cannot find the place
 Where his paw is in the snare:
 Little one! Oh, little one!
 I am searching everywhere.

We live in a world that carries so much pain and tragedy. We have the sensitivity that hears the cry of pain. And what do we do about finding something to help with? That's where those of you that have delved deep into pain can help society. We're not a very compassionate society – oh yes we write our cheques and put money into emergency aid - but you have thought deeply about this. You've got a tremendous educational function.. We have all sorts of allies in this business of education and helping people to cope with what you have seen deeply, by engaging with the human experience of pain which needs to be shared, not just among doctors but in society.

Discussion

Michael talked about failing to give his time when he was running late and this is a real problem when managers want you to fit in as many patients as possible in a session. You may have to let it run over but this will mean patients waiting. The only way round this is to think together with managers about what the clinic is for. In the pain clinic the first appointment should usually be not less than hour, and the patient has a golden minute where you shut up and listen when the patient may voice what they have actually come to see you about and in they may talk about suffering rather than pain and you may be the first person to listen to this. This may not fit with a policy of doing lots of interventions to generate income.

As well as listening and giving people the opportunity to tell their story it is important for them to have an empathic understanding of the practitioner's point of view so as well as being heard they are being understood and knowing that we get it is therapeutic

One of the other speakers in the meeting on religion and suffering (Elaine Palmer) talked about the need for spiritual care in a secular society.

We live in a scientific age when people are not allowed to have a spiritual side. We've brought Cartesian dualism into health care which has become fragmented with highly specialised people who can't see beyond their own little area.

The science and faith interface is something that has fascinated and intrigued me. John Polkinghorne is a physicist as well as a priest. One of his contributions to the vexed question of suffering in a world created by a God of love is the 'free process' argument. We are all familiar with the freewill argument that a God of love wishes us to respond with love out of our own freewill to God and one another and failure to do so explains why a lot of things have gone wrong. The free process argument suggests that God did something more clever than make a world according to 'His design'; instead he made a world capable of making itself. This free process has allowed us to be sitting here today; human beings have evolved who have conversations like this. This process has obeyed the laws of nature and been absolutely true to whatever were the founding principles, so to speak, of the creative

process; and these laws involve a lot of experiment and diversity - the survival of the fittest and the rest of it. It would not have been possible for us to be sitting here and having this conversation if it were not for the freedom given to the creative process out of which it has been possible for us to emerge. I think it was Polkinghorne who made the analogy that the chances of this happening and us being here today are as slim as the possibility of getting the recipe for a cake correct to one grain of sugar in a cake the size of the sun.

Regarding this question of time, and the time we give patients and to relationships: we live in a society with an obsession with speed. In order to have deep intimate relationships that may make a difference, you need to know what the questions are but for this you need deep intimate relationships. But the deeper you get the slower you have to walk, like trying to walk in deep water, and to walk quickly you have to get superficial. One of our challenges is that we work in a superficial NHS with patients who require deep relationships.

Regarding the theodicy issue, I think part of the problem is the different way we define love. Maybe we have a very sentimental romantic idea of love rather than what Christ showed through his passion that love is accompaniment, love is coming down to the very lowest place that you can possibly come to, which isn't romantic or comfortable or exulted. So if you turn the concept of love upside down then there is no contradiction; it's the accompanying in the catastrophe that can redefine love, and physicians can do that in an amazing way whether it's through death and suffering and irremediable situations.

In the book *The Story of Pain* by Joanna Bourke she contrasts compassion with empathy. With empathy you feel the patient's emotions; with compassion you sympathize with the patient without actually feeling their emotions.

I don't think that is true.

One is accompaniment, the other is getting lost in it. One leads to burnout, the other...

Empathy requires a certain degree of understanding and discernment of what is going on whereas compassion is coming alongside and sharing the suffering.

I think we have to appreciate that some people don't believe in God. I'm reminded of a patient that I had seen over several years who had had an amputation after an injury in the second world war and had been taken to a prisoner of war camp and a priest came and said "now we need to pray". The man said to himself "he bloody thinks I'm going to die" and because he didn't believe in God it gave him the determination to get better and live the rest of his life, and the courage to face the amputation. I listened to his story with some empathy and I hope compassion and he lost the phantom pain from which he had suffered for 40 years. I was very impressed with his passion about his inability to believe.
