



THE BRITISH PAIN SOCIETY

Special Interest Group for Philosophy and Ethics

The Ethics of Care

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Further information and acknowledgements

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To find out more about the British Pain Society Philosophy and Ethics Society Special Interest Group (SIG) visit:
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Introduction

Peter Wemyss-Gorman

Although most of us would agree that our attitudes to our work and our patients must be underpinned by awareness of the need for care, perhaps rather fewer of us may have paid much attention to the philosophical basis of Care Ethics. Realisation of the importance and relevance of this topic to the entire practice of medicine led us to choose it as the main theme for our 2012 meeting.

Only our first two speakers addressed the subject directly, but although our other contributors spoke on a variety of unrelated topics our perception of the universal importance of Care Ethics was reinforced by the way in which the concept of care kept cropping up, either explicitly or implicitly, in their talks and our discussions.

We also became painfully aware of how often the many failings of the health and healing professions in recent times could be attributed to loss of an ethos of care – not because their practitioners are essentially uncaring but because of the many financial, organisational and other pressures that impose other priorities, and of the difficulty of integrating biomedical science with care of and healing of the whole person. We determined that our next conference in 2013 would be devoted to exploring the means of restoring a culture of care to its proper place.

Editor's Note:

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

Ethics of Care – a man on a silver moon

Bryan Vernon

“[The Ethics of Care]...exemplifies an approach to ethics which is grounded in the experience of women, just as traditional ethics has been grounded in the experience of men.”

I was very much attracted to this group as you are still thinking and working things out. Much of my main job involves teaching medical students who often *know* what is right and I'm working on the basis that you don't!

A Silver Moon?

A lecturer I once invited to Newcastle told me that titles are designed to attract or intrigue audiences rather than to inform them about the content. This enigmatic title does both, but probably only for women of a certain age with a knowledge of bookshops on Charing Cross Road in London. Let me explain. In 1985 my wife had discovered the author May Sarton. As her birthday was imminent and I happened to be in London, I thought I would buy some of her novels as a present. I bought them at the Silver Moon Bookshop on Charing Cross Road. Only later did I learn that I had been lucky to be allowed in, as this was a feminist bookshop where men were generally unwelcome as members of an oppressive and powerful group. I think that the person who told me this *might* have been teasing – but the looks I was getting were the same as if I had walked into a ladies toilet. The Ethics of Care has been developed by women, on the whole: on this occasion I am aware that I may be blundering in as a member of several oppressive and powerful groups – male, middle-class, white, paterfamilias with six grandchildren and an Anglican priest to boot. Having established my credentials let me tell you what I plan to do.

Introduction

First I should say that, although Gilligan, Noddings and other feminist writers characterise the approaches of men and women to ethics as being different, they do not claim that all women avoid analysis and universalisation of ethical principles, nor are they denying that men may see moral problems through the lens of caring. However, because a large number of women explain their ethical choices in what Gilligan calls a 'different voice', it seems reasonable to adhere to these stereotypes in what I am going to say. But when I talk about women and men these are broad generalisations and don't necessarily work entirely.

First I shall sketch out what I understand to be the Ethics of Care. I shall rely heavily on Carol Gilligan's work *In a different voice* and *Caring* by Nel Noddings. As a man trying to share what women have said this may be a flawed approach. I have read Roddy Doyle's amazing novel on domestic violence *The Woman who walked into doors*. This is told in the voice of a woman so I know that it is possible for a man to represent a woman's voice - the different voice of Carol Gilligan.

I am on surer ground with what I plan next, which is to give a man's reaction to the Ethics of Care, but then go out on thin ice again when suggesting what scope there is for some alignment between systems which Gilligan and Noddings characterise as male and the Ethics of Care. But as the end of a talk is a good time to go out on thin ice I want to initiate a real discussion in the discussion time rather

than a question-and-answer session with an 'expert'. (A category I am very wary of: we are all rather good at living other people's lives for them because we don't make their silly mistakes in our imagination of what it would be like to be them)

Kohlberg's stages of moral development

Kohlberg claimed that moral development is a six-stage process:

Stage One is the 'punishment and obedience orientation'. To avoid the pain of punishment children do as they are told. Obedience is central and rules are absolute.

Stage Two is more reward centred: the self-interest orientation. Based on the notion of reciprocity - scratch my back and I'll scratch yours - children meet others' needs only if others meet their needs. The question is 'What's in it for me?'

Stage Three is the 'good boy, nice girl' orientation. Adolescents adhere to prevailing norms to secure others' approval and love. The perspective would be that of the family, community or peer group.

Stage Four is the 'law and order' orientation. The focus is on developing a sense of duty, deferring to authority figures, and maintaining the social order to secure others' admiration and respect. A person sees himself as a member of the wider society.

Stage Five is the 'social-contract' orientation. Adults understand that there are different views of right and wrong, but that law is a social contract based on majority decisions where there has been some measure of compromise. They reason about the principles which underlie norms and laws.

Stage Six is the 'universal ethical principle' orientation. Adults adopt a Kantian moral perspective that transcends all conventional moralities. They are no longer ruled by self-interest, the opinion of others, or the fear of punishment, but by self-imposed universal principles regardless of what official rules and laws are.

Kohlberg observed that women tended not to reach Stage 5, and often not even Stage 4. You might therefore conclude that women are not all that good at ethics and that ethics is really for men rather than women. Actually you probably won't, will you, and nor do I.

Feminism and ethics; gender differences in approach

Gilligan writes: 'When one begins with the study of women and derives developmental constructs from their lives....the moral problem arises from conflicting responsibilities rather than from competing rights and requires for its resolution a mode of thinking that is contextual and narrative rather than formal and abstract. This conception of morality as concerned with the activity of care centres moral development around the understanding of responsibility and relationships, just as the conception of morality as fairness ties moral development to the understanding of rights and rules.'

Alison Jaggar has an interesting critique of rights from a feminist perspective: 'The concept of rights was central to the emergence of western feminism but it is part of the same modern ethical tradition that received so much feminist criticism in the 1980s. Building on Marxist and anti-colonialist critiques, some feminists contend that rights are the discourse of the dominant, so infected by their bourgeois, masculine

and western origins that they are incapable of articulating a deep challenge either to local forms of male dominance or to a scandalously inequitable world order. Feminist charges include the following, for example: the right to privacy obscures domestic violence and the right to freedom of expression justifies misogynist pornography.'

Because women are not similarly situated with men, granting them formally equal rights often produces inequalities of outcome; for instance, the advent of no fault divorce has thrown many ex-wives — but not ex-husbands — into poverty. Attempts to avert such outcomes by granting women 'special' rights, such as maternity leave, inevitably backfire in a cultural context that conceptualizes equality as sameness. Special rights stigmatize women as inherently sexually vulnerable or as less reliable workers. At an institutional level, if you appoint a married woman of 29 without children, it could go through your head that they might actually not be at their place of work for next 30 (or 40) years.

Legal equality of rights may obscure inequalities of power to exercise them. The procedures associated with claiming and redressing rights are often degrading, intimidating and humiliating for women; this is especially evident in rape and sexual harassment trials.

Women may harm themselves exercising their rights; for example, millions of women in the US alone have been harmed exercising their rights to have cosmetic surgery or to prostitute themselves. A focus on women's rights ignores the ways in which women's social situations often coerce their 'choices' to exercise those rights.

Finally, advocates of the Ethics of Care contend that rights talk is part of a morality more inherently adversarial than the more basic and important human values of interdependence, co-operation and trust.

Where a man will see the need for an autonomous decision, a woman is much more likely to see herself as a person who is caught in an intricate web of relationships. We are most fully human when we are in relationship rather than independent atoms making choices – quite a contrast to Sartre's view of the independent person making a choice. 'Infants are not self-nurturing, and no human being acquires language except through interaction with other human beings.' Relationship is central to who we are as people.

This means that the context in which a woman operates is important. She needs to know much more detail about a situation before she can decide what should happen. This thinking is much more concrete than abstract. Kohlberg's six-stage process does not account for this approach, and is therefore flawed because it devalues the experience of half the human race. In particular the Ethics of Care is attentive to the feelings of all those involved in a decision. Collecting all the data needed can be quite taxing and time-consuming.

Stories are a feature of writing on the Ethics of Care. Someone writing from a male perspective would tell a story to make a general point which could then be universalized. For instance I might tell the story of the Milgram experiment to show that people should not be an object of research without being made aware that they actually are. A story in the Ethics of Care tradition would stand by itself. 'Another aspect of care's particularity is that its conclusions are non-universalisable; that is, they carry no implication that someone else in a similar situation should act similarly. The radical particularism of care thinking challenges a fundamental assumption of modern ethical theory, namely, that appraising particular actions or practices requires

appeal to general principles.' (Alison Jaggar). However, moral relativism is resisted because you could not say that it is all right not to care.

Care and caring

Not surprisingly caring is fundamental to the Ethics of Care. Noddings talks, rather clumsily, of the one-caring and the cared-for. Kittay talks of dependency workers and dependents. This does not carry the meaning of caring. Another writer talks of caregivers and care receivers. This explicit inequality between the giver and receiver is an important feature because an Ethics of Care is committed to identifying differences in power relationships. These are important in the Ethics of Care. There is a commitment to avoid exploitation and hurt and a concern to ensure that humans flourish. It is not difficult to see the link between avoiding exploitation and feminism.

To care requires us to be receptive to the cared-for, says Noddings. 'I do not "put myself in the other's shoes" by analysing his reality as objective data and then asking, "How would I feel in such a situation?" On the contrary, I set aside my temptation to analyse and to plan. I do not project; I receive the other into myself, and I see and feel with the other....The seeing and feeling are mine, but only partly and temporarily mine, as on loan to me'. She calls this attitude to the other 'engrossment'. It could be called attentiveness. It is demanding, and makes the caregiver vulnerable.

Care is the starting point for ethical action. Noddings grounds this in the relationship of a mother with her child. At some point all of us have been cared for and can identify what it is to be a care receiver. It is this lived experience of mothering which is the root of the moral life. This grounding of the ethical in the private sphere causes some tensions for proponents of the Ethics of Care. Traditionally the private sphere of the home and the family is where women have encountered the ethical problems which they have had to resolve. This has led to criticisms that the Ethics of Care is too parochial, criticisms which have, it is fair to say, been addressed. 'Feminists argue that excluding the domestic realm from the moral domain is not only arbitrary but also covertly promotes masculine interests. For instance, by denying the conceptual resources for raising questions about the justice of the domestic division of labour, it obscures the social necessity and arduousness of women's work in the home.'

What is care? Tronto and Fischer define care as 'a species of activity that includes everything we do to maintain, contain, and repair our "world" so that we can live in it as well as possible. That world includes our bodies, ourselves and our environment'. Bubeck calls it 'the meeting of needs of one person by another where face-to-face interaction between care and cared for is a crucial element of overall activity, and where the need is of such a nature that it cannot possibly be met by the person in need herself'. This contrasts with service, where the service provider is doing something which the receiver could do for himself.

Care responds to others as unique, irreplaceable individuals rather than as 'generalized' others seen simply as representatives of a common humanity (Benhabib 1992). Such responsiveness requires paying as much attention to the ways in which people differ from each other as to the ways in which they are the same.

One criticism is that care can turn the caregiver into a slave, and reinforces views of the ideal woman as someone who sacrifices herself. Noddings counters this by saying that the one-caring can include herself among those for whom she cares:

indeed failing to care for herself jeopardises the care she is capable of giving to the cared-for.

Tove Petterson deals with another criticism of care ethics, that it restricts itself to individual cases:

“Care ethicists have the values, perspective and the analytical tools to identify actions and conducts which are promoting - or curtailing - care. But at the same time this normative theory is also disposed toward ignoring the social structures, or the big scheme of things, where the singular uncaring actions subsume. As the Ethics of Care focuses on the concrete, unique and singular, it detects harm easily overlooked from other perspectives.

Concentrating on the concrete other can nevertheless make it difficult to see the structures and pattern common to the individual cases and concrete conflicts. Political actions for care ethicists do not necessarily, or indeed not only, consist in bringing anecdotes, or the singular, into political debates. Based on the knowledge of particular cases, the care ethicist must also work to identify uncaring arrangements and structures. Failing to see the larger framework of uncaring action, or merely treating it as one of its kind, might conceal uncaring and harmful structures and the abuse of power.

A care ethicist would not be satisfied knowing only whether others enjoy rights and freedom. She wants to explore the totality of the relations—for instance by working to eradicate the causes of harm and organizing the daily lives of professions, society and the international community in ways that ensure and encourage caring relationships.”

This man’s response

I have to call what I am doing a man’s response, not just because it’s mine, but because it fits the stereotype given to men. I am trying to react to the Ethics of Care as a system, a method – and that means that I am in danger of using the wrong language – almost as though I had missed the point. Once this revelation hit me, I just wanted to give up writing this talk. However, I can’t accept that it is impossible for a dialogue between these different approaches. There will be several false starts, we will misunderstand one another, but the goal is to achieve some understanding and agreement about how to approach ethical problems which confront the whole human race, not just half of it. I should also emphasise that this is a man’s response. I don’t want to claim too much for it. It is also my response today. Having a settled response to ideas seems to me to deny the value and possibilities of an uncertain future. If I avoid inattentiveness on the journey back, I may be only two thirds of the way through my life, so my views may change.

Given that relationships and context are central to the Ethics of Care, I think it is fair to say that, as a man considering this method, I find that I feel under attack at times. I feel somewhat vulnerable as someone more accustomed to the comfort zone of principles and rights. I don’t seek sympathy when I say this: it is an important experience for a man, as this discomfort has been experienced by generations of women for whom male ethicists have packaged a system which they find uncomfortable.

I suppose it would be hard to justify an ethics of neglect or indifference. Care is certainly a warm and attractive word. A difficulty that I have, and it is inherent in the

Ethics of Care, is how to judge whether an action is or is not caring. I can accept that many actions take place in the belief that the one-caring is indeed doing that. There is a lovely episode in the sitcom *One Foot in the Grave* where Victor Meldrew has offered to drive a neighbour's son to the garden centre. When he arrives he finds him sat in a wheelchair, so he pushes him to the car, puts the wheelchair in the boot, drives to the garden centre and installs him in the wheelchair. Then he pushes him round the garden centre until they encounter someone in a wheelchair coming the other way. At this point he leaps nimbly from the wheelchair to let the other wheelchair user through. Victor Meldrew is completely shocked. 'I thought you couldn't walk.' 'Oh, yes, I can.' 'But you were sat in the wheelchair when I arrived and you've let me push you all round the garden centre.' 'Well, I didn't want to hurt your feelings.' 'My feelings? What about my bloody back?' exclaims Victor.

The emphasis that the caregiver should care is an important one. Do what I need because it is your job but with no concern for me and I will feel short-changed. On the other hand you may caringly do something for me which I actually don't want. You may remember C.S. Lewis writing in the *Screwtape Letters* 'She's the sort of woman who lives for others - you can tell the others by their hunted expression.' You may say that this is someone who isn't really caring because they are doing things others do not want, but if you cannot universalise and the test of the rightness of an action is whether the caregiver cares, I think this is a little thin. There are also times where mothering, which the Ethics of Care can idealise, feels like smothering for the care receiver.

I have started with a criticism because there is much that I think is valuable. The emphasis on relationships is vital. The autonomous self, free of constraints from others, seems more like a psychopath than a member of society. Women are much better at defining themselves in relation to others. Men have often defined women solely as appendages of men, so it is heartening that the Ethics of Care retains this emphasis on relating, when there is such a strong temptation to discard it. As I think of the ways that relationships have shaped me and given me space to become the person I am, I have to acknowledge weaknesses in the ideal of the autonomous self. The stress on relating came from women operating in the private sphere, but, when I think of the various roles I adopt at work as part of a team I can see that these are dependent on the roles played by others and my relationship with them.

I have always used Al Jonsen's definition of ethics as 'the moral limitation placed on power', which means that I welcome the way in which the Ethics of Care engages with the power relationships involved in the setting of an ethical dilemma. If you have ever had cause to complain to a bank, a mobile phone company or indeed anyone else who has taken money from you for a service they have not provided, you will see that this is not a conversation between two autonomous selves. The relationship between a health care professional and a patient is not an equal one either. Some models of partnership between doctors and patients can put too great a strain on patients. This can lead to the question 'what would you do, doctor?' which seriously wrong-foots junior doctors reared in an ethical tradition that champions autonomy.

I can see the importance of analysing any case in depth and being fully attentive to context and to the feelings of all those involved. There are occasions where it is possible to have an extended conversation about what should be done, but there are others where an immediate decision is necessary. Here I can see the value of rules and principles which can be applied and justified and then perhaps modified on later reflection. I could say more about the value of rules and universalisability: simply put, the question is when can rape be justified? I think that a proponent of the Ethics of

Care would say that it is never a caring act. In saying this, she is promoting care as a universalisable standard.

The Ethics of Care carries an imperative to act in response to another. This contrasts with, say, the components of a legal case of medical negligence where a duty of care must first be established. Some of its aims are similar to principlism. There is an emphasis on avoiding harm and on doing good – although I think it would be hard to found an ethical basis for medicine that did not include these two. The Ethics of Care can deepen what these mean by its emphasis on relatedness.

Concern for the particular is important, and this is what casuistry [the resolving of moral problems by the application of theoretical rules to particular instances, *OED* – it may also mean sophistry!] does so well. It distinguishes one case from another because of a morally significant factor. Each case is unique as each episode of care is unique – but it also shares many similar factors. Casuistry seeks to distinguish one case from another according to the relevant differences. The question I want to ask the Ethics of Care is why these differences cannot be explained in their system.

I am wary of the trump card in ethics. Insights come from a variety of systems of ethics. The Ethics of Care illuminates ethical debate. It is consistent with its method of being fully attentive to the feelings of all those involved that it be one of a number of approaches to ethical discourse that is used. It is a valuable addition to the ethicist's armoury – but it is not the end of the story. It exemplifies an approach to ethics which is grounded in the experience of women, just as traditional ethics has been grounded in the experience of men. We can choose to continue in these parallel universes or see how each can enrich the other in our attempts to develop an ethical approach for the whole human race.

Discussion

How do you reconcile this relationship-based Ethics of Care, which I absolutely agree with and is massively relevant to chronic pain, with an increasingly evidence based quantitative model of medicine?

I don't want this to be a question and answer session so I'm going to throw that one open ...

We are being told we have to do both – to stick to profiles provided by evidence-based medicine and at the same time to practice patient-centred care with its implied relationship basis although a lot of us including me find them incompatible. The ethical dilemma then arises when you say: you ought to be taking this or that will happen, and then the patient says no thanks I choose not to.

I wonder whether patient-centred care which as you put very nicely involves the idea that you analyse everything and then step into that patient's shoes implies a different sort of relationship...

You may be forgetting that the person opposite you is coming for advice – they haven't been sent by the government to sort out – they've come from their own free choice. I quite often (in general practice) see patients who are taking their tablet because they have been given no option and they are fulfilling QOF (Quality and

Outcome Framework¹) categories: you've had XYZ disease so I need to give you this medication so I can fulfil my QOF. You don't even have the chance to tick the box that says the patient has refused this – it's not concordant, not working with you. This brings us back to the mothering and smothering thing because I am forced by my employers into the smothering role – but I need to be able to educate my patients into why they should say no. I am thinking of Statins which have turned out to do much more harm than we thought...

That's change in the evidence base ... there was a distinguished Newcastle paediatrician who had done a lot of work with short stature. Had he lived long enough he would have seen evidence that his treatment was entirely inappropriate, and a lot of people thought thank God he never saw it – not that what he did was wrong as the evidence base at the time strongly supported it. I wonder whether you are saying that you present the evidence base but don't enforce it – does the care come in at that point?

If you care you can't enforce it.

But you want the patient to do what is best for them if there is good evidence...

It's more subtle than that: the technical evidence base is usually about hard outcomes, of stroke for instance, and the totality of life experience is way richer than that so it's valid for the patient to choose in an informed way a quite different pathway even if that increases the risk of stroke. I think that is caring.

I think it comes down to a power differential. Kitwood writes a lot about the power differential in any caring scenario. He did a lot of work looking at poor care in small units looking after patients with dementia. He listed all the ways in which people could be disrespected, abused and poorly cared for but technically they were being washed and fed and watered ... and there was the Panorama programme recently ... The way I like to look at it is through transactional analysis: 'I'm OK – you're OK', which comes a lot into medical relationships; it's the respect, not parenting them too much, being an adult to an adult, walking in their shoes, sensitively kicking it around, so that you're both OK, you've given it your best shot and they've pondered it with you...

But Bernd is saying that he can't do what Paul is saying, because although you can do this in secondary care, in general practice if the patient says I don't want to take the tablets he not fulfilling QOF.

... it looks as if the patient is 'disobeying' ... if you tick that box it seems really harsh...

...a 'difficult' patient!

Evidence-based care?

Evidence-based medicine (EBM) is also based on the idea that this is the gold standard, forgetting about populations and what might happen rather than on what actually will. You've been told to do it because ... you have to give them this tablet on

¹ The system for the performance management and payment of general practitioners in the National Health Service. See http://en.wikipedia.org/wiki/Quality_and_Outcomes_Framework

the stupid principle that everybody is going to respond, and one third of them are not or get side effects. We're hung up on this idea that EBM is somehow holier than the holy whereas there are huge holes in it.

In terms of what you are saying, is that because we aren't looking at all the evidence? Or not interpreting the evidence appropriately? It's quite scientific to go down the route, the implications, of what you are saying. There is an evidence base for doing that.

It's actually lack of scientific rigor. The cosmologists who are thinking of re-writing the big bang are constantly re-thinking their theories and redesigning their experiments – they are constantly re-interpreting and re-interpreting. But we seem to have got this evidence base that is somehow set in concrete ...

... and something like two out of five of new drugs are found after a few years not to be effective. That is part of the evidence you bring to bear: that there is so much more uncertainty in this area. I find sometimes in the medical school that it is wonderful that this is the case, because there is this idea that you have a totally solid foundation of science-based evidence, but that's only where we happen to be at the moment. All I have been saying is where I am at the moment but I hope I will move on, otherwise the prospect of growing older is a bit grim if I've got it all sorted out now! You can say that in an ethical/philosophical area and that seems OK, but we haven't got a sufficient critique of knowledge as it is at the moment to say, well, it is fragile to the future, and that's great. That's why we put money into research because there is still more to know.

I think we're all assuming that there is an answer to find – an objective answer about individual patients' experience. There is an evidence base but we're never going to find out what that one person wants - we're barking up the wrong tree if we're trying to find objective truth – it might exist for planets but ...

There is also a kind of arrogant assumption that the opinions and conclusions we come to are based on all the best available evidence. What used to be called the art of medicine is assuming that that is the case but somewhere we have to put some of our own knowledge and experience and intuition which is not evidence-based and may be at a sort of subliminal level before we come to a conclusion. That may not fit with the scientific evidence because we are actually looking at a much bigger picture.

I'm starting to plough through two years of data from a pain management programme in a very deprived area of South Yorkshire. We've used a well validated and reliable questionnaire and also our own qualitative assessment. It's extraordinary to see how badly we're doing on the quantitative measures – we're showing precious little change at all – but, coming back to care, the qualitative evaluations show that they love it – they love us – more please! We have affected no change but we are perceived to be caring, open, listening ... Somebody was talking about power disparity and we like to think that we are open and caring people as well as good clinicians in that it's not didactic, it's very interactive. When I looked at the quantitative outcomes with my psychology colleague it was: Oh my God ... on these measures they're going to close us down! When we looked at the quantitative measures I wondered if I had typed in the wrong information (one looked good and then I realised she'd given me the information the wrong way round!) The quantitative measures were yet another opportunity to tell us just how bad it was but the dissonance was so enormous. Qualitatively we're doing fantastically; yet we're not effecting any change.

But you are!

What were you measuring?

Oh, the usual things ... efficacy ...

Is it that we can't measure the things that matter? ...

... and you don't know what to ask - you may be asking the wrong questions ...

... but if the commissioners looked ... have we got anybody back to work and off benefits? There are a few people in work, one or two per group, tiny numbers, not good for the economy but great for them ...

There are other aspects of what we do in PMP's and pain clinics like evaluating symptoms ... they can come to you and their symptoms are recognised and appreciated ... you can't get rid of them because chronic pain is essentially chronic, you can't relieve a lot of distress but you can help people to live with it ...

Do you use a quality of life score? These will often show benefits ...

No, it took long enough to do what we did. But one of my colleagues decided he was going to devise his own questionnaire which has never been validated which involves looking at function, not something nebulous ...

But hasn't Tim hit this exactly on the head: what you are talking about is this narrative oriented relationship with the patient – you've really got into their shoes so they really trust you, so when you say I do understand you they take that in and it matters to them ... and that's not about measuring or any scale. That's a real lesson but it's not actually recognised in today's financially driven climate. That brings us back to the Ethics of Care – that's caring. Doing all these scores isn't caring, it's going through the hoops and pretending to care.

But is it just doing the wrong scores? If you look at A and E visits, for example ... What really came out of a recent study of arthritis was that for the first time for years they can walk upstairs which you don't measure but may come out in quality of life measures ... you can get a lot of information out of these but it's how you use the data.

'Selling' pain services

A political problem, when you're looking at commissioning, is how you sell your services to the commissioners. If you're selling it on the functional things you say you're not succeeding on they are going to have problems with your funding; but it depends on what you as a group think is worthwhile and what you think the patients are getting from your service, and so that is how you need to present it to your commissioners. If you are assessing all the wrong things but that's the only data you have to offer them ...

But isn't this colluding with the power hierarchical system whereby the commissioners are at the top with the power, we're their victims and the patients are our victims?

But if you are re-writing the targets for your programme you're not colluding, you're challenging; you're telling them what your clients need and deserve.

In the context of care ethics – is it right to expect something as rational and measurable as functional improvement ... it's rather like: we're giving you all this care, so what you owe us is a functional improvement ... it's the team's unspoken ...

... but is it a functional improvement or a change in your general wellbeing? People may say although my scores haven't improved actually I'm feeling much better ...

I was very struck by your emphasis on feelings. It seems to me that that is the core of it: you can't measure feelings and it seems to me that the answer to one of your dilemmas with quantitative/qualitative disparities about changing behaviour is that it is a non-question. The essence of what it's about is whether the other person felt cared for is, and you can't measure that.

The only measure you could have of that is what they say ...

You can't put a number on that and it's idiotic to try.

We were talking earlier about power and the traditional medical system, and pain management versus intervention. At one time I was thinking that the management approach was mine and I've often been critical of the interventionists, but I have recently taken over a large number of patients from a colleague who injected everything, and all they wanted was to have that injection repeated. He hasn't cured their pain because they are still coming but they are being nurtured in a different way. The situation is made hugely complex by the nature of the clinicians and the patients' expectations ...

... but the injections were probably a ritual – part of ritualised behaviour ...

There is evidence that what patients expect influences their outcome. We don't pay enough attention to that. If they are not expecting evidence-based medicine no amount of it is going to make any difference.

To come back to the pill story: the doctor/patient interaction is really complicated to the extent that the moment I give a pill for high blood pressure I'm physically making this patient ill because before that they lived with high blood pressure for years but they weren't actually ill. Now every day when they take their pill that's a negative reinforcement: I must be very ill because I have to take this pill for it - and I wonder, if they believe in this pill, will they have a positive placebo effect or the negative effect of making them more ill? So I've stopped pushing pills but saying you only have to take this drug if you really want to but it is very difficult. I'm trying to work on the concordance model rather than the compliance one but I'm highly aware that whatever intervention in the form of a clinician sits there we change the whole construct in front of us which the patient brings by giving them something.

Cum Scientica, Caritas: a common ethos for science and care?

Jeremy Swayne

“Is there something fundamentally incompatible between the ethos of science and the ethos of care? Or is it the present day *application* of science that is inimical to the ethos of care?”

I'm delighted to find that my talk follows on so well from Bryan's. I especially want you to keep in mind what he said about the female/male dynamic in ethics which is relevant to what I'm going to say. I hope to provoke continued discussion from where we left off; not a question and answer session, principally because I don't know the answers.

Ethos and ethics

It seems to me that we cannot discuss the ethics of any human activity unless we are clear about the ethos that underlies them; about the fundamental importance of ethos in establishing ethical principles. And surely there cannot be any field of human activity in which this is more important than healthcare and medicine.

Last year I spoke about 'the gradient of the virtues' in medicine; our ethical and moral principles. Clearly, our place on that gradient is determined first and foremost by our *ethos*. Our ethical decisions will be derived accordingly.

The current definition of *ethos* in the Concise Oxford English Dictionary is: 'The characteristic spirit of a culture, era, or community as seen in its beliefs and aspirations'. An earlier definition was: 'The prevalent tone of sentiment of a people or community; the genius of an institution or system'. The word 'genius' here refers to 'The tutelary spirit of person, place or institution', where 'tutelary' means 'serving as a guardian, protective'. In its evolution from Ancient Greek through Latin, (*ethos*) became the origin of the modern English word *ethics* - the moral principles governing or influencing conduct (COD).

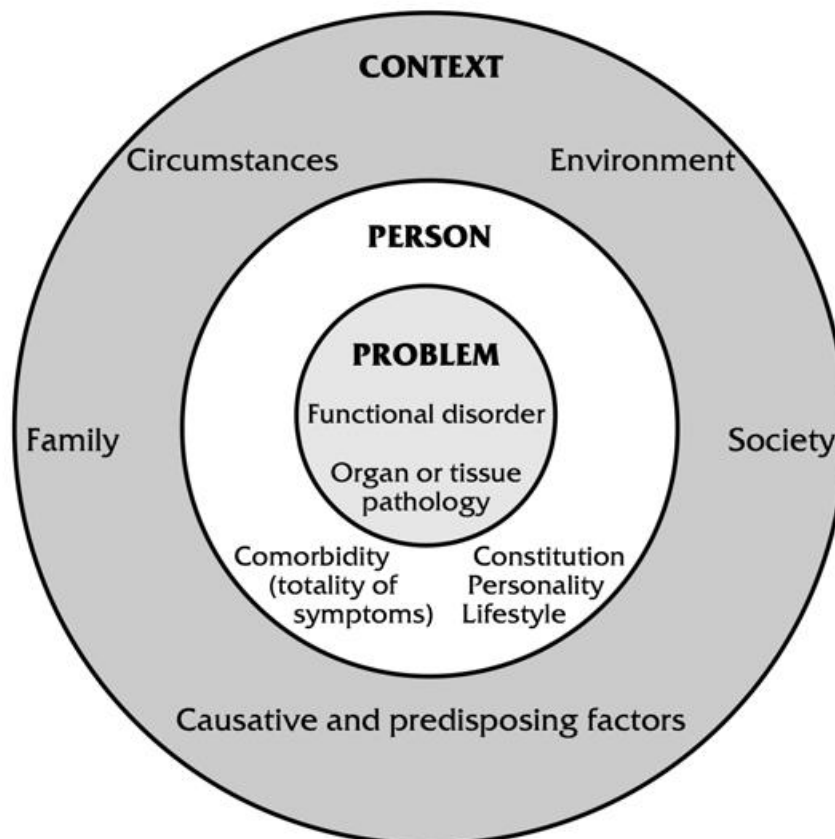
The massive BMA guide *Medical Ethics Today* observes that the original Greek and Latin expressions for 'ethics' and 'morals' conveyed the same idea of a code of conduct acceptable to a particular group. The modern discipline involves adherence to a traditional set of so-called 'Hippocratic' virtues', but that they often need some interpretation; critical reflection about 'norms or values, good or bad, right or wrong, and what ought or ought not to be done in the context of medical practice; a search for morally acceptable and reasoned answers in situations where different moral concerns, interests or priorities conflict, involving critical scrutiny of the issues and careful consideration of various options. It is often as concerned with the process through which a decision is reached as with the decision itself². To put it simply, *ethics* are a process of reasoning, calculation almost, by which a decision is made about our treatment of or behaviour towards a person or group of people; *ethos* is the attitude, philosophy or set of values on which that calculation is based.

² BMJ Books. *Medical Ethics Today* (2012), third edition, Wiley-Blackwell: Chichester

The question

The question mark at the end of my title is not just a rhetorical device. It reflects my real uncertainty and concern about the prevailing ethos of science and care. It is the question that I am putting forward for debate; which will be amplified by the further questions that will punctuate my talk, and that I hope you will answer. My concern is that the ethos of science and the ethos of care have both become degraded, and that the essentially close and complementary relationship of *scientia* and *caritas* in medicine has been seriously weakened as a result.

Cum Scientia, Caritas is the motto of the Royal College of General Practitioners (RCGP), of which some of us here are members. Some members share my concern that the *scientia* of present day medicine is not conducive to the *caritas*; that the two are not always compatible; that our preoccupation with a very narrowly defined biomedical science has undermined our capacity for care. David Haslam, a past-President of the College, has expressed this concern explicitly in a paper with the title Who Cares?, in which he says, 'We use the medical model because the medical model is what we use, even though it may not always be appropriate'³; the medical model being of course the reductionist model of contemporary medical science. Iona Heath, the immediate past-president, echoes the same theme in much of her writing.



Illness is a very complex phenomenon, and the course of illness and treatment is fraught with uncertainty. Good science thrives on the challenge of complexity and the

³ Haslam D (2007), 'Who cares?', *British J Gen Pract.*: 987-993

constant presence of uncertainty, but does our prevailing medical science sufficiently accommodate those two inevitable companions of the precariousness of life?

Medicine's preoccupation with the biology of the disease, risks distracting us from the biography of the person that is both the essential context of the biological problem and essential to its solution. To borrow words from *The Tyranny of Health* by Mike Fitzpatrick⁴, there is a conflict between medicine's preoccupation with the biological imperatives and the attention due to the aspirations of the human spirit. Medical science is focused on those imperatives; the ethos of care is concerned with those aspirations.

Scientia and *caritas* are necessarily complementary in the repertoire of a healing vocation, if that is what medicine still is, and learning to do medicine requires a proper understanding of this. But is it properly understood that science must be the servant of care, and that *caritas* must underpin *scientia*? Are healing and vocation concepts that are seen even as relevant, let alone primary in the motivation of healthcare practitioners, and doctors in particular; and most importantly of teachers and students in contemporary medical education? How much has medical education and medical science to do with human values? This is not a new question. It was raised by Marshall Marinker in a paper presented to the Royal College of General Practitioners 40 years ago explicitly titled *Medical Education and Human Values*⁵. In it he identified the 'hidden curriculum' in medical education that degrades the student's capacity for *caritas*. His challenge remains valid today: What priority is given to the assimilation of an ethos of *caritas* in the education of today's and tomorrow's doctors? How adequately are these principles articulated through the behaviour and attitudes that underpin what it is to be a healthcare professional and that guide our ethical decisions?

If you have seen the film *Patch Adams*, you may recall the Dean's speech of welcome to the students at the beginning of the new term, which concludes with these words: 'It is our mission here to rigorously and ruthlessly train the humanity out of you, and make you into something better. *We're going to make doctors out of you!*' Is that caricature absolute alien to medicine today?

What *is* the ethos of healthcare: the characteristic spirit of our healthcare culture, of our healthcare community as seen in its beliefs and aspirations? Is there an ethos of care in medicine clear enough and strong enough to ensure that medical science is always its servant? Do the biomedical, and indeed the economic priorities that dominate clinical practice allow for the good intentions and humane perspectives that medicine aspires to?

Has medicine's ability to control and manipulate disease processes blinded us to the opportunity and the responsibility to heal? Is there something fundamentally incompatible between the ethos of science and the ethos of care? Or is it the present day *application* of science that is inimical to the ethos of care? And if there is conflict between the two, what can we do about it?

What *is* now the ethos of science? In EF Schumacher's words, has science for manipulation, which he says tends to degenerate into the search for power, subverted science for understanding, which leads to wisdom⁶; so that the 'problem' before us becomes a biological abstraction that can be reduced to a clinical target,

⁴ Fitzpatrick M. (2001) *The Tyranny of Health*, Routledge, Abingdon

⁵ Marinker M. (1974) 'Medical Education and Human Values', *J R Coll Gen Pract.*: 24:445-462

⁶ Schumacher E. (1998) *A Guide for the Perplexed*, London: Sphere

rather than a person with a problem that cannot be separated from the context of that person's life?

In Marshall Marinker's paper he quotes Jacob Bronowski's book *Science and Human Values*, published 50 years ago⁷. Writing about the human values which stem from the practice of science, Bronowski lists three: creativity, the habit of truth, and the sense of human dignity. Of these he says '...[they] are not rules for just and unjust conduct', in other words, they are not *ethical* principles; 'but are those deeper illuminations in whose light justice and injustice, good and evil, means and ends, are seen in fearful sharpness of outline.' So we might say they belong to the ethos of science. In the preface Bronowski asserts that there is also a fourth human value; one which does not stem from the practice of science but has its origins elsewhere. This he describes as the human value of tenderness, of kindness, of human intimacy and love. In these quotations I think we begin to see a prescription for the common ground that the ethos of science and of care should occupy which can be summed up perfectly by adapting a quotation from Iona Heath to the effect that at the heart of the doctor-patient relationship, any healthcare-patient relationship in fact, must be an experience of our shared humanity⁸.

Examples

Here are three examples of the problem as I see it. They illustrate first the difficult relationship between the ethos of care and the ethics of care and the problems that arise from the achievements of medical technology; second the dissociation of medical management from compassionate whole-person care; and third our ambivalence about expressing an ethos of care within our professional role.

Ethos, ethics, and technology

The first example is from a recent BMA symposium on morals and medicine. We were presented with the predicament of a woman in her forties in a minimally conscious state after suffering severe accidental brain damage; with spastic paralysis, incapable of independent movement, and unable to communicate, but with no other morbidity. The roles of the woman, her husband, and the doctor in charge of her care were brilliantly enacted in front of us.

Her husband and family were convinced that her life was one of suffering and had no quality at all; that artificial feeding and hydration should be withdrawn, and she should be allowed to die; and that this was what she would wish for herself on the basis of conversations about this sort of situation at times before her accident. By contrast, the doctor and care team maintained that she did show signs of response and occasional enjoyment to people and the environment; that her life did have quality and should continue to be supported artificially. The enactment was punctuated by brief interventions from relevant experts when issues arose, of ethics, law and palliative care for example, which were beyond the competence of the doctor to resolve.

There was then a debate involving the whole audience, during which a very wide range of questions were explored and attitudes to the patient's predicament expressed, at the end of which a vote was taken as to whether she should be

⁷ Bronowski, J. (1964) *Science and Human Values*, Pelican Books, Middlesex

⁸ Heath I. (1995) *The Mystery of General Practice*, Nuffield Provincial Hospitals Trust, London

allowed to die or whether she should continue to be kept alive. The audience was divided almost equally, with a slight majority in favour of continuing to sustain her life.

The *ethos* of care was unmistakably one of respect for life and human dignity, and deep compassion for the patient and all concerned with her. The process of ethical calculation was exhaustive. But the *ethics* of the situation remained controversial. The question remained unresolved; and in any case would eventually have to be argued in a court of law if a decision to withdraw life support was to be pursued.

The ethical problems and ambiguous role of science arise in many instances because of what medical technology can achieve at the time of a potentially fatal event when the longer-term implications and outcome cannot be foreseen; and then continues to make possible thereafter. And of course this applies in other situations of end of life care as well.

Science and technology have complicated and sometimes compromised the attitude, philosophy or set of values that constitute the *ethos* of care. They have made the characteristic spirit of our medical culture and of our healthcare community, their beliefs and aspirations, difficult to discern, and its tutelary spirit difficult to apply; not only in poignant situations such as this one, but in many everyday healthcare encounters. We have become 'confused.com', so that our conduct towards patients, which in most instances would never be considered unethical, can be difficult to reconcile with the *ethos* of care.

De-meaning medicine

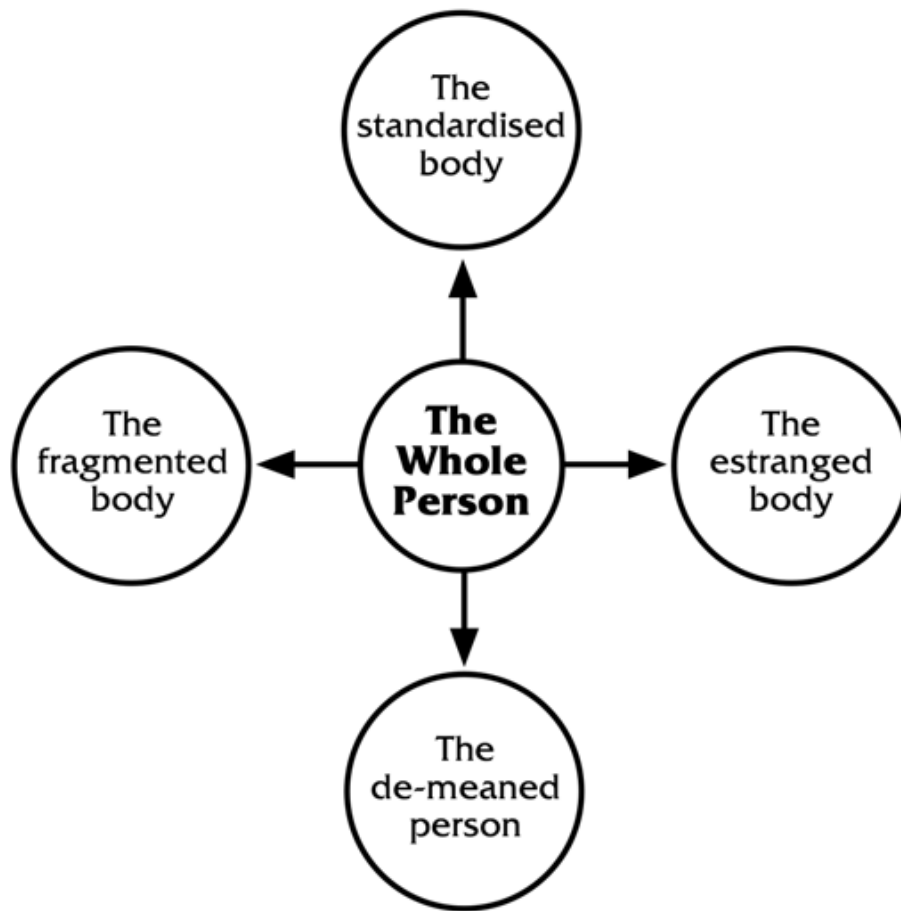
I expect Havi Carel will illuminate this dilemma more fully for us in due course, but my second example is in one of the quotations from Havi that I have used in my book *Remodelling Medicine* in which, among other things, I have tried to address this theme. In *Living with lymphangioleiomyomatosis* she wrote:

"This first person perspective became important to me. I felt that during my frequent dealings with the medical and healthcare professionals it was neglected. No one asked me what had changed in my life or what I had to give up because of my illness. Overlooking the lived experience of illness is a mistake because there is so much important knowledge to be gleaned from it – for example, that the most effective intervention might be helping the patient to regain their everyday life despite their illness. The ultimate aim of medicine is to help those who are ill regain their life, habits and activities. But it is impossible to do this without knowing about the patient's usual life and how it has been affected by illness⁹."

Howard Brody makes the same point: 'When sick I become a *different* person in that there has been a major remains the story of my one, single life'¹⁰. Break or change in my story, a break in continuity. But I am the *same person*, nevertheless, in that the story remains the story of my one single life.

⁹ Carel H, Johnson S, Gamble L. (2010) 'Living with lymphangioleiomyomatosis', *Br Med J*. 340 c848:148-49

¹⁰ Brody H. (1997) *Stories of Sickness*, Yale University Press: New Haven



James Marcum describes the harm that results from medicine's tendency to exacerbate that breakdown of a person's sense of continuity and completeness when it represents me or you (as in this diagram) as a *fragmented body*, reduced to its disordered component parts, a *standardised body* to which our body must be encouraged to conform, and an *estranged body*, alienated from the self, from the lived context of the illness, and from other people¹¹. Here the human values that Bronowski associates with science, and that we should associate with the ethos of care have certainly been degraded; with an effect on the patient that is literally *de-meaning*.

Empathy

In my first example, the prevalent tone of sentiment amongst the audience, the ethos of that community, its empathy for the patient, the husband and the doctor, the experience of shared humanity, was palpable. But it didn't assist the ethical decision, and the necessary resolution of the dilemma in a court of law was unavoidable. In the second example, empathy is either absent or completely discounted. We might assume empathy to be a core component of the ethos of medicine. But are we sure what we mean by it? I am prompted to ask because of a recent article by Daniel Sokol that is my third example. He spoke to this group a couple of years ago and writes very well in the BMJ about ethics, but I was troubled by a recent article in which he contrasts empathy, of which he is sceptical, with imperturbability, which he

¹¹ Marcum J. (2004) 'Biomechanical and phenomenological models of the body, the meaning of illness and quality of care', *Med Health Care Philosop*.7:311–20

commends¹². He says it is debatable whether empathy is a desirable quality for doctors. Quoting William Ostler, he suggests that the imperturbability that Ostler ranks higher than any other quality in a physician or surgeon is at odds with the modern focus on empathy. But in doing so I believe he creates a false dichotomy. He is certainly not writing about empathy as I understand it, because in contrast to the 'outward calm and reassuring coolness' by which he characterises imperturbability, he represents empathy as 'displaying outward effusions of emotion'. To my mind that is absolutely not what empathy is.

The identification with the patient's experience, and indeed with his or her emotional state, that constitutes empathy actually requires to be mediated by imperturbability in most instances. It is not the same as sympathy or kindness, which require outward expression. It involves a feeling response, but it is rarely best expressed by a show of emotion; certainly not effusive emotion. A respondent to Daniel quotes 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'¹³. It is a kind of insight and wisdom that helps 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 so healing.

If Daniel's view represents a prevalent misunderstanding of the nature of empathy, then our ethos of care has lost one of its core components. This compounds the knowledge that empathy diminishes amongst medical students on their way through medical school¹⁴; and the observation that, to quote from a letter to the BMJ, '(Although) empathy is often cited as a core value in the health profession, yet its lack in modern medicine seems to be widespread'¹⁵. [This diagram is a reworking of] a quotation from Bronowski: Compassion, Empathy and Kindness enhance Clinical Effectiveness, Health Promotion and Empowerment. I suggest it as a template for exploring the common landscape of science and care. The words are not intended to be comprehensive or definitive, and you may like to think of others to describe this landscape. It is a tentative mind map against which to set the questions I have raised and the examples I have given.

And as well as responding to those, I would like you to think about these as well:

In your own practice, how often is some compromise between science and care imposed upon you by guidelines, targets, cost implications, time, or other constraints, personal or institutional? Or by the misplaced expectations of patients, for interventions and outcomes that medical science and medical practice have led them to expect, and that have become a coercive influence on what we do?

When this occurs, how do you reconcile yourself to it; how do you cope with it?

And finally, if the concerns I have raised are justified (and you may not agree that they are), what do we, collectively, as a healthcare community do about it? How radical a change in the culture, how much remodelling of medicine and of medical

¹² Sokol D. (2012) 'How to be a cool headed clinician', *Br Med J*:344:e3980

¹³ Gilbert G. (2012) *Br Med J*.,344:e3980

¹⁴ Newton B, Barber L, Clardy J *et al.* (2008 'Is there hardening of the heart during medical school?', *Acad Med*. 83:244-49

¹⁵ Mercer SW, Watt GC, Reilly D. (2001) 'Empathy is important for enablement', *Br Med J*.322:865

education, is required to redress the imbalance between *scientia* and *caritas*? And how do we get there?

Discussion

Medical education

Regarding medical education and the focus on scientific medicine and leaving out empathy – do you think you and I were any differently taught?

No – my concern is that since Marshall Marinker was writing some 40 years ago not much has changed. The medical school curriculum has changed so there is much more emphasis on humanities, on problem based learning, patient centred care and experience of learning in the community. But talking to medical educationists, and indeed observing doctors, I get the impression that the biomedical imperatives dominate the process of *qualification*, and despite the changes in the curriculum people are not enabled to acquire the *qualities* that are required.

I disagree slightly with that: I think that what has happened is that the profession used to teach its own, but in the 1980's medical education fell into the hands of the educationists, and there has been a change. Against that, and at the same time, society has changed. We have a less caring society which doesn't recognise the qualities that perhaps should be seen in the profession. Thirdly we are now ruled within quite narrow limits by a managerial system which doesn't really understand what we do. I wonder if we can ever get back any control over how we train medical students in the right way.

I think you're right – but it's the postgraduate NHS environment that has changed. [When I trained] in Southampton in its early years all the Marshall Marinker stuff was incorporated into the curriculum, and we had education in primary care, integrated care in the second year and all that sort of stuff, and it was fantastically novel at that time. But I don't think it was that that made us the sort of doctors we are; we graduated into a system which is totally different from today. As well as all the rules etc. there are hugely different patient expectations, partly due to the internet ...

Selection criteria have changed dramatically. That may set a different mindset. How are we going to change from the science they have to do to get their three A's at A-level – it's so science based they can't afford any time for anything outside that very didactic teaching - how are we going to change medical schools where the reward system seems to support that sort of thing going on and on?

... I think nurses lost their vocation for care ... [inaudible]

A word Jeremy used briefly but hasn't come into our discussion so far is culture. Mike was talking about loss of the vocation of caring in the nursing profession – the change in culture. I don't know if I'm looking at the way things used to be through rose-coloured spectacles, and most of the things that you read in the papers involving failure of care are at a very practical level, but one gains the impression that the culture of nursing - I'm defining culture in this context as what is acceptable because everyone does it - has changed for the worse.

I don't subscribe to this sense of despair. I think it can be changed and it's up to us to change it. It can be done and it must be done. I come back to what Bryan said - and it's the essence of the argument in my book - that relationships are of over-riding

importance because we have created and colluded with a culture, a morality and a materialist concept of life which we can change only if we are willing to do so through the quality of the relationship we have with our patients. We have that opportunity and it's so difficult because of all the circumstances that we have identified but that is the start. The essence of any change has to come from within that shared experience of humanity with our patients. It has to come through establishing a quality of intimacy, trust and communication; that relationship which we have many times every day. That requires courage and it may involve rocking the boat. This kind of talk doesn't go down well with employers or when you're seeking a research grant. But we have to do it and we can use the relationship that we create with patients to introduce a new understanding of health and medicine – a new set of expectations. I believe it can be done: it will not be quick or easy but if we don't start it will never happen.

I agree with that but I don't think it's anything to do with medical education. Medical education for me is just a matter of giving kids five years to grow up a bit. (I'm a professor of medical education so I can say that.) We probably can do a bit better about not driving humanity out of them but you learn medicine after you qualify. What Mariker was pointing out in this concept of the hidden curriculum was that role models trump everything else. You can teach as much ethics as you like but if you see the other guy behaving unethically that trumps it. There is lots of evidence to show that. The key to it is not just the way we interact with outpatients but the role models of the junior doctors.

I took the quotation from Mariker from a paper in which he took it from a GMC document about tomorrow's doctors which talked about assimilating an ethos. And that is what role models facilitate.

Absolutely, and I think our starting point is for ourselves to try to be appropriate role models for the other people in the medical profession. Perhaps one of my most extraordinary experiences in medicine was when some ex-students that I had taught in Bristol came to see me to ask for some help 'because you were the only teacher we had who was kind to your patients'. That is a terrible indictment. But if a few of us are seen as being kind to our patients maybe that helps.

... That's true but the problem is that once you graduate you don't get enough time with [?] – it's very fractionated nowadays ... (partly inaudible)

But in spite of what Paul says the role models in medical school are still important. For my generation, all our teachers were physicians first; they may have ended up as anatomists or biochemists or whatever, and had adopted the philosophy of the profession. Nowadays the medical students I see [in Canada] are lucky if they see a doctor at all in a week! Psychiatry is taught by a psychologist, our anatomy by someone who has never laid hands on a living person. That makes a huge difference to the role models they have who have completely different agendas from the bumbling old professor who served in the war ... By the time they graduate it's already set in them.

I see medical students [in my GP surgery] to teach them about mental health. I get patients in for them to talk to so they can learn about anxiety and depression etc. I have a really hard time in getting them not to interrogate the patients to the n'th degree and reducing them to complete blubber but they had to do it because they needed to fill in their log book and score their points. It was dehumanising them. But they did get quite good at it by the end. I was quite upset by this and did bring it to one of the UEA [University of East Anglia] tutors' groups and the answer was - oh,

you're just inviting the wrong patients in. That was from a psychiatrist who was writing the curriculum. It was almost as if he was deliberately teaching them to injure.

I wanted to put in a lone voice from the nursing profession. Going back to issues about whether nurses are less caring I don't think that's true. I think we have suffered as medicine has suffered from a media image of what it means to be a nurse. We suffered very much from an idealised one and now the media has swung entirely the opposite way. Nurses, like doctors, are human beings. Most nurses come into the profession with an ideal of what it means to be a nurse, in the same way as medical students, but when they come face to face with the reality of managerialism, processes, pressures to behave in what is seen as a professional manner ... it's a common problem ... when we talk about the relationship of doctors and nurses with patients and between nurses and other professions ... this is not a hub with the patient in the middle .. this is part of our problem, we should all be together on this ...

When I was a houseman there was very much more of a team effort and we worked together very much more than you see now. It's time we got back to a lot more co-operation.

When we trained, when someone came in for surgery they stayed at least two weeks, and in the old Nightingale wards the sickest were up by the desk and got a lot of care and as the two weeks went on they went to the other end and were practically self-caring when they left, and when they weren't they usually went on to have convalescence. Now people coming in for major surgery will come in the night before or even the same day, and by day three they will have gone home, and in 14 days you will have had several different patients in every bed. The other difference was that there were students as well as trained nurses; there wasn't a care assistant in sight. Now most of the care is given by assistants. (I have been in Palliative Care for 20 years and that may be the ideal ...) The Care Assistants are wonderful. It's not their fault if they haven't been trained, but there may be only one other [trained] nurse on duty, and she has so much paperwork, all the drugs and all the very sick people to look after. We have to recognise this: women now have choices they never had. Who goes into nursing if they can get a high-paid job in the City or excel in other professions? Women aren't going into it in the same way, but the ones that are still want to give good care. I talk to some wonderful trained nurses; some of them are so overworked trying to keep up the end of nursing ... a standard drug round ward can take three hours. If you are late giving a drug you have to sign a piece of paper saying why. Every patient is supposed to have a documented nurse visit once an hour; on a 33-bed unit this is not going to happen. There is so much pressure – it was a joy to be a nurse 30 years ago but ...

I am concerned about what you are saying about UEA. One of the ways we try to counter this at Newcastle is when students go into the third year we give them a session where they have the opportunity to look at the ethical issues raised by them, and in particular to get them to report when there has been a tension between therapy and education. Where they see an example that has been inappropriate or unprofessional care; where they have seen a conflict of values either between themselves and the team or themselves and the patient and how they handle that, which is a way of processing these things and will often feed them back, and will often make a difference. I remember some years ago, particularly for some reason in dermatology, but I suppose it felt very invasive for someone to find nine medical students standing around looking at their rather demeaning skin condition. Things have changed as a result of reporting that back. We used to do a lot of sessions in O&G where we got students to say where they had seen examples of very good and

very poor communication so we didn't so much emphasise the bad things as reinforce the good. We actually stopped doing that because we weren't getting any more examples of poor communication. That was not because they had reduced their sensitivity but they weren't seeing as much. I don't want to paint everything as if it's absolutely fantastic, but I do want to provide a bit of balance and show that there are some good things happening and changes for the better.

I would like to reinforce that as a challenge to Paul as I think you can do more within medical education as with Bryan's example and I believe you can help to preserve the ethos of care which despite the selection process a lot of young students do come into medical education with, by giving people the opportunity to talk about it. The little experience I have had has surprised me by the way the students I have spoken to resonate with the things I have been talking about, and their open-mindedness and commitment to preserving those values. Is there not then room, opportunity, to develop that kind of resonance?

Yes, of course there is – I overstate my case as always [inaudible aside and laughter] – the truth is that we can give our students a lot of good meaningful experiences over the five years and we all try to do that by our various means and there are all sorts of issues to do with humanities and all the things that Bryan has mentioned that achieve that. But what long term value has that got when the exam is all about the genetic predisposition to this and the biochemical pathway to that. We know that at the Peninsular medical school the students who get the best marks don't actually turn up to the touchy-feely things because they know that their time is better spent with the books and then they'll pass the exam. All those nice experiences as a student pale into insignificance against the exam drive; and then when you get into the current culture of medicine, once you make that huge transition into an F1, it overshadows all the nice experiences. That's my view – I can't support it with much evidence.

But if what you do is examine it, it becomes compulsory and this is what we effectively have done in Newcastle

We can't go back to what life was like when we were housemen because the world has moved on. We actually have to work with the world as it now is which as we know is very target driven. There are some things we can do about our own role modelling but that's a difficult route on its own as everybody is very rushed. Last year I sat in on a cardiology revalidation process and it was all about how many interventions have you done, how many intravascular defibrillators have you inserted? - which reflects the perceived value of what they needed to get through. But college curricula are beginning to include things about interpersonal skills... and things like multi-source feedback are starting to happen which may come into the culture ... good things that are happening. So there are ways through this but they may demand working with the current model.

What about inter-professional education? – because that is a formal aspiration of the GMC and the RCP etc. – but to what extent is it happening? And if it happened better would the interaction between, for example all the disciplines represented in this room in the training process facilitate the kind of evolution that we would like to see?

One thing I was going to say about postgraduate training was that it was suggested that the loss of the firm was a sad thing but I would argue that it was quite a good thing, because the doctors were a little unit that would march round and didn't belong anywhere as their patients were spread out. I know there is a loss of continuity of care when the doctors are based on wards but they are sat on the ward with all the other healthcare professionals, seeing what they do, watching the relatives come,

how those interactions go on with the firm it was a very hierarchical structure which was very bad.

But making things work at a ward level is still looking backwards - no-one stays more than 24 hours unless they're dying, and all of us, and most GP's, are outpatient or community based, so it's a whole different model of care; almost all of our patient contacts are outside hospital wards, and that's not what we grew up with, but what new doctors are growing into.

There are a few wards in our hospitals where they have one or two consultants who do conduct ward rounds which include Allied Professionals, which provides an immense opportunity for multidisciplinary education.

It's absolutely critical that education is not about taking people away and 'doing education' but about giving them the opportunity of working and learning together ...

It's basically teamwork - after the merger of Imperial with St Mary's we set up a combined problem-based teaching programme. We had nurses and physiotherapists as well as medical students and learning together worked very well. But I notice this has fallen by the wayside. The other thing is that medical students are no longer around. They come to anaesthetics (and pain) for two weeks – but they aren't around like they used to be.

We have been talking about acute hospital admissions but most of the failures of care that get publicised are in long-stay wards, geriatric wards and care homes.

Innovative projects in education are very much dependent upon individuals and when those individuals move on ... not embedded in the culture ... (inaudible)

We're talking about these functional issues but I think it's much more fundamental than that and I'm not sure whether you're taught in a firm or attend a particular medical school matters that much. It goes much deeper ... it's easy to blame this on the NHS ... I'm not sure how to change it. It has to be personal, individual. A lot of it is about role models as Paul was saying. It's very easy to look at the other systems and say they are wrong - I'm not saying they are or that I manage to do it – but it's about us changing rather than trying to change everybody else.

Just thinking of some of the things that are said in the Ethics of Care literature: you also need to have the kind of system that promotes caring but you're right - it's also at the individual level. It's no use spending all your time with the systems; some of the people who do don't really seem all that bothered individually. Noddings uses the example of Gandhi whom you can sanctify enormously for what he did, but his family life wasn't that good. You can have those who are really good at the structural level but fail at the individual level and somehow we have to have something holistic which goes across the board.

It's easy to blame the system ...

... it's got to go beyond blaming ...

... it's not a question of blaming, it's trying to find the right way and why we can't set things up. The current system makes it difficult for you to change things into the way you want.

There is a difference between ethics teaching and the pursuit of ethics. We have a very powerful professor of ethics at Imperial and they get quite strong ethics teaching, but they don't get anything about ethics of care.

We talked about the old way of doing things and about role models being very helpful but looking at that list on the screen there [creativity, healing, integrity, wholeness, openness, truth, wisdom, understanding, love of creation, love of others, respect, dignity, altruism, justice, humility, generosity, kindness, tenderness and intimacy] and reflecting on my work with small groups of students for whom I act as academic tutor - they are basically A-level science-based students coming into medical school - I don't think they have anything like the understanding of most of those things and other aspects of humanity that they might have if we were to introduce them to Dostoevsky or Tolstoy, and make them do it as part of the course. Then they would know what they were looking for and what we are talking about.

That's what Graham was saying: if we have totally science-driven students - they read Nature and can talk about the latest articles at their medical school interviews, but know very little about Dostoevsky... they do not read widely. They wouldn't have a grasp of how those words [on the screen, above] relate to twenty-first century medicine.

... that also relates to age and life experience ...

Perhaps a bridge to that is not to expect people to read modern classics etc but to approach people where they are coming from? Affective neurosciences - whether or not you judge that as concrete evidence - could be a modern bridge into thinking about affect and interactions between people, and we could help them to see that there is valid neurobiological evidence that that is a valuable thing to do and cultivate.

... I don't think it matters where it comes from but to get people thinking about these issues somehow ...

*But we're still selecting for medical school people who we expect to be competent scientists as soon as they arrive. I'm reminded of a wonderful book, now 50 years old, called *We Joined the Navy*; cadets were being selected for Dartmouth and the board were discussing them. One of them said: 'X is a wonderful cadet, he's just right for us, he's already got a degree in maths, he'll be great'; and the chairman says 'no - you have to realise that in the Navy we are looking for half-wits. We supply the other half.' So we select scientific half-wits and we supply the humanistic background when they come to medical school.*

Looking back on my medical career the person I remember most as having taught me most... I don't remember much of what he taught us about... but I do remember the way he communicated with patients - to see how he latched on to what was really bothering the patient ... and the expression on the patient's face ... it was so much more than simply being polite. So it's more the role model, more the example rather than...

... I completely agree but my point is that in the last five years in the pain clinic I didn't ever have a single person with me. If all these outpatients are consultant based and there are no junior doctors or medical students ...

In my field there is an obsession with structuralism and end-stage joint destruction, and to help people to think holistically you have to teach people to think scientifically initially to get them to understand the basics of physiological disturbance. Most

people are very mechanistic and structural, so to get across the idea that people can suffer with physiological disturbance is a major start and that is not very prevalent in physiotherapy culture. You have to use the vehicle of science initially to get them to think holistically.

That's not so true of occupational therapists. Some of their models are extremely holistic. There is a big manual for professions that are maintaining the ability of daily life which includes models of healthcare which would be quite foreign in many of the contexts we have been talking about, and if there were better inter-professional education it would help people to understand these mysterious words.

Managing expectations

You [JS] were talking about managing patient expectations and I was wondering if the clinicians in the room felt that was something they could reasonably be expected to do. You mentioned the medicalisation of society: is that something we should support or discourage?

My answer is yes, clinicians should be doing it, should be able and should have the courage to do it, and should have the kind of relationship with their patients that allows them to do it.

You can't see your patients without addressing that. As a GP your situation is that you have an open gambit because you don't know what that patient brings through the door, and the extra skill required is to try and find out what their ideas, concerns and expectations really are from what they know gets them through the receptionist or triage system or through the family member who has made the appointment for them. So they are sitting in front of you and you need to find out what it is that makes meaning for them and what is the role you have in the consultation. It's very often more challenging than the sore throat they come in with ...

... and they don't always say what's wrong – and sometimes they will leave without picking up the courage to tell you ...

Anyone who doesn't manage expectations in chronic pain is asking for problems. In vascular surgery you can manage expectations ... one of the biggest problems is the time factor: to really work with someone so they go out realising this is how it is and life stinks – that takes time and may take more than has been allocated.

One of the issues a lot of my patients have is that they don't know what expectations they have. A lot of them are quite resigned to their pain but they come to you because they have this pain – they many have been to several other specialists ... but what is upsetting them even more as part of their whole problem is that they no longer know what expectations to have. They don't know what medicines we can give them – all they know is they want relief of their suffering.

But the flip side of that is patients come to see Graham (Sutton, surgeon) with a hernia and he asks 'why have you come to see me today?' and the answer is 'because my GP sent me.'

It's still not quite deep enough... reducing expectations to what you can provide within the constraints of the NHS as it is at the moment ...

Is there a case for the RCGP changing their motto from With Science Care to With Science and Taking Costs into Account ...?!

Can I give two quick examples of expectations: one was a referral from the orthopaedic surgeons. He wanted the patient to have facet joint injections, so I took the story and did the examination but couldn't find anything to inject. I had an unsatisfactory conversation with the patient and decided to bring the case to our team meeting. Our very holistic German consultant colleague agreed that injections wouldn't be appropriate, but the other consultant said 'ah, but there is a bit of politics here: Mr X had asked for the injections so we ought to do them.' So I couldn't meet expectations by clinical criteria.

...so by giving the patient the injections all you are doing is reinforcing the orthopaedic surgeon to keep sending those referrals – you're not educating them...

In contrast with this another patient with very heavy mental health difficulties. She'd had every treatment and nothing helped, and every test and everything was normal ... so I thought I'm going to give it to her straight – gently and kindly ... and it was absolutely extraordinary to see the shift in her physiology – the more gloomy my assessment became and, and how this was it, and she was going to need to find accommodation within herself and work with the mental health people and with us if she thought it would be helpful ... and gradually during the course of that conversation where I had nothing to offer save for my best explanation of chronic pain and how to live with it there was this lift in her face and a smile, so I said 'it's wonderful to see you smiling – what's happening?' She replied 'I feel so much better because I didn't know what to expect – you have told me how it is and I think I can live with that'. So two completely different expectations ...

In the first example you were also dealing with the expectations of your orthopaedic colleagues and his political plan...

The patients' agenda

There is good evidence that if you get the first consultation right you don't end up with all the crap that we usually see ... I don't mean to devalue the patients... I mean we created the crap because part of the suffering is very often that they haven't been listened to. The numbers of times I've heard 'you're the first person who has listened' ... it makes me very humble ... but what has everybody else done? I had one patient who was just talking and I was listening but I had no idea why they were there or what was expected of me or how I would solve his problem, but then he said 'that was very good - I understand my problem much better now'. And I still don't know to this day ... I think what happened was I provided that room and I didn't rubbish any of what the patient was bringing. In his mind everything made sense but I thought that was really astonishing. If you give the golden minute in general practice and don't interrupt them you can get to the bottom of the problem quicker ...

In my clinic I say to the patients: tell me your story. And I don't interrupt them for twenty minutes, and at the end a lot say that's the first time anyone has done that. But there are other patients who just look at me and say 'haven't you read my notes?'

David Hasler said there are two agendas going on in the consultation: the patient's and the doctor's, and the doctor will often deal with his or hers first. In the notes of nearly every patient I see my practice manager has written-in which data is missing

that she needs to fulfil our QOF. It's a horrible way to practice – only when you have dealt with this does the patient get a word in.

In a study based upon patients' unvoiced agendas they spoke to the patients before and after they had seen the doctor. They found how little of the patient's agenda had been dealt with in the consultation, and what got in the way was the biomedical filter. They also studied how many of these unvoiced agendas went on to cause problems. As Bernd said if you get that initial consultation wrong and don't give that little bit of extra time then and there you are building up this bow-wave of problems.

Jeremy made the point that there is no OT representation here today, and I think we are getting very stuck in the medical model. There are people here who aren't trained in the medical role and we need to be sharing ideas but we're not even doing that here – we're stuck with medical training etc and forgetting that there are other people in the room. I've trained in both the medical and the psychological models so I've got the luxury of having both of those to inform where my practice is; and I find myself working on my own. We're talking about how do we share, how do we move this on, and if we are looking at working in isolation ...

Pragmatically from that, the number of non-doctors applying for our meetings has gone down because there is no funding, there aren't any medical students or junior doctors applying, so we won't be able to propagate a different view of things because it's only us coming. It's a real worry.

Most of the accounts of inter-professional training and working that I have read suggest that it works extremely well among the allied professions, but doctors are extremely reluctant to have any part in it.

Going back to attitudes to caring among medical students and student nurses: a lot of this starts at home. A lot of people don't have what I would call a normal family life so a lot of these things have been missing from their own lives. A lot of people now don't care for their parents – it's quite unusual now. My own mother-in-law died at home with us. So a lot of young people grow up not knowing anything about caring because they haven't had that example in their lives and you can't replicate living with elderly relatives – things are so different now. And that's going to be true of patients as well as professionals.

Targets in healthcare –a necessary evil?

Graham Sutton

“I’m going to talk about the ethics of funding. What’s that got to do with the ethics of care? Well, if you haven’t got any funding you can’t do very much caring.”

This comes out of a sort of dialogue with my wife on the lines of ‘Why do you get involved in medical management?’ – ‘If I don’t someone else may not do a good job of it’ – ‘there doesn’t seem much point in it’ – ‘there is a point; there may not be any money left in the system for you to look after your pain patients and you can’t prove it does any good anyway’.

I’m going to talk about the ethics of funding. What’s that got to do with the ethics of care? Well, if you haven’t got any funding you can’t do very much caring. I did actually wonder during the earlier talks whether caring was necessarily more expensive than being uncaring and I don’t think it necessarily is, but caring is still going to need money. So I’m going to talk about NHS historical funding, the present financial situation and a bit about outputs, efficiency and challenges and targets. I haven’t any solutions to give you but hope we may find some in the discussion.

History

I’m not going to go back to the very beginning of the NHS but at its inception it was not only supposed to be self-funding by keeping the masses in good health and therefore full employment, but it would actually generate money for the country, and clearly that was not going to be the case.

I do want to take you back to 2000 and Blair’s NHS plan. He felt that the NHS was letting people down. It was at that time being funded by about 3% of GDP, but patients were waiting too long for treatment, there were unacceptable variations in care both around the country and for different patient groups. In exchange for the 5 P’s: Partnership, Performance, Professionalism, Patient care and Prevention the NHS plan made a deal that they would significantly increase funding. Which they did: expenditure had remained at about 3% of GDP between 1974 and 2000, and then it was increased to the European average of about 8% of GDP. In 2011 with a change in government the funding changed and there was no further increase, and taking healthcare inflation into account there will actually be a reduction in funding for the next few years. That’s going to be pretty challenging. So I’m going to examine which of the 5 P’s were delivered as the result of the increase in funding in 2000. What went with this was an agreement that there would be some imposition of targets, so that the government could ask if there had been an increase in output with the funding increase.

Targets

Most people hate them - we were talking this morning about QOF points - and over time targets are becoming increasingly broad; they cover more and more aspects of everybody’s care: primary, secondary, and specialist. They are becoming increasingly challenging; they started off simply with ‘you have to achieve that by then’, but now there is no wriggle room. As people have become more cunning at finding ways round them they have closed down all the loopholes, like putting

referral letters or admission cards in a drawer and 'forgetting' them for months, that used to exist.

But have they done any good? I obviously can't go through them all so I want to talk about one or two types, with apologies to those who hate them. The first are access time targets including referral to treatment time, delay in diagnostic imaging, and delay in emergency departments. Secondly there are quality improvement targets, things like hospital acquired infection, mortality and single sex accommodation. These are quantitative measures, and some more qualitative assessments (although they are usually converted to numbers) have been introduced more recently including Patient Reported Outcome Measures (PROMS) and patient and staff surveys.

[The next part of the talk was illustrated by graphs taken from *The Quarter*, a document published quarterly by the DOH, with a retrospective once a year.]

Targets have undoubtedly been successful in reducing MRSA infection. Prior to 2007 we just used to accept that patients acquired MRSA in hospital, but then there was a drive to reduce MRSA bacteraemia and we achieved it, the quarterly incidence having come down from nearly 1400 in 2007 to a stable 350 or fewer since mid-2010 and in Portsmouth we now have on average about three per quarter. So it has almost disappeared. We don't know which of the measures: hand washing, patient isolation, naked below the elbow, that changed things – perhaps it was just awareness that we could do something about it. I admit I do feel ashamed because I was complicit in saying I don't know what to do about it but lots of things were done and there has been a dramatic change. Not only has there been benefit to patients but probably a big impact on costs, because each infected patient does cost the NHS a huge amount of money. There has been the same progress with *C.difficile*; again we don't know which of the measures, infection control nurses, isolation, screening (patients are screened *before* they come into hospital) have been the most important. Our figures didn't take an immediate sharp downturn when we moved into our spanking new easy-to-clean hospital which suggests that the crucial factor was less the environment than people becoming more aware of what they did.

There has been another sharp drop in mixed sex accommodation. I don't know how important you think is, but a lot of people feel very strongly about it. (It's interesting – in primary care if you want GPs to do something you pay them, you give them QOF points. They get paid for doing something right but in secondary care we get fined if we do something wrong. We get fined £250 for very breach of the single sex accommodation rule and if you have a four-bedded room and you put one man in with four ladies you make *four* breaches of the rules and get fined £1000! So you pretty quickly sort that out.) But that is a quality improvement. But it's getting more complicated: when we designed our new hospital the healthcare planners said you don't need single sex accommodation in unconscious recovery or ITU, or day surgery. Now we are told the sexes must be separated when they go to second stage recovery, which is going to be quite challenging.

To move on to Referral to Treatment targets: when we were first given targets for access to outpatients and for operations they were separate, and you were told you had a certain number of weeks, say three months, to see them in outpatients and if they needed an operation they would have to be admitted within, say, six months. So what you did was to see them, perhaps send them off for a test and bring them back – and it might be a year before you first told them they needed an operation, which was a very long time. So what they did was to say we want every patient to be pathway complete within 18 weeks from when the GP writes – it doesn't matter how long they take in outpatients, how many tests you need to do or how complex their

problem. And it's been done – over 90% of patients are getting their treatment started in 18 weeks. Patients much prefer this to the old system where they were dropped into an abyss where they were waiting for results of investigations.

What about diagnostic imaging? Although there has been an increase in activity from 2008 to 2012, apart from holiday times the waiting time has remained hovering around two weeks. So we are getting a good service.

Of course it doesn't cost any more to provide a timely service than one which is six months out of date. If your secretary is typing up the clinic letters the day after the clinic it doesn't take any more activity than waiting six months; you may have to do some catch up to get there but in some ways it's easier, more efficient and more effective to do things in a timely fashion. So the NHS may have become more efficient with shorter access times, but what you have to balance against this is the question: does shorter access alter demand?

George Alberti said that about 2% of people who turn up in Emergency departments would benefit clinically from waiting more than four hours, so we've been given 98% as a target. I think most hospitals do struggle to achieve this, but about 95% of patients are seen within this limit. This is a great improvement since the days when patients sat on trolleys for hours and hours, although it can cause some anxiety if you've only got 20 minutes left to find a bed. This may increase demand because it might be tempting to admit someone so ED isn't breached rather than wait a little longer to be sure they are stable and send them home. The way to deal with this is to make sure that the first assessment is as early as possible; as if this is after three hours it doesn't give you long to assess the trajectory the patient is on.

The mismatch of demand and funding

So real NHS expenditure has grown, targets largely have been met, mostly in ways that are of benefit to the patient rather than just to manipulate numbers, and in some ways quality has improved. The old methods of demand management involved rationing by waiting list which is a dreadfully dishonest and inhuman way of controlling healthcare expenditure, in effect saying you can either go private, die or decide you don't want it done, or wait until you eventually get to the top of the waiting list. We can't do that anymore and have introduced new ways of managing demand and maybe some are more honest even if some are still rather manipulative. For instance in my hospital we have introduced a BMI (Body Mass Index) limit for orthopaedic surgery, insisting if this is over 35% that some attempt should be made to reduce it unless there are special circumstances. We also request that patients should stop smoking or at least attempt to. PCT's have introduced the categories of Procedures of Limited Clinical Value (PLCV's) and Procedures Not Normally Purchased (PNNP's). Those are increasing. In my patch we have not done varicose veins, unless the patient has an ulcer or is bleeding from them, for at least eight years. We don't remove cosmetic lumps and bumps. So we are trying to control demand but some of those measures are pretty unpopular.

So we are stuck with this dilemma of the mismatch of demand and funding. Nicholson [Sir David Nicholson, Chief Executive of the English NHS] says we can save about 20 billion by efficiency but I don't know if there is much track record to support this. So there isn't a lot you can do: Nicholson says that he's not going to increase funding, and in the present state of the UK economy, if we carry on spending 8% of GDP it's going down with it. We can try to reduce demand but the old methods don't work anymore, and the 'new' methods are somewhat discredited.

We are in danger of getting back to 'postcode lotteries'. We have demographics that are altering demands for healthcare upwards all the time. The expectations of patient and their relatives are continuing to increase.

Can we improve productivity? As far as elective care is concerned, planned care is pretty efficient. Patients say to me sometimes that they feel they are on a conveyor belt as they come in for surgery on the same day and go home on the same day. In Portsmouth 99% of elective surgical patients go home within six days; planned discharge for joint replacement and Caesarean section patients is three days. We can't make that much more efficient.

Can we make the staff any more efficient? Can the same staff do more activity or fewer staff do the same? The ratio of output to input in the NHS has in fact declined by 0.2% between 1995 and 2011. The Nicholson plans for saving 20 million pounds over the next seven years will demand a 5% improvement in this ratio. No health service in the world has achieved that sort of efficiency gain.

The future

So I am anxious about the future. We have less funding and no evidence of an efficiency gain. We have achieved a lot but where are we going in the future? I do think scheduled care at the moment wasted money. The purchaser/provider split rewarded failure in some ways: in primary care if someone isn't managed very well and they get diabetic ketoacidosis so they have to come to secondary care and we get paid for it. Obama's healthcare reforms involve a managed purchased year of care so there is no reward for failing; if the people providing that have to purchase secondary care because someone has fallen through the net they have to pay for it out of the same budget. The demands on secondary care from things like out of hours set-up's, nursing home admissions and deferred transfer of care of people who are medically well and don't need to be in hospital involve quite a large expense.

There is a breakdown between healthcare, social care, welfare and employment which all seem to work along completely separately but are intimately related. If we can do something about integrating these rather than rewarding secondary care financially for picking up the failures and drop outs of this perhaps we can get somewhere, but there isn't much to do in elective care.

So more questions than answers. I don't intend to stand here and answer questions but I will defend myself if necessary!

Discussion

You were talking about same staff more care and fewer staff same care but you didn't mention cheaper staff ...

You talked about efficiency, and regarding your slide about this which I didn't quite understand ... can we still say that we are more or less efficient when we are looking at a potentially different group of patients coming through the door especially as regards out of hours care?

The x axis is money which is easy to measure and the y axis is productivity. The latter is not simply a matter of adding up the number of outpatients seen and operations done, there is a correction for complexity. But I don't know that it has captured every nuance of the changes that have taken place in the last sixteen years

like the technical advances and demographic changes. But the point is made that there is little evidence that the NHS has become dramatically more efficient in that time and those of us who work in it would accept that we're not getting a great deal more output for the amount of money that's being put in to our service, our hospital or our department.

We were making the distinction this morning between service and care, and what you have described are very important improvements in service. Can you comment about any improvements in care from your experience as a clinician?

That's difficult to quantify. I mentioned Patient Reported Outcome Measures which are a sort of attempt to quantify care because if you ask patients what they thought about it ... A recent survey suggested that there had been a significant drop in patients' opinions of the NHS. They tried to separate patients who had actually experienced care from those who had just read about it, and the biggest fall was in the latter. The press and the government do us all a disservice by continuously harping on about how bad things are. The vast majority of patients do experience pretty good care. But it's probably something that needs more qualitative assessment rather than attempts to quantify it.

That's a very pertinent question; one of the reasons I asked Graham to give this talk was that very often everything focuses on the acute service rather than chronic care and it seems to me that the burden of the financial demands on the health service is increasingly from chronic care such as outpatient pain services, mental health services, care of the elderly and care in the community. Graham's patients want this efficient conveyor belt – they do get good care but they are more interested in service. Our patients want care above service. That's an interesting dichotomy which hasn't really been addressed.

The NHS has been designed by a surgeon for short sharp episodes, not for chronic illness and that is the problem. How do you improve 'productivity' in long-term illness which is increasing as the population gets older?

The DOH uses the hip replacement model to work out everything. They struggle with chronic conditions. But that's where the greatest gains could be achieved because at the moment many patients with chronic conditions don't get the best care because it's not very joined up. There are some models: in the Isle of Wight and Torquay where integrated care has encouraged a breakdown of this artificial separation this has led to more efficient care: it costs less and the patients are cared for better.

It's very difficult politically ... as a provider of secondary care with my pain clinic I want to go to talk to the commissioners of primary care and say let's redesign the service – let's break down these barriers and have patients go where they need to go and have excellent care wherever they are, but my hospital won't allow me to do that. There is one woman who does all the negotiation each year and she won't listen to any clinicians. I know one colleague who got so incensed ... he sat outside her office but she refused to see him. What she does is to look at the previous three years and negotiates on that so you can't actually change it.

One of the reasons for increasing costs is technology and we're brilliant at introducing new technology ...

...untried and untested?

... Yes ... surgeons are very good at this! ... What we seem very bad at is getting rid of the redundant technology. This is one of Nicholson's arguments: you can make the 20 million savings if you get rid of stuff – if you're doing MRI's you don't need a CT as well. Do you think there is scope there?

It's not going to close the 20 million gap. But we are very bad at this. One of my bugbears is whenever anything goes wrong we don't throw out the thing that has failed, we introduce another check. If car manufacturers did this they would never actually produce a vehicle. They would re-engineer that process to stop that happening. I think it now takes me twelve signatures to do a hernia under LA; I have to sign that I've done the check list twice - we add layer upon layer. There are inefficiencies in our processes as well as our technologies.

We've looked at the whole costs but what is the breakdown between administrative/managerial and clinical costs? There seems to have been an explosion in the former.

I don't know the answer to that factually. One of the problems is do you call me, or a senior nurse, a manager or a clinician? I don't think the NHS spends a great deal on management compared with other comparably-sized organisations. It may seem that there are a lot of managers but we would like to spend more on *better* management in Portsmouth. At the moment we spend too little and get poor quality staff because we don't pay enough – if we pay peanuts we get monkeys. I think good management can actually save money. Managers are there to facilitate what only clinicians can do. Several managers I have spoken to say they want to put us in an environment where we can be most effective and care for people as best we can. Unlike us, their jobs depend on hitting targets.

Thinking of productivity, in our trust we have massive cost improvement targets. The other day a manager said to me 'Do you realise the nurses have managed to save five percent, and management have saved ten percent but consultants less than zero'. I said 'hang on, we're all working harder and longer hours for which you don't chart – how do you measure that?' How do you measure productivity?

Numbers of operations, numbers of patients you see in a clinic or a year ...

...and therein lies the problem. If you let your patients talk for 20 minutes uninterrupted and try to stick to half-hour appointments you have a manager breathing down your neck to fit even more in ... better 'productivity' ...

These days many more people are involved in someone's care. There is always difficulty with measuring productivity because you're not comparing identical products. Every patient has a unique journey through the hospital; they get to see lots of people and over the years they employ more people to do those jobs. Obviously the management costs are included in productivity. There are more staff because there is more work to be done even though there is the same number of patients. If you include in productivity fewer MRSA infections, shorter waiting times, deaths from cardiac events etc. that's productivity! If you put more money into a factory you build more cars but hospitals don't work like that. People at a senior level should be saying to management 'you're looking at the completely wrong figures - go away and come back with something appropriate'.

But on your definition technology is actually reducing productivity. Take cardiac surgery: in the old days we could do six pumps in two theatres between 8.00 am and 4.00 pm. Now you are lucky if you can do more than two in each theatre and finish

before 7.00 pm. Vascular surgery takes even longer. Is it a real measure, this productivity? Is there something else we should be measuring: patient outcomes, A&E visits post-procedure etc ...

I worked in a pain clinic for three years, and I found it so frustrating, coming from general practice where we were working at a very different pace. Primary care is generally more productive with less management input than secondary care. The appointment system drove me nuts. There is an office somewhere in the city which takes all the calls; it has nothing to do with the clinic and it's all on a computer screen which isn't lined up with any others and you need 18 passwords ... the cheapest computer system we had in general practice would do all of that for very little money. And there is the lethargy of the staff. I understand them: everything you want to do is a drag, you need five signatures for everything you want to do and that makes people work at a different pace; they don't want to do anymore because they are frustrated. It was very sad to see that, coming from a different environment – it wasn't their motivation to care but after ten years working in that environment you change as a person.

You talked about vocation; I trained as a nurse before I became a doctor so I could compare both perspectives. I came to this country [from Germany] as a junior doctor in 2000 when Project 2000 was introduced, and I thought it was a complete nightmare. No nurse knew the patients any more ...

I have a very different view on management – I think it has destroyed a lot. If units were broken down within the hospitals so the pain clinic would be responsible for itself and make its own appointments ...

...that's old-fashioned! ... it all has to be centralised ... this is production line medicine!

You and Mike have touched on something very important: we can't speak to commissioners because they are in a different section of the health services; what you experienced as a clinician in one section of the NHS is completely different from your experience in another section, and it ties in with what Cindy was saying this morning that we now have doctors and allied professions all in their little bubbles and there is nothing joined-up any more.

Are Mr Lansley's new plans [the Health Services and Social Care act] going to make matters better or worse?

A curate's egg. The bits that do something about breaking down some of those barriers are positive. But it's been so fiddled with that I don't know if it's going to be workable. I don't think it's going to make the sea change we need.

Rationing healthcare

I am sure that there are efficiencies we could all make but I feel that we are trying to provide this endless healthcare system which is going to cost more and more, and I wonder whether we are having the right discussion and should be talking about rationing.

I agree. I don't think the NHS can continue to be a free-at-the-point-of-use universal all singing all dancing service for the foreseeable future. It's up to the profession to

decide how we are going to make sure that it is not the most disadvantaged who aren't able to access it.

Does anybody think that we don't have to ration one way or another?

There is a problem with the word ration. Everyone should have care – do you mean when you are talking about health care rationing are you rationing care? - rationing looking after individuals? You don't need to spend a lot of money on individuals especially if they are near death, to give an obvious example. But should we be thinking more about expensive medical technology and who gets it, but be sure that everyone who needs care gets it.

We were talking earlier about managing expectations. The media generally both in factual and fictional presentations encourage a wildly over optimistic public expectation which is now part of the national myth. Before we can achieve what you were saying about caring we need to define care. The rest is optional and may be a luxury. But to do that and make it politically and socially acceptable we have to change expectations, and that's a totally different approach.

People want to live forever and don't actually think they are going to die, and if they do we have failed.

I had a colleague who used to introduce himself to patients: 'good morning. I'm Doctor X – I'm not going to fix anything' and then expanded on that...

The NHS is a highly complex huge employer with loads of departments, ideas, bureaucratic concepts and they keep changing it in a way that no big commercial organisation would – they just sling in another change and everyone has to rush around and implement it. There is a huge amount of research into organisational change which is ignored. There is research from Harvard business school on numbers of staff, people in big groups working ideally together, how do you manage change, leadership concepts; all this stuff out there which is never applied in the NHS.

There was an idea a few years ago of taking the NHS out of politics so it would sit to the side of government and not be the responsibility of the minister of health ...

The publicity that is coming out isn't accidental – I think it's politically driven negativity about the NHS to 'prime it up' to be sold off – and public opinion would already be sown ...

There's a powerful piece of data that public opinion has suddenly gone down but users have not noticed any change...

... that's partly because the changes haven't percolated through yet.

There isn't time to discuss this now but I just want to put down a marker, which is to do with doing the opposite to what Paul [Dieppe] was talking about and looking at the problem with the telescope the wrong way round. He was talking about the problem of advancing technology, and the alternative is to look more seriously, critically and imaginatively at what you might call low technology interventions.

As a counterbalance to the bad stories about the NHS we might ask: who was doing these breast implants [with defective materials]? They were predominantly private, not public and there are quite a lot of bad private stories that need to be told.

The NHS picks up the tag for private work that goes wrong.

Difficult patients and the Victorian values narrative

Claire Martin

“As professionals we have to think about the way we can quite easily dismiss people as difficult; some you haven’t been able to help and some don’t fall into a neat slot.”

Some years ago I wanted to choose a topic for my MSc dissertation which would find a link with the social side of the things we do in pain clinics. I work in an integrated pain team – we don’t have an acute and a chronic service and see both inpatients and outpatients – and it has always fascinated me to see the decisions people made when they referred patients. Considering about 80% of patients in hospital are in pain, why did they select these particular patients to refer to the service? Some were referred quite openly, not because of their pain, although this might have been a focus, but because the staff found them difficult to manage.

When people ring up to refer patients to the pain service they are very careful to avoid saying ‘this is a difficult patient’ but as soon as you arrive on the ward it’s like ‘... thank God you’ve come!’ And by this time the patient is angry, dissatisfied and prepared to dismiss any suggestion you might make.

Research

When I reviewed the literature it became blatantly obvious that although everybody seemed to know what a difficult patient was hardly anyone had done any research at all. I only managed to identify thirteen articles in the previous ten years that could possibly be described as research into difficult patients and attitudes to them. It was a strange selection of articles with some by chronic pain patients reporting their experiences, how they felt they been stigmatized and had had to become challenging in order to obtain the services they felt they deserved, others by clinicians saying what they found difficult about patients, and some who tried to look at it from both sides. There was a lot of what has been called ‘grey’ literature: people writing to the medical press and sounding off about being made to feel inadequate, angry, or challenged – loads of this sort of thing but very little research. Of the articles I found two were papers written on the basis of the same study and two were unpublished dissertations.

The first piece of nursing research was in the 70’s by Stockwell titled *The Unpopular Patient*. It was a case study of a ward where she talked to patients about what they thought about the service. She also talked to nursing and medical staff and it was clear that at a human relationship level they liked some patients and disliked others. There have been a couple of attempts to revisit this; a lot of the words used around difficulty are very judgemental, and such judgements are not made on anything clinical but on how they act and how they make you feel.

Difficult patients and labelling

Everyone seems to know what they mean when they talk about difficult patients and who they are: they tend to be confrontational, they come every time with a different symptom, just as you think you’ve nailed something they move on to a different complaint. Despite often expressing complete dissatisfaction with the service they have received they keep coming back. We have been talking this morning about

patient expectations and these people don't understand the limits, not only of medical knowledge but of resources of time and money. They expect priority; and seem to think they should have a clinic entirely to themselves even though there are twenty people in the waiting room. They get cross if they are seen late but don't mind keeping others waiting. Judgemental words keep cropping up, such as ungrateful, non-compliant, disobedient, dislikeable, rude, smelly, and has an inflated sense of entitlement (I love this expression 'external locus of control' which sounds lovely but means exactly the same thing!) There are lots of stereotypes, for instance people on long-term benefits, compensation seekers and the person who comes to see you the first time with their DWP form. Some come with letters from their GP's saying they have 'drug seeking behaviour' which makes it difficult to resist prejudgement, whatever you might find when you actually meet the patient.

So everybody seems to agree what makes a difficult patient. I tried to impose some sort of framework on the subject for my thesis. I thought that many of our chronic pain and disabled and socially disadvantaged patients were the victims of labelling. We give them attributes that mark them out as somehow different, and we need somehow to move away from this language towards a language of relationships. Anyone who has been in nursing will know that there are many ways of labelling at handover so that the next shift are pre-warned – be it only the way you say 'there's Mr Bloggs in room 6 ...' Already you've made a prejudgement about that person and decided which people are going to be easy and which difficult to deal with.

Victorian values

There is an interesting ongoing narrative in the media regarding proposed changes to disability and incapacity benefit. Margaret Thatcher is the most famed proponent of the idea, which was started off by Samuel Smiles and his book *Self-help, Character Thrift and Duty* (1859), that somehow there are right ways of living and behaving which involve hard work, independence, self-reliance, filial duty and conventional ideas of what makes a family; and bad and undeserving ways. Just as we have the deserving and undeserving poor so we have those who are deserving and undeserving of sickness benefits. This narrative is really obvious in all the papers and all the debates about scroungers, people who insist on their welfare rights, people who aren't really disabled, how easy it is to get disability benefits - you only have to go to the doctor's and say your arm hurts – and people with seventeen children enjoying a lifetime on 30 grand a year. There is this perception that somehow people have brought this all on themselves and are therefore undeserving of our support. Typical of recent headlines include 'Beat the Cheat' (The Sun) encouraging people to spy and report on their neighbours if they seem to be making false claims for disability payment, '75% of incapacity claimants are fit for work'; and generally feature words like 'scrounging families' and 'workshy'. There is a widely held belief that most of the people who are in some way dependent on benefits or healthcare, and need a lot of appointments and transport and so on, are in some way cheating hardworking families out of their income.

The thesis of my review, supported by accounts of the way patients are treated by staff, suggests that it would be quite astounding if the dominance of this narrative didn't affect staff in some way. We all get this rained on us every single day and we are under more and more pressure in the NHS. As professionals we have to think about the way we can quite easily dismiss people as difficult; some you haven't been able to help and some don't fall into a neat slot. And some are challenging and some exhausting. It's easy, and it helps protect yourself, to subscribe to that view because

you can sleep easier at night because you don't have to worry about not helping them.

What does this mean for patients in pain?

We see many patients who have illnesses and chronic pain but that may not be their true problem. They may have miserable lives which aren't helped by their perception of being judged. They don't want to use crutches because they think people will think they look funny or wheelchairs in case they are judged as lazy. They may have been for a DHS assessment and have been mortified and demeaned by it.

Discussion

Where do you get this idea that a patient is difficult? Is it someone on the staff that starts that rumour? I once did a lunchtime chat with a group of GPs and I was horrified to discover that they were all convinced that all patients with chronic pain were malingerers, and all out for benefits. They weren't at all interested in my views on how to manage chronic pain. The senior partner of the practice actually said 'I don't think we should be doing anything special for our patients' when I suggested multidisciplinary pain management.

I don't agree with those GPs but I can see how that happens because GPs see people that they shouldn't see for disability assessment. I don't think that I should be part of the assessment process; I can't be caring for someone and at the same time be the one judging whether they are fit to work or not. This always puts me in a very difficult position. So I think what you may have seen was that these guys have lost the view of where this has come from and have ended up being judgemental. This has been a political scam because they wanted to filter off anyone they could and the only way they can do this is to make everybody go through Atos¹⁶ and this is just a tool to fail everybody. Only the ones who will defend their claim in court will get their benefits reinstated. You have to be a pretty determined patient to do this and get GPs on their side to get there. I have found myself more than once supporting my patients but it's the wrong way round ... it's putting the cart before the horse for political reasons ...

I work in an inner city and see a lot of people in poverty and I do see the potential reverse incentives of the benefit system: people make themselves disabled because they don't know any other way. I agree with Bernd that it's very difficult for us because we are the care-givers and their advocates but we're put in this position of having to say yes or no. My first job as a GP was as a locum in a single-handed practice where everybody had their blue badges because the doctor always said yes, which is very easy. When I was asked to renew the badges it was very difficult because I was trying to be professional and trying to make it fair.

People working for Atos have one of the nastiest and most difficult jobs in medicine; they get a bad press but they're not allowed to touch a patient in case Atos gets sued so if someone can't lift their arm they can't use passive and active testing and have

¹⁶ For the benefit of non-UK readers: Atos Healthcare is the privately owned agency delegated by the government to conduct disability assessments for people claiming disability benefits. Their employees have been widely criticised for finding people with serious illness or severe disability fit for work.

to guess whether it is can't or won't. They are in a system which has institutionalised them in this way.

We all have to understand where others are coming from if we are to have to have an intelligent discussion about what is happening in society and we need to understand the complex things that motivate people.

...we are seeing patients in the pain clinic who have been right through the system without ever having had a proper neurological examination ...

...aren't there questions about professional integrity and humanity. How have those Atos doctors allowed themselves to be put into a position where they cannot act professionally?

The sort of doctors that do that job – some are between jobs, some perhaps can't get any other job, though perhaps I'm being unfair. It's not valued; it's not a nice job. I invited one to come to a GP study group as I wanted to get my head round the system, and understand what is expected of me. I asked 'what's helpful to you?' and they replied 'if you really think a patient has an issue, write as much as you can and give us lots of information. If you're not sure keep it brief ...' Now I know when I write these forms how to play the game. These people are not valued – they are criticised and even hated, but it is a valuable and important job if done well.

Some full time GPs do it for extra money in the evening.

It's a horrible example and one of many where the health profession should be standing up and saying this is wrong. We collude for all sorts of reasons many of which involve self-interest, or an easy way out. This puts us pretty far down on my gradient of virtues¹⁷. We do have choices in these matters if we choose to exercise them. But this may require courage. We can't differentiate between all sorts of behaviours in the health professions which are technically ethical but actually contravene the ethos of care.

It's unprofessional in the old-fashioned sense – you're not professing the virtue of vocation.

It's a common experience that we see people in the patient clinic who have had exhaustive investigation, may have had laparoscopies or appendicectomy and only then come to see someone who will talk to them about their pain. The problem with this idea of the difficult patient is that it covers such a huge range; it covers every patient that makes us feel uncomfortable, at one extreme because they actually are unpleasant, and we get called to see them because they really are difficult to manage in a ward environment, and at the other extreme the trouble seems to be that they've never had anyone prepared to listen to them and get to the bottom of their problem. Each 'difficult' patient is unique, but often this has not been acknowledged and they are treated as if they are all the same.

We also do the reverse, actually. How many times have you seen a referral letter which said 'I would be grateful if you would see this pleasant ...' [laughter] but we don't see 'this awkward bastard'! There may something subtly hidden which may make it more difficult than we expect ...

...this fascinating and complex patient ...

¹⁷ See Jeremy's talk with this title in the 2011 transcript.

I love these patients – they are a real challenge, if you've got the time and the resources - particularly if we've got junior staff with us – to try to understand where they're coming from and what their problem is, how they've got into this situation and why they are behaving that way. We do run into problems even so; there are patients where we have to call it a day and walk away. But in the majority of cases, with our expertise, we can make progress in this way.

Iatrogenic difficulty?

Can I make a point as someone who doesn't have a lot of that kind of expertise [as a surgeon]? Many people come to you with an awful lot of baggage from people who have made them feel very difficult. Most doctors who can't make people better and don't even know what's the matter with them mistreat them. I have to confess to having detected it happening in myself: you blame the patient for the fact that you don't know what's the matter with them. You're in a lucky position as you are able to deal with these patients but don't underestimate the baggage they come with because they have been abused by previous doctors who have felt helpless – they are usually quite good doctors who can help lots of people but when they can't they take it out on the patient.

One of the ways we can help is to help patients see why they have had such a bad experience with doctors who aren't used to seeing people with chronic pain which isn't going to go away, and that's difficult for doctors.

You said you like these patients and that's important. Most doctors don't, and there is a subtle undercurrent here about who we like and who we don't like. It's a facet of medicine which rather bothers me: most of us in the health professions come from middle class backgrounds and have middle class values, but we're trying to treat across the whole spectrum of society. We actually don't like a lot of people whose lives are shit, and these are the ones with the biggest health problems. We're lucky if we do like dealing with them but I fear that most doctors don't.

It's being prepared, having had a sequence of experiences and encouragement and education and reflection that enables you... ultimately, in the pain clinic, one of our responsibilities is to help manage these patients ...

Therein lies the rub because we get lumbered with patients who are difficult because other people have been unable to diagnose and fix them. But we don't have a quick fix and it doesn't fit in with the economic model of the NHS. We need the resources to treat these patients with a much longer course than a quick fix operation.

With some of these people it's a behavioural problem as well as a medical one and they have never been challenged or told their behaviour is unacceptable. Sometimes I arrive on the ward and all the family is there haranguing the staff and I may be the first person to say unless you shut up I can't possibly help you...

...but to challenge them may need a psychologist who knows what they're doing ...

We were talking about role models and one of the things I remember when I was being taught about communication skills was a senior GP saying there is no such thing as a heart sink patient; it's your heart that sinks because you are feeling a loss of power to help them. It's very important to recognise your own weakness, and once you've established what may be the cause for that thinking, if you are confident

enough you may be able to turn this around. There is also the time thing – if I'm already behind in my surgery and I know the next patient is also going to be challenging it's going to be difficult but I know I mustn't take it out on my patient. If I get a letter of complaint it is often a time issue; or the patient might not have felt I was being sympathetic when I thought I was, but they may have sensed that I had something else on my mind. The key to that may not be more resources but training all the people looking after patients – not just doctors – to recognise that if you start thinking badly about a patient you need to start thinking about yourself.

In fact there is no difficult patient – it's a label that we impose on them. Like the dog trainers say: there are no bad dogs, only owners.

What is the agenda about taking people off sickness benefits? It's not so they can all get back to work; if you've been on sickness benefit for a year you've got a 5% chance of ever working again. That's not a secret, so this is just a political device to get people off sickness benefit and on to job seekers so they are less expensive.

... getting them off the unemployment numbers ...

One of the reasons why that has a wide appeal, and you see it in the screaming headlines about scroungers etc, is the universal trait in human nature to want to believe that other people are worse than you. It's not exactly self-righteousness – it's more the opposite: if you feel badly about yourself and you can identify someone who is worse – a scrounger or a difficult patient for example – you feel slightly better about yourself. I don't think any of us are immune to that. It's one of the barriers to improving things because it is so fundamental in human nature.

How can you say what is a productive use of time? You may see a patient for an hour every month; it might be productive in containing and controlling their problems and easing their journey but it doesn't look productive at all on paper...

But that's looking at a very small area, and if you look at it in terms of employment ..., social... welfare etc., and add all these things together, it becomes very effective indeed if you can stop them making the demands on society that they do at the moment.

We were talking earlier about MRSA and C.Diff - there is no one specific thing that you could put your finger on that caused that; there was a cluster of factors and if you tried to do a trial to see which one it was it wouldn't work. In the same way we have this focus on people who are difficult and we have to do a cluster of things to get results.

Low tech high touch

We need to look at things through the other end of the telescope... for low technology solutions which might be extremely cost-effective.

I heard a lovely phrase recently: 'what we need is low-tech high touch'!

Going back to the low-tech theme, perhaps we should be asking what might be gained by a more pervasively holistic approach to care and about the use of complementary medicine in that context. There was an interesting study of Scottish doctors who were asked about their capacity to offer patients holistic care. They all valued such a concept very highly and they all wanted to provide it, but they were

unable to do so because of their institutional constraints. They acknowledged that one consequence of not being able to provide it was that patients would go to complementary practitioners themselves. There is a potentially interesting tie-up between the capacity of complementary practitioners to offer care and time and the possibility that they may actually reduce the burden of long term sickness. One thing that disappoints me about attitudes to investigation of what certain types of CAM might contribute to long-term care is that these potentially very significant questions are not being asked, or where they are the results are not taken very seriously. They tend to be clinical outcome studies and not controlled trials. One of the claims that complementary practitioners make is that they can reduce the burden of long-term illness, particularly with early intervention. There was a trial at Bristol Homeopathic hospital of about a thousand patients, all of whom were referred by GPs, and the majority of whom were in some kind of specialist care. The clinical outcomes were very good, often including a reduction in the burden of prescription drugs and the frequency of attendance at other kinds of health care. That kind of study is replicated in various other contexts but not taken very seriously because they are not controlled trials.

Medico-legal work - ethical aspects in pain

Tim Johnson

“The legal system is male-dominated, oppressive and powerful. It very much relates to principles, rights and rules...[but] what I have got most from the work is the knowledge and interest you get from chronic pain patients by studying them in this sort of detail. I know of no other way you can get this experience of how people live their lives with pain.”

I'm going to try to emphasise some of the aspects of ethics and philosophy involved in medico-legal work, and look at types of practice and the process of producing a medico-legal report.

Yesterday when we were talking about the ethics of care I wrote down some of the words Bryan and Jeremy used and I can safely say that none of them appear in medico-legal practice! *Advocacy* is something we don't do, that's the job of the solicitor; I've never seen much *compassion*; *humility* never; *openness* definitely not - there are aspects of the work that require you to have information in privilege that isn't disclosed, and you often have information that the person in front of you doesn't know that you know; *generosity*, *tenderness*, and *intimacy* – no. The legal system is male-dominated, oppressive and powerful. It very much relates to principles, rights and rules. I love the phrase someone used yesterday; 'a discourse of the dominant' which summarises it very well. There is very little right to privacy. We do our best but when you are working for the defence the priority is to obtain as much relevant information as possible.

Medico-legal practice

The sort of cases we do include:-

1. Personal injury

This is the biggest group. Typically it involves someone with neck pain after a car accident and a whip-lash type injury.

2. Clinical negligence

There are an increasing number of claims arising out of pain practice, such as misdiagnosis or a needle that should have gone into a facet joint causing nerve damage. A bigger group involves pain arising in other specialties such as a botched surgical operation with infection and/or revision, or a duff hip replacement which is very difficult to walk on. We have to try to discover and prognosticate what is happening in a patient's life and anticipate what care they will need.

3. Miscellaneous

I have been involved in a number of cases where it has been alleged that testamentary capacity has been affected by drugs. An interesting example was that of a lady whose family disputed (unsuccessfully) her will which left all her money to

the handyman with whom she had been quite familiar over a number of years because it was written when she was on morphine.

Unfortunately there are an increasing number of deaths attributed by coroner's courts to therapeutic opioids.

The occasional criminal cases mostly involve accusations of perjury arising from civil cases for personal injury where people have over-egged their pain pudding and been caught out and prosecuted for fraud. I get involved as a witness as to fact.

We need to distinguish between civil cases - by far the biggest group - where the parties are the claimants and the defendants, and criminal cases where there is a plaintiff and prosecution. The biggest difference lies in the burden of proof. In a civil case this depends on a balance of probabilities: is it likely that this happened or not more or less than 50%, in contrast to the latter where guilt has to be established 'beyond reasonable doubt'. This is the sort of area that you're often not very sure; it could go either way and it can get very messy. In most of the cases you are appointed either by the plaintiff or the defence, but with small claims you can be the single joint expert. Those are rather nice because you can say what you like; they can ask you questions and the court will accept what you say.

The process

Usually you start off with a letter of instruction from the solicitors which draws your attention to the parts of the claim that they want you to examine, and then you do an examination of the medical materials, starting off with the patient's. Usually I prefer to see the patient, without having looked at many of the records, to get their view of it. Then you have the opportunity to look at all of the records, and my advice to anyone doing this is to look at absolutely everything: there is a huge amount of valuable information in records from occupational health, employment, Departments of Health and Pensions, benefits claimed etc. Then they send you sometimes dozens of reports which have accumulated by the time pain specialists become involved, mainly from orthopaedic surgeons and psychiatrists who have concluded that there is nothing wrong with them in their specialties so it's a pain problem and they come to us. Then there may be reports from care specialists regarding accommodation – does the house need to be adapted because the claimant can't use stairs? There is also surveillance evidence in many cases.

Having pulled all this together, one is usually asked to write a report. The next stage is that you are asked Part 35 questions¹⁸, (both parties having produced reports) usually by the other side. This can be a very lengthy and tedious process picking apart 'what do you mean by "is unlikely to return to the workforce".'

The next stage is when you get together with the expert on the other side to have a discussion and produce an agreed opinion, or an agreed difference of opinion. Somewhere along the line there will be a conference with counsel who is leading the case and providing the solicitors with legal advice. Usually before you go to court there is a settlement, and only about 5% of personal injury cases and 3% of clinical negligence cases actually get to court.

¹⁸ Part 35 of the Civil Procedure Rules, covering experts and assessors.

The report actually starts off with liability and breach of duty and that's very rarely a problem for pain reports. It's unlikely with a clinical negligence claim against a pain practitioner that you may be asked to comment on breach of duty. A link here with the Ethics of Care: was that duty of care and all the things we have been talking discharged or breached in some way? It's usually fairly straightforward: something happened which shouldn't have happened. The next question is: can this breach of duty be thought to have acted as the causative agent of the problem or the pain? Then a detailed description of what the problem is and the effects of the disability, distress, loss of enjoyment of life, and lastly prognosis.

A typical case

I thought I would take you into the amphitheatre of medico-legal practice by describing a 63-year old female who fell onto her left knee when she tripped on an uneven stone or something in the car park when she was leaving work at a supermarket where she was employed. It was classified as an industrial accident and she was suing the supermarket.

She had a long history of depression and was a frequent attendee at her GP's surgery with a wide variety of pain complaints associated with stress. There was some reference to abusive relationships throughout her life. There had been one episode of left knee pain - the same joint – eight months before the accident which had been quite significant and took her to her GP, in amongst all her other pain symptoms, but no further problems with it. There were relationship and financial problems and she had a poor work record.

She went to the A&E department fairly soon after the injury. It was clear that there was no major damage to bone, joint or ligaments but there were some minor degenerative changes on the X-rays. The GP managed her conservatively but eventually sent her to the orthopaedic department who did a couple of arthroscopies, joint injections, MUA's (manipulation under anaesthesia) etc. Over a period of about two years, during which she saw about eight or ten junior orthopods, (never the consultant) matters only became worse. They began to think of a CRPS (chronic regional pain syndrome) problem and sent her to the pain clinic where they found no evidence of this, although there were some possible elements of neuropathic pain. She had a long trial of blocks and medication but nothing seemed to work. When I saw her she was highly distressed, severely disabled with exaggerated pain behaviour. There were inconsistent levels of disability. She staggered about the consulting room holding on to things and went out using crutches, but if you followed her down the corridor and watched her go out into the street she was walking much more normally. Looking at her shoe wear (something we don't normally do in the pain clinic but can tell us a lot about the patient's gait) confirmed that although there was no doubt pain in her left knee there was a lot of exaggeration.

We are going to get two sets of reports on this case: the claimant's expert's report is no doubt going to say her problems are the result of this injury using 'indirect mechanisms': by this we might invoke the fact that she had assumed there was something much worse wrong with the knee than the underlying arthritis and this took her along the path of injections and arthroscopies. Had it just presented as further knee problems, this constitutional problem would have been managed differently by the GP and she wouldn't have ended up in the highly distressed state that she is in now. The defendant is likely to say that she had a bit of a knock on the knee with a few abrasions and the natural trajectory of her pain symptoms was unaltered by this accident.

How long after the accident did the pain become as bad as it is now? I see a lot of patients like this and there always seems to have been a gap - it's rarely 'aagh - quick get an ambulance'.

In this case she did go straight to the A&E department; it was a nasty knock and it was important to exclude fracture or whatever. But this delay is interesting: in many cases people think this is going to settle down - you have a car accident and typically the pain comes on the night after and is much worse the next day. They may go to A&E then, or may often wait a week thinking it will get better, by which time they will have got more anxious about the problem.

Did she have elements of neuropathic pain?

Not specifically. You would be looking for increased sensitivity or allodynia outside the immediate area of the injury. You can see this after surgery with vague location. There was no radiation. Of course any pain is neuropathic in the sense that it involves nerves and you can have hypersensitivity on top of nociception. There was certainly no evidence of CRPS or any indication that antidepressants or anticonvulsants would help – and they had been tried anyway.

I'm interested in the timing of when this or patients in general decide to move into the whole litigation process, or whether indeed there is a typical timing. For this lady it seems that she's not gone far into the pain management trajectory before making her claim.

Actually it's now three years since the accident and she has been in the pain clinic for the last one. I suspect that she actually started claiming about two and a half years ago.

... her previous knee pain? ...

Just this one episode among many other joint, back, abdominal pains etc. – she was full of pain.

I notice you refer to her as a patient all the time rather than a client which seems to imply that despite the absence of all the things like compassion etc. that you said had no part in the judicial process, you do seem to have a sense of duty of care yourself.

It was my intention to avoid talking about patients! When she was seeing the orthopods she was the patient, but when she was seeing me she was the claimant. I probably switch between the two ... I don't distinguish ... I use the same processes as when I am assessing a patient.

Was she keeping a diary?

I don't know. Some patients do for many years...

... I'm often suspicious when they start keeping a diary in the ambulance on the way to the hospital ...

It depends on the context - if they've had a neighbour who has had difficulty claiming for a perfectly genuine accident which was not their fault and advised then to write everything down that was sound advice.

Surveillance

This is one of the most intimidating areas. It often happens in high value cases which seem to be going along a long while or where the defendant's solicitors are particularly worried about a history of previous claims, or a high level of claim for what seems a very trivial injury. Sometimes patients are caught out, and there is a wide gulf between what they tell doctors and what they are seen to be doing. There are companies who do this professionally; there has to be some editing of hours of video and there are other companies who will do this to highlight deficiencies. The film might not be representative: the patient might be having a good day; people with fibromyalgia may save their energies for one day to do their shopping and people with chronic pain do get good at pacing themselves.

Patients are sometimes filmed with their grandchildren and they may feel as if the whole family is being intruded on and compromised.

The joint report

The joint report is supposed to be a meeting of minds but can be quite an adversarial process. Generally speaking, as regards pain management, I am quite impressed by the people I work with on doing these reports. You might have slightly different views but in most cases it's possible to arrive at an agreed opinion. We try to be as objective as possible and avoid being labelled as a defendant or claimant expert. There are about a dozen pain doctors in the North doing this kind of work so we mostly know each other. Our separate and joint reports are all used as evidence.

It's possible that your perception of that case might change in the course of that discussion.

Yes. I was involved in a case of a woman with back pain who I didn't examine thoroughly enough. I normally check for joint hyper mobility syndrome but I forgot, and the claimant's expert pointed out that she did, and this is a risk factor for back pain. This actually rather backfired on her case, but if I had picked it up it could have been identified as an important trigger for her having the problem.

The settlement

These cases rarely get to court, but are settled in a series of meetings, and all these reports rarely get to see the light of day. Sometimes it seems unjust, particularly in clinical negligence cases. They may be settled because there is a risk in going forward with the case although no-one is admitting liability. Personal injury cases are generally settled in favour of the claimant if something goes wrong that shouldn't have; there is a perception of the big rich hospital and the poor patient and sometimes they get more than they deserve. With the bulk of the personal injury work there is some sort of pain problem but there seems to be a degree of exaggeration which is often impossible to quantify, particularly if there is surveillance evidence although this may in fact support the case, for instance if it shows a limp.

The main headings in these claims are for care and loss of earnings. Sometimes we are under pressure and that has to be resisted. But generally the system is reasonable; it's very cumbersome and very expensive but in most of the personal injury cases it gets settled with a reasonable outcome, albeit with some collateral damage: the patients get changed by the process.

I have had patients who have great difficulty getting better because they fear that if they don't show this sort of behaviour they will lose any compensation for their pain and suffering. So the whole process is counterproductive on yet another level as it can produce very dependant people – even if they win their case they are not the same person.

You're absolutely right. Chris Main distinguishes exaggeration to deceive as opposed to exaggeration to convince. We do see both in pain clinics. One of the areas that has accelerated is that of claims for Disability Living Allowance. If when you see accelerated pain behaviours you probe a little bit behind the finances of the situation you may find that this has been stopped.

When I was an anaesthetist I had a negligence claim against me. One of my patients ended up with a nerve palsy after a horrendous operation – a bloodbath of a spinal procedure - during which I thought the patient had died. He sustained a weird sort of brachial plexopathy, and was awarded £30,000. I didn't think I'd done anything wrong; in fact I was happy that I'd kept him alive. But you just have to accept this sort of thing.

One thing that can be very uncomfortable is criticism of colleagues. In clinical negligence cases it's not good to be making reports against your best mates. In a small world like pain I know people from all over the country. In doctors.net you see criticism of anybody who does legal work, especially clinical negligence. I know of experts who will only do defendant work.

I must admit I am now much more suspicious of patients and don't always accept what patients tell me without cross-checking. One patient was referred from the orthopaedic team for an epidural. There was a reasonable indication for this with some disc fragments in the canal, and considerable disability. He came into the clinic extremely disabled with two crutches. I did find out that he had been a builder and business had been very poor; he had been trying unsuccessfully to claim disability living allowance. But there was something about the level of disability: he took about an hour to get from the car park leaning on his brother, so after I had arranged the epidural I decided to follow him down the corridor. He was very slow for the first 20 yards but got progressively quicker and after he had paid for his ticket I had trouble keeping up with him as he marched along briskly swinging his crutches!

Do you think he was trying to deceive you or convince you?

I think this was deception. But it was a difficult situation. Should I go ahead with arranging the epidural? I now had knowledge that suggested he didn't need it. Ethically, could I justify putting him at possible risk or using time and resources someone else could benefit from? Any thoughts as to what I should have done?

Do the epidural with saline

(Several mutually inaudible suggestions)

In most cases you can't go wrong by telling the truth. So having consulted several colleagues and the legal department, I wrote a carefully-worded letter to the patient saying that as I was leaving the clinic I happened to notice that his gait was normal which gave me some cause for concern, and we needed to discuss this again, offering him another appointment. He did come back again but only after he had

seen one of my colleagues privately and been given an epidural. He insisted this had been marvellous and could he have another!

Why if you were suspicious did you offer him an epidural?

It wasn't until he had left the room that I began to have doubts. Incidentally his brother was complicit – families often are.

What do I get out of medico-legal practice?

Why do I do it? Well, money does come into it - it's quite well paid. But it's quite preoccupying; there's a lot of hassle and deadlines can be tight. You do get to travel, and visit some interesting homes, and see some weird things. You don't get much respect for the clinical negligence and personal injury work, but in the coroners' courts you do sometimes get to feel you are helping to change the world a little bit.

What I have got most from the work is the knowledge and interest you get from chronic pain patients by studying them in this sort of detail: the access to their records, their lives and their behaviours. I know of no other way you can get this experience of how people live their lives with pain.

Trust me – I’m a patient

Paul Dieppe

“Trust matters most when there is uncertainty, when the stakes are high and when there is dependency on another person, and that is absolutely where we are if we are ill, so trust is critical in healthcare.”

In a sense this is a sort of counterpoint to the ethos of distrust that seems to run through the legal process that Tim [Johnson] has been talking about. I’m not sure what the word trust means; it’s one of those words we use in medicine, and philosophy and ethics in particular, without really knowing what they mean. The psychologists are the best at this because they take a word and then invent a way of measuring it, and then it becomes a reality.

So what is trust? It’s hard to define but when preparing this talk I looked up a couple of definitions. The first was: ‘a firm belief in the reliability, truth, ability or strength of: someone or something’. The second was: ‘firm reliance on the integrity or character of a person or thing’. Trust is expressed in a firm handshake and it struck me that the handshake is a sort of high touch low tech intervention. Maybe we don’t use touch enough in medicine.

Trust matters most when there is uncertainty, when the stakes are high and when there is dependency on another person, and that is absolutely where we are if we are ill, so trust is critical in healthcare.

Research

I have been involved in research into trust over many years. For a while I was running the MRC’s healthcare research collaboration and I funded and helped with Mike Calnan’s and Rosie Rowe’s research on trust which ended up in the publication of a book *Trust Matters in Healthcare*. They talked about three key issues. The first was the erosion of trust which Onora O’Neill highlighted in her Reith lectures some years ago. The second was the dependency of trust relations on structures and organisation in the health service. The third, which we have already touched on in this meeting, was the lack of trust between doctors and managers in the NHS, at least in secondary care. That is a real problem, and must lead to a dysfunctional organisation. Calnan and Rowe tried to suggest some possible ways out of the situation. They also found that the little literature on the subject was incredibly doctor-centric. It was mostly about the trust that patients are supposed to have in their doctors, not the other way round. It wasn’t relational trust. Nor was there any mention of us trusting other healthcare professionals.

The amount of trust that we expect our patients to invest in us is enormous. The GMC has said: ‘trust is a critical component of the doctor-patient partnership. Patients must be able to trust doctors with their lives and health.’ It’s always this way round; it’s not relational trust. None of the GMC stuff puts it the other way round as in my title. We don’t trust patients; it’s commonplace in hospitals to say things like ‘you can’t believe what people say about giving up smoking or drinking’. We ask ‘is his pain really as bad as he is making out?’

We (Calnan, Rowe and I) wondered about turning this the other way round. Betty Barnes and Nicholas Brennan have headed up this work and we have two papers

ready for publication, 'Trust between doctors and patients – a review of the evidence base' – Brennan et al, and 'Trust me I'm a patient – an evidence synthesis of qualitative research into consultations for Medically Unexplained Symptoms (MUS)' – Barnes et al. The material mostly comes from the USA, is mostly of low quality, most of it is about primary care and about oncology and palliative care, and it is very doctor-centric. There hasn't been much in the last decade; people aren't looking at this area and empirical work is very sparse. The qualitative work is the more interesting. There seem to be three main issues for doctors seeing patients with medically unexplained symptoms: first the concern that some patients may be exaggerating their symptoms for some gain such as money – a very common reason for doctors to say they don't trust patients. Then there is the belief that they are being manipulated by their patients, and thirdly the inability of doctors to find congruence between what they believe might be going on and what the patient believes, so you can't find a common narrative and enter a trusting relationship.

The main issues for patients were worry that doctors did not believe their description of their symptoms, and/or the severity of their problems, lack of trust in doctors who did not examine and investigate them fully to 'nail the cause', and the related problem of their search for legitimacy.

There is also evidence that if the patients do not feel they can trust the doctor, they behave differently. They do not tell the doctor everything. They are less likely to comply with the suggested treatment and they are more likely to look for another health care professional, engaging in doctor-shopping and seeking help from Complementary and Alternative Medicine (CAM).

Calnan and Rowe described three forms of trust:

1. 'Forced trust'. If you're in a situation where you are very ill and in critical care you don't have any option - you just have to let people get on with it.
2. 'Unconditional trust'. I still come across this: the 'gosh doctor you're wonderful!' effusion. It really makes me uncomfortable, I don't know why.
3. 'Earned trust': - in most situations in health care you have to earn trust.

I think that's a rather narrow way of looking at it. First of all it's not a binary concept, as if there were levels of trust and you can trust someone a little or a lot. In health we need a lot – what you might call deep trust.

Another thing that has worried me is the concept of instantaneous trust (or distrust). You hear people say: as soon as I saw him I knew I could trust him, or as soon as he walked into the consulting room I knew I couldn't trust this man. What's that about – how does that work? I find this quite perplexing but it is a real issue.

Relational trust

What seems to be missing from the literature and what may matter most is relational trust. How can we help establish deep trust between ourselves and another person in the healthcare situation? There is some suggestion from qualitative studies that your patient will not trust you if you appear not to believe them and take them seriously, or if they detect incongruous behaviour, such as your saying it is all psychosocial but still doing some more biomedical tests. Patients pick up our mixed messages. We need to learn from this especially when dealing with patients with MUS (Medically

Unexplained Symptoms: what a wonderful term! – it just shows the absurdity of medicine). We do get mixed up – we worry that there may be a cancer we have missed. People pick up on this and regard it as dishonest, and they don't trust us. They may have lost trust in the medical profession as a result of a series of such encounters when they come to see us, and in the pain clinic you often start in a bad position with people who have learned to distrust.

Trust is hard to regain once it has been lost. How can we try to do this? The research suggests that the vital elements include being able to make the patient feel 'safe' and 'validating' their experiences. 'Safety' is the critical issue. A medical encounter of almost any nature is an anxiety-inducing situation which most people feel very unsafe in. Getting to a feeling of safety is a major component of getting the right autonomic nervous system balance and evoking the 'nurturing response' that I talked about at a previous meeting.

Validating interactions have been described by Linehan as involving the therapist accepting and taking the patient's responses seriously, without disregarding or trivialising them, communicating this acceptance, and conveying that their responses make sense and are understandable. Validation sounds a bit like empathy, but it's more than that. The concept has been developed in Dialectical Behaviour Therapy, where the process is said (by Fruzzetti) to be not just agreeing with someone but 'about finding the *kernel of truth* in the interaction' and thus only validating elements that are already valid, or true, in some way. So if someone is showing strange or exaggerated pain behaviours there are kernels of truth about that person and what has gone wrong in their lives which may explain why they are in a mess. You need to validate those kernels of truth and work with them, not simply accepting all the other garbage the patient has come out with.

Conclusion

"The best way to find out if you can trust somebody is to trust them."
(Ernest Hemingway)

We must move on from 'trust me I'm a healthcare professional' to 'and I will trust you'.

Discussion

Paternalism

I've always been intrigued by the old-fashioned picture of the paternalistic doctor. Paternalism did exist but not, I think, generally. You said that patients had to feel safe but it has to be more than that. They have to feel accepted for who they are before they will tell you what they want to, and in this there is a human interaction between the doctor and the patient.

But 40 years ago paternalism was the norm! Nearly all doctors were male and ...

... I remember doctors when I was a child who were not paternalistic and seemed genuinely concerned ...

... I hadn't heard the term until recently ...

It was a bit paternalistic ... you got a packet of pills which were just labelled 'the tablets'...

... we used to give Esotcal tablets to patients in A&E and it's just lactose spelt backwards! They were very effective!

Some patients want us to be paternalistic, don't they?

No, they want us to take control – that's not quite the same thing. If I go to the doctor I don't want him to ask me what I want him to do.

Roles

We were talking in the pub last night – where the best work of these meetings goes on – about working with actors, trying to create dramatic representations of good and bad, trusting and non-trusting consultations. What the actors are teaching me is that there is no such thing as authenticity, which is a bothersome concept. They said to me 'it's all just performance like us'. But I replied 'ah, but for a really good consultation you need to be totally authentic and honest with yourself, who you are, and with your patient.' And their response was 'well, you should use being more authentic'. We can use the concept of selves: we are many selves, so where is the authenticity in those? The analogy one of the actors used was 'when I'm on stage I'm three or four people: I'm one person worrying if I've left the back door open, another thinking gosh I look good in this outfit, another is thinking my god I'm going to forget my next line, and quite a big part of me is being the character I'm acting. I'm all of those people at once.'

Is that necessarily being inauthentic? Can the awareness of what's going on be a kind of authenticity?

It is an awareness of who you are and what aspect of you is involved with another person. It leads into the idea of resonance with another person and when you get into that.

What I [Jeremy Swayne] was talking about yesterday wasn't to do with whether medicines do anything but the question of how you can get good interactions that you can't demonstrate by randomised controlled trials. The one thing that is a constant feature of that kind of consultation is the validation of the patient. It is absolutely essential that the style of the consultation and history taking takes that seriously. It is a sort of aphorism that you never distrust any piece of information given by a patient. That is a powerful healing thing. There is also an aphorism in the Oxford Handbook of Clinical Medicine which says, precisely, 'where there is no trust there is no healing'. That seems to reflect to me a two-way relational state.

When, like players on a stage, you are assuming different roles ... when you are playing the trusting doctor is it possible to entirely suppress the critical un-trusting doctor? I've never thought about that before but I wonder ... do I adopt a different persona when I am seeing a patient clinically? ...

That in a way is the sense of what I am saying: which self are you? In the clinic we are both of those people: a bit of us is trying to connect and believe and care, and another bit of us thinking ... I just wonder about this ... someone in the background whispering ... could this be malingering? Can we immerse ourselves in just one of those roles? I don't know.

That may answer a question: you mentioned patients taking an instant dislike to a doctor. That doctor is playing one role – his standard role in the clinic. I find myself often playing a different role with different patients or the same patient each time they come in, and working quite hard at it. When I have students with me I want - as well as the technical pain stuff - to look at the consultation and work through the consultation. It's hard work. If you're just playing this single persona, it might be why people take an instant dislike ... it's chemistry, the same as why don't I like some patients.

... something to do with mirror neurones? ...

Mirror neurones are fired by expressions and voice etc. - they're not kind of in the ether. We are extraordinarily sensitive to minor facial changes ... It may be that the instant dislike is triggered by facial expression ...

... even the way the patient gets out of their chair in the waiting room may trigger that before they've even said anything, and it's hard for you to get back into your stage role again to work with this guy ...

I learnt when I was in GP training to be aware of the past experiences you carry around with you and of the way that a patient might trigger off a reaction which could cause difficulties in your relationship, for instance if you were bullied or abused in childhood by someone who looks like them. I've got many selves in myself that I can't control but if I can recognise when it's happening I may be able to do something constructive with it.

Phenomenology, which we discussed at a previous meeting, may come into it...

This isn't just about the relationship between individual doctors, nurses, physios etc with their patients, but it also involves the system. This can be quite abusive and sometimes seems to be set up to generate a very negative attitude to trust. I've had recent experience in orthopaedic outpatients where the system is very efficient but very dehumanising, and this can even be a problem in pain clinics. I don't know how we can get around this.

Prejudging patients

A prejudicial picture of the patient leading to premature loss of trust may start with the referral letter. Sometimes this conveys a lot of information, and one thing that often comes across is the GP's level of distress, which may be enormous – they may be absolutely despairing. I have to have a serious talk with myself – maybe I'm running late and I'm tired and I have other things going on in my head and it's 'Oh My God ... look at this ... they've been ten or twelve times a year to the GP for years with every possible condition ...' and I have to go 'phew ... OK' - and walk out into the waiting room and do my very best to be open and receptive however this patient is going to be. And quite often the patient is fine. It's just that the letter was full of the GP's distress. Do you remember when Alex Cahana (pain professor from Seattle) talked to us a few years ago he said he doesn't read the notes ...

... I don't read the notes either because it does affect my attitude to the patient ...

... I do that when I'm faced with a difficult patient, although I may with a straightforward one. I make a point of saying to the patient 'I haven't read your notes

because I want to hear it from you - I'll read your notes later'. Actually it's quite positive because the patient thinks 'someone is listening to me'.

How many times do you find that the pain they describe to you bears no relation at all to the referral letter?

... I read the referral letter to the patient ... and discuss what they think they've come for... there's often a big disparity ...

...but you're already biased ...

...on the other hand if you've acknowledged that what they are telling you is different from the referral letter it gives them an opportunity to see that you are not fixed.

Do your patients have the opportunity to see your letters and your notes? - because otherwise they don't know if they can trust you ...

They do – it's hospital policy to give copies of letters.

Using words like manipulative and malingering is very disabling for a clinician. I never use them because it immediately blocks me from doing anything very useful for that person. So I use reflective listening: if someone is coming in with their suffering, no matter how annoying or challenging they are, that is coming from suffering and they are hyping it up because of some abuse they have had before; there is always a reason why they are annoying or demanding. I often say: you're obviously pretty upset – there's a lot going on here – and you can see them visibly calming down; they don't need to exaggerate any more.

I'm interested in patient involvement in planning services, but as soon as you suggest this to colleagues there is a complete dissonance, and it's a real struggle for clinicians. It's obviously important for commissioning but our colleagues really find it difficult to accept that patients are people with expertise, and can offer a new angle on what we should be offering.

That's interesting because in the research world that has become pretty much the status quo. There is real patient involvement now in most major research studies; it's not paternalistic, it's real, and it changes research for much the better. Maybe the research community needs to teach the NHS about the value of this.

... we have the expert patient pathway - it can be very useful ...

Trust in the medico-legal setting

I want to return to the idea of trust in the medico-legal setting, because I think it is relevant. Sometimes when you see a claimant there seems to be some exaggeration. If you explore that with the patient you can come to a new understanding with them – that you understand the complexities and may be able to help them if they will be straight with you. You are there as a person to be trusted and I think it's possible to work towards that.

Does that work? If you are on one side and you encourage the claimant to be open and honest but they think that other side are going to jump on them and say their case is rubbish they won't be open.

I have thought it's always best to straight down the middle – never to exaggerate or polarise, and go for what you think is the truth. Having uncovered this and worked through what you think is exaggeration, you try to get to what you perceive is the truth, and paint the case with the good and bad in it. When I am seeing a claimant for the defence there may clearly be a lot of antipathy, and you can sense the apprehension that it's going to be a very adversarial process. But sometimes when I am trying to understand where the patient is coming from and what happened to them I can break through; something can emerge which may not be a very high level of trust, but something that does work in breaking down the barriers and resolving the dispute.

You also said there was no room for privacy. There must be a conflict between getting to the truth of the matter and how you handle that in terms of privacy and confidentiality.

Yes - the more you know the more you can comment on...

...you have to share it ...

... but you're sharing it with people all of whom have taken an oath of confidence about their dealings with the patient.

I rarely see patients where there has been a straightforward statement of what the problem is. There has nearly always been some hiccup, usually because the claim is very large or ... so the privacy has to be invaded in order to explore that.

Relational trust

When Paul was talking about relational trust I was very much reminded of a wonderful talk that Father Andy gave at one of the early meetings about what he called sincerity of the heart, contrasting it with feigned sincerity. If anyone is interested I can copy it and send it out.

I was struck by the phrase kernel of truth - sometimes called the centre of the case. You may have to discern it from different kinds of information. That kernel might be revealed by a patient, for example by the way they describe their physical sensations consistently...

The dialectical behavioural therapists centre on this. They emphasise body language and facial expression as the way of detecting the kernel of truth, not so much from lies as from the irrelevances around it. So you know you have hit someone's emotional centre from their body language or their tone of voice. Some of us are very good at detecting that within a consultation and some are rubbish.

What is often important is allowing the patient to present the raw material out of which ...

... absolutely – you give them space to do that and that is where the safety comes in – if they don't feel safe they aren't going to go anywhere near there ...

Jumbulance and the Ethics of Care

Chris Chisholm

“A lot of our VIP’s feel they don’t belong, that they are the victims of prejudice and that the system has let them down.”

The Jumbulance Trust

The Jumbulance Trust is a small national charity. We employ the drivers and a part-time secretary and nobody else in the Trust is paid, so everything else we receive goes directly for the benefit of our VIP’s, as we call them – not patients or clients. We have affiliated self-funded groups throughout the UK. I have been involved over the last ten years, starting in Berkshire, and since I moved six years ago I have been running the Hampshire group which runs four holidays a year. Other groups run one holiday a year, and some are for disabled children or parents and children. My background is in palliative care so there will always be patients with palliative needs in my groups. Over the years, there has been an increasingly proportion of long-term disabled, both people with things like MS who are highly dependent, and people with very long-term conditions like cerebral palsy and polio who have got to the stage when they have real problems and enormous care needs; nobody else will take them and they can’t fly. They enjoy it so much they want to come again and again and the only way we can accommodate this is to grow. There are now several new groups in Berkshire and Hampshire which I have been helping to set up.

About a third of our clients have palliative care needs and I am very insistent that we keep it that way; some of them of course do die which leaves room for someone new, which is why I don’t like to have the holidays fully booked too early. Referrals come from GP’s, district nurses and social workers, and people self-refer.

We have three jumbulances which look like ordinary buses that simply take wheelchairs but they are much more than that. There is a platform lift, and three exits for safety reasons. Inside the floor is completely flat. On one side there is a row of seats which have more leg-room than normal and on the other there are beds. These can be taken out at our destination (we go all over Europe so some of our journeys are very long). Vehicles of this size would normally accommodate 56 people but we only take 20 or 22, so we have a lot of space. There is a kitchen at the back and a disabled loo which is big enough for three people so there is room for two assistants. This is absolutely essential as it is a major anxiety for a lot of people. There are curtains round the beds so you can do what is necessary on them. There is resuscitation equipment by each bed with oxygen and electrical points for nebulisers, ventilators etc. We are offering 24-hour care, given by volunteers including nurses, doctors, physios, OT’s and lots of ordinary helpers who have no professional caring background. There are a lot of women who are natural carers – they may have brought up a family and grasp what we are about very quickly, but I have to say in fairness that although the Ethics of Care is the domain of women we do get a lot of men applying; we need them as we pair up our clients and our volunteers one-to-one, men with men and women with women; if you need a nurse you are paired with one but if you need less care you are paired with a helper and the nurse will go in when needed.

Difficulties

Do we ever let people down? Inevitably if someone applies in September our trips may be full, we usually have three months off from November as few people want to go away in the winter and it may be too late for them; they may have died before the opportunity comes up for them. Some groups only want to take people from their own area where they have fund-raised, but in ours we will take them from elsewhere. Sadly there is a lot of disparity of provision throughout the country: there is only one group in Wales and nothing north of South Yorkshire. Last year we did a fund-raising trip coast-to-coast; we took a jumbulance to demonstrate what we had to offer, and visited hospices. Earlier this year I followed an international conference on palliative care in Gateshead with a tour of hospices to give talks to patients and staff. But sometimes we are blocked - one Cheshire home didn't even want me to come as they said their patients weren't interested – so people are denied the opportunity even to learn about us. And out of that not one hospice or organisation has come back to us. I don't know what it is about some areas: we are a completely voluntary organisation and we are asking a lot from people. Sometimes people will say 'we want our council to organise this' or 'why don't the health authority offer this' – well, they're not going to, that is the reality, and it is very difficult to get things going in the North.

I find it very frustrating that when I go out every spring to give talks to patient groups, social workers and even medical students - a mixture of recruiting and trying to find new potential clients who don't know about us - to hear again and again that the day centre for long term disabled or the hospice day centre is closing or has been closed, or the respite budget has been stopped. People who live on their own are deemed not to need respite because there is nobody caring for them. We consider that we give excellent respite, indeed a real holiday, so someone looking after an aged relative or a young person needing a lot of care can actually go on holiday themselves without feeling guilty.

But this is being stopped, so a lot of people say I'd love to go but I haven't any money, and that worries me. If possible I go and see them at home and help them to fill in a form about all their care needs, and if they say they can't afford it I can look for funding. We never turn anyone down, so if you want to refer anyone do remember that – it's not difficult to find money if you know how.

People have to give me their trust and it's a big step, and we have to trust them, which may be difficult if people aren't completely honest, for instance about their weight, which is practically the only reason I have to turn people down. (There is a maximum of 20 stone imposed by the platform lift, which has to accommodate the wheelchair and the driver as well as the patient) I did have to turn down one gentleman but, wonderfully, when I got in touch the next year he had managed to get his weight down to 19 stone!

There can be a difficulty in taking older people: we have lovely young groups for which we have no problem getting funding; everybody wants to give money for children, and we get plenty of money for hospice groups. But we have to recognise that if we take long-term disabled older folk who desperately need what we can give them - something to look forward to and a reason to carry on - it is sometimes difficult to get the funding, but we have never failed. This year, however, I have had to look harder than ever for funding but I have not so far been refused. The money is

still there but the funding organisations all tell me that whereas they had an enormous pot and were getting lots of interest on it that pot has diminished and whereas they were giving out £60,000 grants per quarter they now only have £6000 to give away. But there are some very generous people in the charity who say 'if you need some money, Chris, just let us know' nobody else knows who they are, and I can always rely on them. But we are very lucky – there are people in the area where we live in who can afford to do that.

My only really difficult issue, which nearly led me to come out of Jumbulance in the 90's, concerns AIDS. When I helped set up the West Berkshire palliative care unit in 1992 a quarter of the beds were allocated to people with AIDS. A couple of years later a gentleman with AIDS applied to go on a pilgrimage to Lourdes. I was going on that trip and knew that there were places available. To my horror, when he sent in his application the Across Trust, who was running the jumbulances in those days, returned it with a refusal. They were unwilling to tell me why over the phone but in the end one of the trustees wrote that they were unhappy to accept him because of his diagnosis. I was so angry – I had the distressing task of telling him why he couldn't go, and I pointed out that they only knew the HIV status of people who were honest enough to tell them and in any case it wasn't an issue as although we don't wear uniforms we are professional nurses and take the usual precautions including wearing gloves with all our patients. I pulled out of this group and announced that I was leaving altogether, and felt bereft. I spoke about the issue at the next national group leader's conference, but shortly after that the Across Trust went bankrupt! I became a trustee of the new trust and of course we now take loads of people who are HIV positive.

But there are lots of good things going on: a few weeks ago I was at the National Council for Palliative Care meeting with Marie Curie and the voluntary services working with statutory authorities trying to pull everything together to do with long-term care. I was there to say you have really got to be innovative, and look at organisations like us who are providing so much better respite care than nursing or care homes, and work with us. I got a very enthusiastic response and was invited to speak to lots of palliative care organisations across London. Last week I was at meeting of an organisation called Together for Short Lives run by young people for young people with palliative care needs, about the transition from child to adult services - a big issue and people often feel totally abandoned when they move. They are not getting holidays and I was very pleased to tell them about the Trust.

Our volunteers

People who apply and people who refer them are quite realistic in their expectations, and we have to match up the clients with the appropriate volunteers as soon as we know who is coming. We have every kind of nurse: Cheshire Home nurses are particularly good with long-term disabled. We don't get every kind of doctor - they are all GP's and palliative care doctors. As a trust we try to give lots of opportunities: we subsidise young people under 25 such as medical students and nurses but also disadvantaged young people from the community who may not have the opportunity to travel. We are sometimes asked to take people with learning difficulties or even mental health problems who may be sponsored, for instance by a Rotary club or a church. This is asking quite a lot of the group leader in matching them up as they may need a lot of keeping an eye on. We took one young man with drug and alcohol problems who said he couldn't stay up late or get up early to help; we put up with this for a couple of days and then my daughter who is an OT in forensic rehabilitation took him in hand and within 24 hours he had knuckled down and was doing

everything! It was wonderful to watch him blossom into a carer – something previously quite foreign to him, and he already wants to go on another trip.

I spend a lot of time recruiting young student nurses who are always thrilled when they come. They may decide that that we are an older group and that they would rather go to a pop festival like Glastonbury with a group that works with the army who provide tents with wooden flooring, but overall everyone is benefitting so we're not really losing them.

Making a difference

Some of our long-term VIP's are heavy on care, or heavy emotionally to be with. There are times when you see someone has applied to come again and you think – Oh no! ... but you have to step back. We have one lady who can only move one hand and lies in her room for 357 days a year and has eight days with us, when she actually gets out and does something. Some people are in bed for 22 hours out of 24, and we have to replicate that level of care. But they may get in a wheelchair to socialise at dinner; or go to the pub and drink beer if necessary through a straw; they will go up Snowdon or on a lake in the Italian Tyrol. It will exhaust them but they do want to do it.

You may have seen the headlines recently about a 64-stone woman who had to have her house partly demolished to get her to hospital and was quoted as saying 'I want to have my life back'. She is one of the many people out there who need both support and opportunities to achieve just that.

A lot of our VIP's feel they don't belong, that they are the victims of prejudice and that the system has let them down. When they are referred to us they are very much at the end of the road. We don't do any research but we do give out a questionnaire at the end of the trips and the feedback is very rewarding. Many of them say it's enabled them to get back a sense of fun, that they had forgotten what it was like to feel joyful, that they feel alive again, and that they belong again. This can't be measured and it's something very difficult to get across to people when you apply for funding. Some will say that when we first met them in the hospice they were very near to giving up, but *we have opened a door*. And that's what we try to do – to open doors for people who have lost most choices in life. They feel it's all over and we say 'no it isn't!' It's not just the holiday but they need people who will go on supporting them, and relationships may continue afterwards. I have said that the VIP's get a lot out of this but the helpers get just as much. It can be life changing for both.

Discussion

I was interested in your Lourdes experience. I've been there a couple of times recently. Like you I'm not a Catholic, but I have an interest in the caring and the potential for healing. I think extraordinary things do happen there. Talking to people there I was very struck by the fact that for a lot of those closely involved, it's much more valuable to the carers than to the pilgrims. A lot of professional carers go there, and a lot of people like high-powered bankers who give up several weeks of their time each year to be a carer. The miracle of Lourdes is as much about what the givers get out of it as the recipients of care. The other thing about Lourdes which resonated with what you were saying is that the pilgrims, very sick people, are treated as if they are very special – the most important people there. In the rest of their lives that never happens.

Those sorts of elements of care don't happen anywhere else – certainly not in the NHS.

When people ask what our organisation is all about, I reply, unashamedly, that *it is about love in action*. It's a win-win situation for everybody.

How do you decide who goes on these trips – you must get lots of people wanting to go?

I suppose it's basically first come first served, but the problem is that people who have been before are there in January wanting to come. I am very insistent with our group leaders that we have to save some places for people who still don't know about us, so if someone is referred from a hospice in July we still want to be able to take them. But if some of those places aren't filled at the last minute we are going to lose out financially – the hotel and everything else still have to be paid for. It's partly a matter of experience in the group leader how to judge the risk.

I haven't mentioned the drivers – we have to take two on our European trips; they are working long hours for eight days non-stop and they may only have a day off between trips to clean the buses, so they really need their winter break. We are also registered as ambulances and subject to all sorts of risk assessments and protocols, and we try to stick to the EU regulations for driver times.

You put me in mind of a theme we might explore with one of our Thursday speakers, which is that of assisted living in relation to assisted dying; it seems to me that there must be a seamless relationship between the two. What you do must have implications for other aspects of end-of-life care?

Obviously I am a proponent of excellent palliative care, and for me this is a continuation of palliative care. I went once to a lecture at the RSM given by Baroness Ilora Finlay - she's amazing, still doing her on-calls as well as her work in the House of Lords. She talked about a patient who had come to her as a last referral because they wanted to go to Dignitas to end everything. She asked if there was anything else she could do for him or anything else he wanted to do. He replied that he really wanted to go on a cruise with his wife which would be the last thing they would do together. She asked 'has nobody, your doctors, nurses, palliative care teams ever tried to enable you ...' But he replied that they had put up all these barriers – you'd never get insurance, what happens if you die on the cruise etc... So she said that's not a problem; just give me a few hours and we'll get his sorted, and it was. A few weeks later she hadn't heard from him so she rang the GP wondering if he had died and learnt that they had had a wonderful time and were already planning to go again! And there was no more mention of assisted dying. I don't think any of us who have not been in that situation can appreciate how something relatively simple like a holiday which we take for granted is really important. Sometimes it's not the pain or the disability ... I think many people go to Lourdes ... of course deep down they would like a cure, but many go just to gain the strength to keep going ...

...and to be cared for

Dame Cicely Saunders used to say 'you're important because you're you'.

I want to refer back to the first speaker [Bryan Vernon] who said 'central to caring is the relationship between carer and cared-for which derives from our experience of being mothered. This relationship necessarily creates vulnerability in the carer; indeed for any valid relationship the carer needs to open themselves up to this

vulnerability'. That is a massive challenge. How do you know how to do that? In my experience the jumbulance is a bubble: it's a very clearly defined space and time and you know the person you're going to be allocated to. It's like a step back from your normal life where you can be a different person; we've talked a lot about different personas and different roles we play, and you can play the role of 'what if I was a wonderful ideal carer what would this ideal carer do in this space'. It's only for a week and if you hate it you never need do it again ... But it is the most amazing ... the carers get so much more out of it – we are so grateful to these VIP's who allow themselves to be carted around and mothered ...!

But why is it so difficult for a doctor in a consultation lasting half-an-hour or so – never more than an hour – to put yourself in that position then?

It's a skill that you have to learn. I learned it partly by being a mother ... but when you go on the jumbulance ... let me tell you something embarrassing! The first jumbulance I went on, to Ireland, I was a bit shell-shocked, but my cathartic moment came when one of the ladies got very travel-sick. I can deal with most things but not sick...

[A GP volunteer] The doctor/patient relationship in the consulting room is constrained by so much other stuff whereas in the jumbulance ... the first trip I went on I was very apprehensive: when I saw all the illnesses the patients had I was worried sick but Chris said: 'you'll be fine – you'll soon be laughing and having fun'. I didn't believe her but I came back with strained ribs from laughing so much! I couldn't think that I could be so happy in one week, work so hard, and learn something about patients and how we treat them that I would never see or think of. Even when I see them at home I pop in and out; there you have them for a whole week.

There was one lady on opiates, taking Oxycodone 80mg twice a day, and she missed two doses... I was amazed she didn't go into withdrawal. She was very small, less than 50 kg., riddled with rheumatoid arthritis, and although she was on a bed she was shaken around quite a bit – but she didn't say a thing. People don't seem to miss their painkillers – they don't have time to have pain! [Chris had remarked on this in a previous talk about Jumbulance – people often simply forget drugs they appear to be heavily dependent on]

I took her out in a wheelchair; I wanted to go into a supermarket and asked her if she minded and she said oh please do – I haven't been in a supermarket for 10 years. She normally never left her home and rarely her bed. She was lovely to be with and enriched the group. It's a very special experience – life makes different sense after it – I can recommend it to anyone.

I have had several patients who have said they wanted to go to Dignitas, and one of the reasons they gave was that they would be unable to go at a time of their choosing later. Is this something with which you had made the connection, or part of the purpose of the Trust: to help people to live and give them choices?

We've never been asked to do that specifically ...

... but if they knew of the availability of choice ...

Why we need to legalise assisted dying

Raymond Tallis

“Why is it better that nature should take its cruel course than that a doctor should hasten the death of a patient?”

I am particularly grateful for the opportunity to talk about assisted dying to this group of clinicians above all because you have a sense of two things: one is the possibilities of medicine: what can be done to control intractable symptoms – if you don't know nobody does; and the other is that you are often faced with your limitations.

This is an issue about which I have felt passionately for many years. I am going to spend a lot of time talking about the misconceptions and bad arguments against assisted dying. The reason I can be an authority on them is that at one time I was in thrall to them myself. When I was chair of the ethics committee of the Royal College of Physicians I believed a lot of the things that I now know to be untrue, illogical or fallacious. But before I set out my arguments, I owe you a clear account of where I am coming from. A year ago, I was elected Chair of a new group – Healthcare Professionals for Assisted Dying (HPAD) I took over this role from Dr Ann McPherson. I was privileged to know Ann, sadly only for short time before she died in June 2011. By a bitter irony she had a hideous death which her daughter – a consultant dermatologist – described in harrowing detail in the BMJ on the 16th June.¹⁹

The key aim of HPAD is to change the law to permit physicians to assist the death of mentally competent, terminally ill patients, who are suffering unbearably despite receiving optimal palliative care, at their request (by writing them a prescription for life-ending medication, within strict legal safeguards). This was a choice Ann McPherson was herself denied.

Opposition

That anyone could oppose such a humane ambition may seem astonishing. But there has been opposition, in some cases highly organised opposition, to a change in the law. Some opponents have appealed to religious principles, which may not be accepted by all, such as ‘the sanctity of life’, but sometimes wrap up their opposition in a cloak of pragmatic concerns intended to instil fear. They frequently talk of ‘the slippery slope’, arguing that if Ann had been allowed her wish, people with disabilities would be pressurised to choose death against their wishes and ‘burdensome’ older people would be advised that they were surplus to requirement. Given that I was a geriatrician it's highly unlikely that I would be in the business of inviting older people to accept assisted dying against their own wishes.

One might expect the leaders of the church to be opposed to assisted dying (though they are at odds with 70% of their flocks in successive polls). Unelected Bishops had a major role in the rejection of Lord Joffe's Assisted Dying Bill in the House of Lords in 2006. As well as opposition from religious leaders, perhaps more shockingly, there appears to be strong opposition from the medical profession: the leading medical Royal Colleges, such as the Royal College of Physicians and the Royal College of

¹⁹ Mcpherson, T. (2012) ‘Without assisted dying our mum died slowly and in pain’, Personal view, BMJ 344, 7861: 35

GPs are currently against assisted dying (although the latter are in the process of re-thinking their position) as is the British Medical Association.

Healthcare Professionals for Assisted Dying (HPAD)

It was this that provoked Ann, along with her friend Professor Joe Collier, and supported by Dignity in Dying, to establish Healthcare Professionals for Assisted Dying (HPAD) in October 2010. Its aim is very simple: to change the law, medical culture, and medical practice 'so that needless suffering at the end of life becomes a thing of the past', and to this end to permit physicians to assist the death of mentally competent, terminally ill patients, who are suffering unbearably despite receiving optimal palliative care, by writing a prescription for life-ending medication at their request, with strict legal safeguards. HPAD challenges the medical profession's illegitimate extension of its authority to matters that are for society as a whole to decide. Individual doctors are of course entitled to express their views on the ethical case for, and the potential social impact of, liberalising the law. So long as no healthcare professional is obliged, against their conscience, to help a dying patient achieve an assisted death, the role of their representative bodies should be confined to speaking on those areas where they have special expertise; for example, the safeguards and codes of practice necessary should any law be implemented, and more explicitly medical matters such as determining prognosis and setting guidelines for optimal end-of-life care. I believe that for the profession to go beyond this is a gross example of paternalism.

At this point, it is important to set aside an objection to this argument that I have often encountered. Is it not sometimes the duty of the medical profession and indeed parliament to be paternalistic and to ignore public opinion? After all if there were a referendum on the death sentence today, we would find that the majority of the British public would be in favour of bringing back hanging. This analogy cuts no ice because those who are seeking to restore the death penalty do not envisage themselves or their loved ones being strung up. Those in favour of assisted dying are advocating something they would want for themselves or for those they care for. This is why the paternalism argument is irrelevant. Whatever happened to 'patient-centred care' and 'no decision about me without me'?

It also brushes aside the views of those healthcare professionals strongly in favour of assisted dying, whose voices have been silenced. That may be why, in its very short life HPAD has acquired over 600 members, who are committed to working for a change in the law. Many of us resent the way in which the debate has been hi-jacked by special interest groups inside the profession as well as without. Recent polls have supported this view, although the medical profession is divided: for example, the most reliable information suggests that between 30% and 40% of doctors are in favour of decriminalisation. What's more, only a third of 1,000 doctors in a survey in October 2011 were opposed to having assisted dying for themselves. And, most tellingly, 62% of respondents in a survey of 1,000 GPs felt that the representative medical bodies should adopt a stance of neutrality towards the issue, as the BMA have done. It is interesting to compare this scientific poll with the outcome of the BMJ vote in the wake of the call to the BMA to be neutral. This was a fantastic tribute to the speed and efficiency with which those who are opposed to assisted dying can organise their membership to create an inaccurate impression of the views of the medical profession as a whole. It went a quite different way: 83% against neutrality. This was so surprising to the BMJ that they did a bit of forensic psephology. They found votes coming in from Mongolia and Nigeria, many of them not doctors. The

poll enabled people to vote more than once and included returns from a person in Iceland who voted 168 times (167 against and once for neutrality!).

Neutrality

Given that there are physicians of good will, deep religious convictions or none, many with expertise in palliative care, with passionate views on both sides of the debate, the proper stance of medical bodies is one of neutrality. This does not mean indifference; rather what the American physician Timothy Quill has called 'studied neutrality'. This is what the Royal College of Nursing has chosen, after a survey of its members that produced 49% of responses in favour and 40% against. The fact that the nurses are more in tune with the public on this issue is not entirely surprising. As Joyce Robins, co-director of Patient Concern has written, 'Nurses...are likely to be at the bedside of the dying and hear and understand patients' and relatives' feelings. Doctors appear briefly so it is easier for them to stick to...the status quo'; to put it bluntly, it is easier for the less imaginative among the medical profession to bear the sufferings of others heroically as they do not have to experience it minute-by-minute, hour-by-hour, day-by-day as nurses do. HPAD members believe that until the colleges and the BMA adopt a position of neutrality, there will be a serious obstacle to a full, open and honest debate on assisted dying.

The case for assisted dying

I am an optimist and I believe that we shall bring these bodies round to an appropriate stance of neutrality and that, with this obstacle out of the way, parliament may indeed come to support legislation in favour of assisted dying. Indeed, my optimism extends to the belief that rational argument, rather than pre-rational opinions, will win the day. Unfortunately, most of our efforts in winning the argument will have to be directed at countering the bad and sometimes dishonest arguments that are already in play. And it these false arguments – and making a case against the case against rather than the positive case for - that I want to focus on today. But I must spend a little time on of the positive case. And here it is. Firstly, unbearable suffering, prolonged by medical care, and inflicted on a dying patient who wishes to die, is unequivocally a bad thing. From which it follows that not doing (or worse still forbidding) what has to be done to prevent this is unacceptable cruelty. I add this because I believe it is not those who support assisted dying but those who oppose it who have the moral case to answer, and should be on the defensive. And, secondly, respect for individual autonomy – the right to have one's choices supported by others, to determine one's own best interest, when one is of sound mind – is a sovereign principle. And that's it.

The objections

So much for the positive case. Unanswerable one would think. But, of course, it has been answered and I want to devote the remainder of my lecture to dealing with the objections that have been raised by opponents of assisted dying. I want to concentrate on the knottier problems. They are made more difficult by the tendency of many of our opponents to conceal what really lies behind their views. Here it is, set out with exemplary candour in the speech given Baroness Richardson of Calow when the House of Lords gave Lord Joffe's Bill for to legalise assisted dying its second reading:

“There is no doubt that the [Joffe] Bill has shocked the religious communities...It has undermined the security some of us have felt that God is to be in control of life and death.”

Most of our opponents are sufficiently savvy to know that appealing to the sanctity of life would cut little ice in a present-day British society – even among those who profess religious beliefs there is little opposition to assisted dying. The data from the most recent British Social Attitudes Survey (and consistent with findings over many years) reveal that religious belief seems hardly to reduce the tendency to be in favour of assisted dying, with 82% in the general population and 71% of those who designate themselves as having religious belief supportive of assisted dying. And indeed for many (including some members of HPAD) religious belief is a key factor in their support for the availability of compassionate assistance to die being made available for dying, competent people. I want to be clear that I am not arguing against religious belief or indeed the right of people who believe that assisted dying is wrong because of their religious beliefs to make their case. My objection is what Mary Warnock in her recent book *Dishonest to God* has described - how religiously motivated opponents will duck and weave between absolutist arguments based on faith and pragmatic or consequentialist arguments that appeal to empirical ‘evidence’ about anticipated adverse consequences for society. This is what we might call the belt and braces or belt and gaiters approach, slithering between arguments from principle and arguments based on facts leads to the generation of factoids. You will all be familiar with the Groucho Marx quip: ‘These are my principles but if you don’t like them I have another set in the drawer’. What applies here is: ‘These are my (inviolable) principles but if you don’t like them I have some facts in the drawer that will bring you round to the same conclusion as me’. So I want to deal with some principle-warped factoids head on. I shall also examine a couple of principles that enshrine fundamental values – one religious and one secular. The religious principle will be that of the sanctity of life and I will show how it has never been regarded as unassailable in any society – and so it is irrelevant to the case for or against assisted dying. Most importantly, it has no relevance to the question of the value of life as invoked in this context. The secular principle I shall look at will be that of the right to have decisions that affect only one’s own welfare respected – the principle of autonomy – and I will show that while there are problems with this, they are common to the application of all ethical principles in real life. And between my exposé of factoids and examination of principles, I will look at a factoid about principles: the claim that doctors involved in assisted dying would betray their professional ethos.

Let me deal in short order with some of the factoids put in circulation by opponents of assisted dying. I am not epidemiologist of error but it seems to me that the commonest argument is that AD is actually unnecessary – or would be unnecessary if optimal palliative care were universally available. This is not true as my experience as a doctor for over 35 years made clear, when I was responsible for patients whose symptoms were uncontrolled even when they had first-rate palliative care. And Ann’s own death – typical of so many others (including my mother and father) - is eloquent testimony to the failures of palliative care in some patients. International experience also confirms that palliative care fails some patients. To take one example, for the last ten years, assisted dying has been legal in Oregon under the Death with Dignity Act. Oregon has among the best palliative care of the 50 states in USA and yet nearly 90% of those seeking assisted dying are in receipt of hospice care. This is of course not to belittle the huge importance of palliative care, which can help a great many dying patients achieve a dignified death, but to acknowledge honestly that it, like other modes of healthcare, has its limitations.

There are those who argue that the availability of assisted dying as an 'easy' option will inhibit investment in palliative care. I have heard it said by someone on several occasions that palliative care does not exist in countries where there is legislation in favour of assisted dying. International experience of course does not support this. The usual pattern is that liberalisation of the law, (in some countries, such as Netherlands, far beyond anything I would support), has been accompanied by increasing investment in palliative care services. In Oregon, the proportion of people dying in hospice care – a marker of the availability of palliative care - has more than doubled since the Death with Dignity Act was introduced.

An authoritative report (2011) from the European Association of Palliative Care, which actually opposes assisted dying, concluded that:

"The idea that legislation of euthanasia and/or assisted suicide might obstruct or halt palliative care development thus seems unwarranted and is only expressed in commentaries rather than demonstrated by empirical evidence... There is scant evidence of the supposed underdevelopment of palliative care"

It is also confidently asserted that liberalising the law will break down trust between doctor and patient. This is not borne out by the evidence. A Europe-wide survey put levels of trust in the Netherlands at the top. And this is not surprising: in countries with assisted dying, there is a tradition that discussion of end-of-life care is open, transparent, honest and mature, not concealed beneath a cloud of ambiguity, as it so often is in the UK. And the knowledge that your doctor will not abandon the therapeutic alliance with you at your hour of greatest need, will foster, not undermine, trust.

If these factoids don't deliver the results that are desired, then the antis up the antes: more quasi-facts, rumours and urban myths, are mobilised. If assisted dying for terminally ill people is legalised, then we will have embarked on a trajectory that will lead inevitably to assisted dying for people who aren't dying but have a non-terminal chronic illness or disability, then to such people who do not wish to die and/or cannot express their wishes either way. In addition, the Slippery Slopers tell us, it will create a culture in which it is expected that when you are frail, infirm, and judged to be a burden to others, you will be expected out of decency to seek assistance to die. And it is implied that this is what is already happening somewhere or other.

What exactly is HPAD advocating?

The first point is to make clear what we in HPAD and Dignity in Dying stand for: a law to permit mentally competent terminally ill adults who are suffering unbearably as a result of a terminal illness to receive medical assistance to die at their considered and persistent request. This is not the same as assisted suicide, which is to help chronically ill or disabled people who are not terminally ill to end their lives, and contrary to what our opponents would claim we are not advocating legalising this. I am personally opposed to that although some cases such as that of Tony Nicholson do test one's opposition to the limit. Nor are we in favour of voluntary euthanasia, when terminally ill adults (or sometimes chronically ill or disabled adults) can have their lives ended by a doctor. More specifically, we are opposed to any law that would go beyond assisted dying to assisted suicide and extend it to people with disabilities who are not terminally ill; elderly people who are not terminally ill; people with non-terminal illness; people who are not mentally competent, including those who have dementia or depression. I have laboured this point as assisted dying, assisted suicide

and voluntary euthanasia are often confused, but the distinctions are not vague or unclear and there is nothing unequivocal or confusing about our position.

Interestingly the general public is quite clear about the distinction. While a consistent 80% plus people support assisted dying, the support for assisted suicide is much less, running at about 40%, even if they rely on others for all their daily needs.

More objections: the slippery slope and the fear of error

There is international experience to which we may refer to settle the argument about the inevitability of the slippery slope. The most relevant is the experience in Oregon. It is most relevant because the Death with Dignity Act which was introduced over a decade ago is very close to the laws that have been considered in England, and I would like to see, though the Joffe Bill has more safeguards. In the decade since the Oregon Act was introduced the proportion of deaths that are assisted has never risen above 0.2% - about 1 in 500. The average age of those who have assisted dying is lower than the average age of deaths so the elderly are not disproportionately represented. The typical profile of a person who avails him or herself of assisted dying is a strong-willed, middle class person used to getting his or her way – not groups traditionally depicted as ‘vulnerable’. What is more there is no evidence of extension of assisted dying to assisted suicide for people with non-terminal illnesses, nor any advocacy in Oregon for this. Needless to say, the Oregon experience has also been misrepresented. In a debate Mary Warnock and I had with him on Start the Week, Lord Gummer reported that the rate of assisted dying in Oregon had increased by 300% in the first few years of legislation. This was true but it did not indicate that this was something out of control. The full picture was that the number of assisted deaths increased over about five years, as the law influenced practice, from a minute figure of 16 to 64 and that since then the percentage has remained, as I mentioned, low at 0.2%.

I am going to come back to the slippery slope when I talk about principles and values, but I want to make a couple more points on this issue. If there is a slippery slope, legislation with all the safeguards envisaged in a Bill such as the one proposed by Lord Joffe would, to steal the ethicist John Harris’ metaphor, apply crampons rather than skis. The Dutch experience, frequently misrepresented by those against assisted dying, illustrates this. There, rates of non-voluntary euthanasia (i.e. doctors actively ending patients’ lives without having been asked by them to do so) decreased from 0.8% of all deaths in 1991 (approximately 1,000 deaths) to 0.4% in 2005 (approximately 550 deaths). In the UK a study published in Palliative Medicine in 2009 found that in 0.21% of deaths attended by a doctor life was ended with an explicit request from the patient (in other words, voluntary euthanasia) and in 0.30% of cases, life was ended without an explicit request from the patient (in other words, non-voluntary euthanasia). This means that approximately 2,600 people being given direct help to die, with or without their explicit request, outside any relevant legal framework. The present clinical, ethical, and legal fudge, in which ploys such as continuous sedation, and starvation and dehydration are in some cases used to get round the prohibition on assisted dying, is unacceptable. Those who are concerned for the safety of patients, far from opposing a change in the law, should support legalising assisted dying in view of the scrutiny it would bring to bear on medical practice (which is exactly what has happened in Holland and Oregon). Not only is it possible to devise a law with sufficient safeguards against abuse without making it so bureaucratic that it would not serve the needs of dying people but such a law would itself be a mighty safeguard.

Let me wind up my tour of factoids, with a final group that are generated by the fear that mistakes would be made – mistakes that are of particular concern since, in the case of assisted dying, they are irreversible. Our opponents often treat us to tales of individuals who asked to be assisted to die, and then, after talking to an understanding physician, one who is (to coin a phrase) into Care not Killing, change their minds and subsequently live long, happy, contented lives. The caring not killing physician will receive a post card from their patient announcing that they have just climbed the North Face of the Eiger single-handed without ropes. I exaggerate of course but some of the stories beggar belief. However, they carry huge potential weight and lead people to draw very large conclusions from them. As Bertrand Russell said, 'popular induction depends upon the emotional interest of the instances, not upon their number'.

How shall we address the concern that physicians may not read the patient's mind correctly and/or his or her ability to make a rational decision? Well it is easy to build in time for reflection in any law: it should include ample opportunity to change one's mind. The experience in Oregon is compelling: only 1 in 100 of those people who discussed assisted dying with their doctors actually received and cashed the prescription, and of those only 1 in 2 actually took it. Moreover, many people will have taken comfort from having banked a prescription and many more from knowing that this option is available. The knowledge that you have the potential opportunity to escape from an unbearable situation may make it more bearable. All the bills including Lord Joffe's that I have seen envisaged a cooling off period. You can make a decision well in advance of the terminal phase, so you have the option when and if you want to use it. Where there is doubt about the patient's mental competence or about the absence of a treatable depression, psychiatric advice can be sought. This is less easy to sort out in the case of trips to Dignitas or self-administered suicide, given that as the law stands at present, patients cannot even discuss assisted dying with their doctors. I suspect that once you have embarked on a journey to Switzerland it is very difficult to change your mind. You have boarded a train you cannot get off.

And as for the rationality of a decision, there are ways of testing competence and the presence or absence of reversible depression. What is more, in every other area of medicine there is a presumption of competence: the patient is presumed to be of sound mind and able to make a rational decision unless there is clear evidence to the contrary.

What about the other worry: that the diagnosis could be wrong? In most cases, this seems highly unlikely. A candidate for assisted dying will have widespread advanced illness, clear objective reasons for suffering, in which palliation has failed, and the ultimate outcome will not be in doubt. Rejecting the option of assisted dying for all patients will not of course save the occasional misdiagnosed patient from unnecessary death from medical error; it will simply ensure that that avoidable death – as well as that of all those correctly diagnosed - will be more prolonged. What is more, consideration for assisted dying will prompt review of the case and this may turn up the very rare example where clear-cut, advanced disease turns out to be nothing of the sort.

Much attention has been paid to errors doctors make in prognosis. In fact, again the likelihood of the prognosis being seriously wrong will be considerably less in very advanced disease, though there is much work to be done on this and some members of the HPAD Steering Committee are looking into this. Most studies have shown that doctors over-estimate the prognosis, expecting patients to live longer than they do. But it may be irrelevant: people can as it were bank their prescription and decide to

use it at a much later stage than their initial negotiation. What is more, doctors already rely on estimates of prognosis when they move to management plans that will shorten life – such as withdrawing life-supporting medical care (insulin, artificial ventilation), exploiting the double effect (of which more presently), colluding in the patient's death by starvation and dehydration, or initiating continuous sedation. There is always a risk of prognostic error whenever death is hastened. The truth is that medicine is a probabilistic art. This is evident when we look at the outcomes for elective or non-emergency surgery in patients who may in many cases be reasonably fit. One very large study revealed that one in 10 elderly patients died as a result of the elective operation. We accept that. So why do we set impossibly high standards of certainty and clinical accuracy in the case of patients who wish to die when we settle for much lower standards for patients who do not wish to die? Why do we raise the bar above the balance of probabilities, above 'beyond reasonable doubt', to 'beyond, beyond reasonable doubt'.

Why in this context do we believe, as we do not elsewhere in medicine, that it is better that thousands should suffer unnecessarily than that a very rare mistake might be made? Why can't the patient make the decision? Why is it better that nature should take its cruel course than that a doctor should hasten the death of a patient? One cynic suggested that doctors oppose assisted dying because they are trained to hasten death only by accident. (Or accidentally on purpose) And this option is worth scrutinising. Doctors wishing to avoid assisted dying and yet humanely committed to achieving the same end will make liberal use of ploys such as the double effect (where the primary intention is to control symptoms though this may accidentally hasten death), of withdrawing treatments such as insulin and/or artificial ventilation which will ensure death with 100% certainty, or the institution of continuous sedation which reduces a person to a breathing body or worse still standing idly by while a patient has an unassisted death by thirst or starvation. So what is behind this anomalous and, it seems to me, in some cases unacceptable behaviour, which exploits distinctions without real differences? After all, Everett Koop the former US Surgeon-General described withdrawal of dialysis in terminally ill patients as 'euthanasia by omission'. Something is clearly at work here, making people think irrationally.

One could argue that the unavailability of assisted dying spares doctors from making decisions. Without a law in place, the decision is already made: 'I can't help you'.

And exploring this takes me from arguments based on matters of fact, or factoids, to arguments based on matters of principle or declared values.

The Hippocratic Oath

I want first to stop off briefly at a half-way house: at the notion of professional codes of ethics that are supposed to prohibit assisted dying. This is summarised in a recent letter in the BMJ. The correspondent said: 'I went into medicine to save lives, not to end them' (David Samuel, *Talking to a Brick Wall*). Behind this kind of statement is the feeling that to participate in assisted dying is to contravene, even to betray, the solemn undertakings of doctors entering the medical profession. The classical version of the Hippocratic Oath includes this promise: 'I will not give a lethal drug to anyone if I am asked, nor will I advise such a plan'. But it also adds (in the same paragraph) 'and similarly I will not give a woman a pessary to secure an abortion'. In other words, doctors involved in abortion would also be in breach of the Oath but this does not cause problems for the vast majority of the profession. It also enjoins doctors to be chaste and religious. Well you may judge my chastity from the

fact that I have two children and the fervour of my religious belief from the fact that I am a strong supporter of the British Humanist Association. In neither instance do I feel that I have betrayed my professional calling. So the classical Oath is an anachronism. It has been brought up to date in various ways. One widely used version introduced in 1964, has this key paragraph:

“Most especially must I tread with care in matters of life and death. If it is given to me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my frailty.”

This seems to allow for assisted dying. And The Declaration of Geneva, adopted by the General Assembly of the World Medical Association at Geneva in 1948, and most recently amended in 2006 says only that:

“I will maintain the utmost respect for human life.”

Which, as we shall discuss, is consistent with supporting assisted dying under the circumstances we envisage. It does not say anything about not taking life. In short, the claim that support for assisted dying violates the fundamental ethos of the medical profession is unfounded.

Principles

In the third part of my talk, I want to look at the matter of principles head on. I want to focus on two principles or bases for values: the sanctity of life which is invoked to demonstrate that assisted dying is wrong in all circumstances; and the principle of respect for individual autonomy – the right to have one’s choices supported by others, to determine one’s own best interest, when one is of sound mind. In both cases, I shall test their validity by looking at consistency of their application.

First, sanctity of life. Life is a gift of God and we may not take away a life God has created, even at the request of the person whose life is at issue. In fact, this is an absolute principle. But is it? Can it be? In actual practice, the history of those religions that explicitly profess the sanctity of life as an absolute, basic principle – Christianity, Judaism, Islam – are not at all consistent in its application. The notion of the ‘Just War’, where people will be killed in large numbers and against their will rather than individually at their request, is accepted; in many explicitly religious countries, judicial execution is commonplace and this may not only be for murder but for lesser crimes, or for non-crimes such as apostasy or blasphemy or being gay. You may say that this kind of thing refers only to distant countries about which we have only prejudices, so let me give you two examples nearer home: the Anglican response to events in WW2 and to the Iraq War. In 1944 Charles Bell, the Bishop of Chichester, condemned the area bombing of civilians in German cities: it was, he said, an unjust pursuit of a just war. He was opposed by his fellow bishops including the Archbishop of York who said: ‘It is a lesser evil to bomb [i.e. kill] the war-loving Germans than to sacrifice the lives of our fellow countrymen or to delay the delivery of many now held in slavery’. It appears that it is better to kill others directly in order possibly to save others directly. Utilitarian calculus, after all, trumps the ‘inviolable’ principle of the sanctity of life. One could be forgiven for concluding that the principle, while supporting the position that it is always wrong to assist someone to die who is terminally ill and longs to die, will suggest that is less wrong to kill a perfectly healthy man, woman or child who does not wish to die.

Let me take an example even nearer home. The present Archbishop of Canterbury has taken a violently opposed position to assisted dying. Making it legal to help a desperately sick relative to die would, he said, 'cross a moral boundary' and 'enter very dangerous territory'. The present law on assisted dying which means that helping a loved one to die may result in a 14 year jail sentence 'serves us better than opening the door to the legal ending of lives'. Now contrast that forthright response with his statement on the eve of the Iraq war. 'Doubts persist' he said, in his joint letter with the Archbishop of Westminster 'about the moral legitimacy of a war with Iraq'. This muted response to a war in which large numbers of people were predictably killed - 600,000 people as it turned out - who had no wish to be, was at the time when 2,000,000 of his fellow citizens had taken to the streets to protest out loud by this clearly unjust and criminal war. One could be forgiven for thinking that there is a strain in religious belief that sees assisting the death of someone who is dying and wants to die as morally more hazardous than raining death on a city filled with people who want no such thing.

But we need to dig a little deeper. Why do the opponents of assisted dying invoke a clearly vulnerable principle whose theological resonance would be rejected by most people? I think it is because it seems to be the only way of defending, standing up for, or protecting, something that we would all wish to defend, stand up for, protect: the fundamental ethic of valuing human lives – our own and those of others - as infinitely precious. This is expressed in the reason given at a recent Synod by Rowan Williams for his rejecting legalisation of assisted dying:

"It will create an ethical framework in which the worthwhileness of some lives is undermined by the legal expression of what feels like public impatience with protracted dying and 'unproductive lives'."

Behind the appeal to the absolute (but in fact negotiable) principle, there is the implicit claim that the religious notion of the sanctity of life is the only source of the value we place upon life – as much in a secular as in a religious society. If we question it, we shall devalue life; and we shall particularly devalue the lives of those who are powerless or are already likely to be devalued. Elderly people, people with disability, people who have mental illness will be at risk.

Most of us can see that this is nonsense but it is nonetheless worthwhile spelling out the obvious. Let me personalise this to make it clear. My wife and I have been happily married for 40 years. We can imagine a time when one of us is terminally ill, nearing the end in unbearable misery and wanting to die. We would like there to be a law to make it possible for us to get the help one or other of us may need. Let us suppose that I become terminally ill first and I ask her to seek help from a physician to help me to die and she complies with my wish. This cannot imply the following: she is colluding in my devaluation of my own life. If I am devaluing my own life it is only the next two suffering-filled weeks – not the last 70 or 80 years. Neither of us is devaluing human life in general or the irreplaceable preciousness of human beings. Neither she nor I are devaluing anyone else's life: the lives of old people, of people with disability, of people from minority groups. She is respecting my judgement of the value of the last few days of a life – days filled with unbearable suffering. Indeed, we are enhancing the value of life by doing our best to prevent our lives being diminished by the sustained horror of unbearable and pointless suffering. We are respecting what those things by which we judge our lives and find our shared personal experiences. So much for the appeal to the (in theory inviolable) principle of 'the sanctity of life'.

It is time now to turn to my second principle: that of autonomy. Perhaps because it is the most obvious case for supporting assisted dying - other than an aversion to the cruelty of insisting that people go through Hell - the right to have one's choices supported by others, to determine one's own best interest, when one is of sound mind, has attracted the most baleful attention from our opponents. Most of the reasons for attacking the appeal to autonomy may be set aside. The first, that we do not belong to ourselves but are God's possessions does not get much traction in a secular society. Most of us happen not to believe this. If it were true, however, it might lead us to deny ourselves the right to any autonomy, not particular expressions of autonomy in certain highly specific circumstances. The second is an inescapable truth and one that, again, does not lead to any particular conclusions except a reinforcement of what is called the harm principle. Let me say a word about this, principle. It is difficult to improve on its first formulation by John Stuart Mill:

"The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinion of others, to do so would be wise, or even right..."

(John Stuart Mill *On Liberty*)

He spells this out clearly enough for everyone to understand: the only part of the conduct of anyone, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign. Our opponents have argued that assisted dying is not something that concerns only the individual who is directly affected. There will be effects on society as a whole through, they claim, the devaluation of human life. I have dealt with this already. But there is another challenge which I think requires more thought. It relates to the question of consistency: if you argue for assisted dying on the basis of respect for autonomy why do you restrict its availability simply to people who are terminally ill and meet all the criteria we have been talking about? Why do you oppose a law that would go beyond assisted dying and permit assisted suicide for people who are not terminally ill, even though they request it? Surely a human right is a human right? If so, won't the principle of necessity lead us some way down the slippery slope? It may not lead down to the involuntary slaughter of people who are seen as undesirable, surplus to requirement or merely unproductive as Williams suggested. But it may take us to place us where none of us would like to be.

Let me explore this. Supposing you come across someone about to jump off a bridge. You establish that he is not being forced to do this at gun point. Do you then say 'good luck' and let him get on with it? Of course not. Even less would you be willing to accede to his request for assistance in jumping off. There are several practical reasons why one would treat this case differently from that of a dying patient seeking assistance to die. We have no history of what has led up to his despair; we have no idea of the cause; he could well have an entirely solvable problem; we could save him for a happy life. To say get on with it would be a callous indifference to human life.

We don't have to look at such an extreme example to see that we do not simply accede to people's wishes even over things that seem to affect directly only themselves. This may seem to be a rowing back from the assertion of the primacy of autonomy. Should the invocation of autonomy authorise the progressive extension of the cases in which dying could be assisted? If it did not lead to this slippery slope

wasn't this was because the principle of autonomy was being applied inconsistently? Haven't I joined the Groucho Club along with my religious opponents? I think it is possible to deal with this problem entirely honestly. In all cases, the application of a non-absolute ethical principle has to be put in context; it is right to begin with the principle but it may not always be right to apply it without limit, and this applies to every aspect of human life. Assisted dying respects autonomy and it has a clearly defined scope. Assisting anyone who wishes to jump off a bridge will have clear cut adverse consequences, spreading an ethos of cruel indifference to what may be remediable suffering - precisely this devaluation of human life that our opponents accuse us of.

The challenge

So this presents us with a challenge: we have to judge the place where the gain in individual autonomy is offset by harms to society as a whole. To some extent this will be a calculus of benefits, harms and risk of harm. This apparent rowing back from the boundless application of the principle of autonomy is entirely different from the appeal to and deviation from the principle of sanctity of life for which I have just criticised some of my religiously motivated opponents. For their deviations are from a principle that is claimed to be absolute and inviolable; and their deviations are into killing in war, and other modes of behaviour that require further justification; and the original principle sits ill with a utilitarian calculus of greater and less benefits. The harm principle that limits autonomy is a utilitarian principle that makes up part of a coherent picture that weighs autonomy and harm in the same scales.

The need to restrict the application of the principle that supports it is not a problem unique to assisted dying. It is present throughout our judgements of the correct thing to do. We all have to do something that I have called 'dichotomising over a continuum'. Take for example free speech, which gives me right to express my views without censorship. This sounds fine – an unquestionably Good Thing. But it may have unintended consequences which require us to mobilise a second principle to modify the first: the harm principle. If someone exploits the principle to indulge in hate speech – say, making anti-Semitic remarks designed to stir up hatred – the harm that is caused has to be reined in by invoking another principle banning the use of free speech to cause harm. Anyone who is considered to cause such harm will have their claim to exercise their autonomy over-riden and is justly charged with a criminal offence and if necessary put into the slammer. There will however be a continuum, rather than a natural break, between totally acceptable and totally unacceptable speech; this will probably be a continuum and yet we have to draw a line at right angles to this at a point that will seem to some arbitrary: we have to divide a continuum in two. This side of the line is a legitimate exercise of free speech; that side of the line is an illegitimate and criminal abuse of the principle of free speech. And the same applies to considering the age of criminal responsibility; or where we judge a medical treatment to be futile; or indeed as to what counts as the double effect – just as much as to the decision to assist dying.

There is, in short, nothing uniquely flawed about limiting the application of the principle of autonomy when we use it to support the case for assisted dying. The main point is that the legalisation of assisted dying is extending the application of the principle of autonomy, even though it is not rendering it boundless. I would be interested to know what you think of this argument. When I presented it to the Noble Lord, Lord Carlile, his response was at the cognitive mid-point between a counter-argument and a punch on the nose: 'Twaddle', he cried. Such are the joys of carrying the torch of reason and humanity in this not always reasonable and not always

humane world. There remains the fact that any good principle cannot determine from within itself the scope of its application, and can always theoretically justify actions we do not wish. We have to decide on an age of criminal responsibility but the sharp cut off is an artefact. In the case of assisted dying, the continuum of the application of the principle of respecting autonomy has clear points at which it can be considered no longer to be sovereign. There are clear distinctions between terminal and non-terminal illness; between people who do and people who do not have a serious illness; between people who have and people who do not have mental competence; between assistance to die and euthanasia; and between voluntary and involuntary euthanasia. If there is a slope downwards from one to the other, it has a high coefficient of friction.

The law

We are back now in the realm of consequences and hence facts. Before I end, I want to make one brief foray into the law. Even those who accept the facts and the arguments that I have set forth still oppose legislation on the grounds that only a small minority of dying people would seek assistance and an even smaller number would use the prescription. Wouldn't legislation prove a sledgehammer to crack a nut, a leap in the dark which threatens all of us, for the sake of a few people? Even if it did not have the dangerous consequences our opponents claim, it would most certainly upset many prelates (though not their congregations), something not to be lightly dismissed. Well, I happen to believe that even small numbers of people going through unbearable Hell are important and there is something wrong in a society that cannot see that. What is more, the availability of assisted dying would bring much comfort to many more sufferers than actually use it because it brings an all-important sense of having some control, as we know from the Oregon data I referred to.

It has been argued that since the DPP has not referred any cases sent to him for prosecution things are fine at present, no law is needed, so let us muddle on in the usual British way. This will not do. First, assisting someone to die remains a criminal offence: the relative or friend is the suspect and the patient the 'victim'. Since 'suspects' usually spend months under investigation before being told whether or not they are to be prosecuted, there is huge anxiety and stigma at an already intensely distressing time. Thus a de facto history of sensible decisions so far is not as good as a law that permits assisted dying within clear limits and safeguards. What's more, a future more hawkish DPP may have a quite different attitude and use the 16 tests of motivation (to determine whether an action is malicious or compassionate) – yes, 16 tests - to draw different conclusions. And, above all, it remains a criminal offence for any medical qualified practitioner or other professional to give advice. So it is all down to amateurs who have to carry the unbearable burden of responsibility. We therefore need a change of the law – and soon. And having arrived at that conclusion, which will not cause you any surprise, I will end.

Using philosophy to make sense of chronic illness

Havi Carel

“I want to suggest that illness leads to a disruption of the lived body rather than simply dysfunction of the biological body ... So we really need the first-person account that can be provided by phenomenology.”

One of the tacit questions lurking in the background of Ray Tallis's talk, and one of the most important questions that we need to ask when we try to decide if a life is worth living, can only be answered by the person whose life it is: whether it is worth living *for them*. One point of contact between the two talks is to be really thinking about how little we appreciate the differences between individuals, and within individuals their own changing positions towards their lives over the course of many years. It will be important for us to spend a little bit of time thinking about the subjective experience of what illness might be like. This resonates with what Ray was saying: it's very easy to make universal stipulations of the kind: all life is sacred. Peter Singer the Australian ethicist has replied to that by saying what people really mean is that the life of white relatively well-off people in Western countries is worth living; if people who purport to hold the sanctity of life position really cared, they would do something about the massive inequality and suffering going on in other parts of the world. And they privilege human life over animal life. People who object to abortion and physician-assisted suicide on legal or moral grounds are happy to tuck into a steak reared in areas of destroyed rain forest or clams exported from the Ivory Coast. So there is a real sense in which, as Ray rightly said, every moral decision we make has to be made against its particular context and every context has its blind spots, and he made a terrific job of picking out those that characterise this particular debate about physician assisted suicide.

What I hope to achieve is to point out some other blind spots that might characterise the experience of illness. Often, people in large institutions or organisations such as the NHS rely very heavily upon principles, guidelines, targets and so on. These are good if you want to establish a minimal threshold for behaviour or treatment etc. but I don't think they are helpful when it comes to trying to work with an individual patient, with their individual story, circumstances and desires. One point of contrast implicit in Ray's talk was that between people who are severely disabled but report having a very good quality of life, say they are very happy with life and their level of wellbeing is high, with those with chronic depression who, even though their bodies and organs are working fine, still see no point in continuing to exist. So there are all kinds of tensions that arise out of the desire to make use of universal stipulations and decisions. My work is to turn the lens round and to say: let's try to think a little bit more about what it means for a particular individual with a particular disease at a particular time. The final example I want to give is that of QUALY'S (Quality adjusted life years). A recent paper which quite alarmed me equated a QUALY with one year of life lived by a healthy, able-bodied individual, so people who are genuinely disabled but also genuinely unperturbed by their disability, would be discriminated against as two years of their life would in effect be counted as only one.

Phenomenology

This is a particular approach within philosophy that helps us to understand the first person experience. I want to suggest that illness leads to a disruption of the lived

body rather than simply dysfunction of the biological body. Moreover it is important to understand that when we change physical possibilities we actually change people's subjective way of being as a whole. So we really need the first-person account that can be provided by phenomenology.

Phenomenology describes the essential structure of human experience. It is useful for illuminating the quality of subjective experiences, their personal meanings to an individual over time and their pattern and coherence. It would of course be very unreasonable to ask you as health professionals to engage with all these in a very systematic and serious manner when you have time constraints, and your training doesn't necessarily enable that.

Phenomenology is metaphysically modest; it doesn't make metaphysical claims about what a person is or what is real, but simply uses thinking about human experience – things, phenomena - as its fundamental tool and the fundamental object of our study.

Husserl, writing about music apprehension, wants us to think about what it takes for human experience for us to be able to hear a melody. It's not enough for us just to hear a succession of discrete notes; we have also to be able to retain the note that has just passed and to have some sort of expectation about the notes about to sound in order for us to hear the melody.

“The tone begins and ‘it’ steadily continues. The now-tone changes into a tone-having-been; the *impressional* consciousness, constantly flowing, passes over into ever new *retentional* consciousness.”

(*On the Phenomenology of the Consciousness of Internal Time*, p.31)

This is an example of the kind of work phenomenology does. It doesn't comment on any empirical aspects of experience, but does give us some insight into the conditions and possibilities for having a particular experience.

[The audience were invited at this point to spend 20 seconds looking at a painting of a pair of old boots by Van Gogh, and asked for their subjective reactions: the answers included; ‘*they made me wonder about the life of the person who had worn them*’; ‘*These flat bits of colour became a pair of boots in my head*’; ‘*you might strip away the experience and say they aren’t shoes at all, just different shades of brown paint*’; ‘*there’s a narrative about these shoes – who wore them, where they lived, what they do – all rather abject*’.]

The point of this exercise is to think about some of the other things that happened in the 20 seconds - you may have been thinking you're getting a bit peckish, you may need the toilet, you may have been looking around the room; you may have been thinking about the fact that the slide is only an image projected onto a screen, or perhaps thinking about the passing of time. You may have been using imagination or empathy to try and guess what the shoes are meant to represent and so on. And all of these different acts of consciousness are actually what phenomenology tries to study. So if I were an art historian and this was an art history class we would be looking at the painting and discussing *it*, but in phenomenology we discuss *ourselves*, what we feel and what we recognise with respect to a particular phenomenal stimulus.

Here is what Heidegger saw in the picture:

“From the dark opening of the worn insides of the shoes the toilsome tread of the worker stares forth. In the stiffly rugged heaviness of the

shoes there is the accumulated tenacity of her slow trudge through the far-spreading and ever-uniform furrows of the field swept by a raw wind. On the leather lie the dampness and richness of the soil.”

(Heidegger, *Basic Writings*, p.159)

Famously these shoes belonged not to a peasant but an urban working-class Parisian, and Van Gogh picked them up in a market, so Heidegger used his imagination quite incorrectly. The moral of the story is that phenomenology is a very rich source for training the mind and that empathy and imagination are very useful tools when you try to understand what somebody else, whose life may be radically different to yours, experiences. But on the other hand we need to be cautious about overestimating our ability to empathise with what is going on in other peoples' minds.

The kind of phenomenology that I use in my work, and I think might be useful to you as practitioners, is one that takes embodiment as its starting point. Philosophers from Plato through Descartes right through to the twentieth century, at least in America, have been very keen on studying the mind as divorced from the body. Plato talked about a soul that is eternal and continues to exist beyond the perishing of the body, and this was picked up in Christianity and to an extent in the writings of Descartes, the great dualist. When Merleau-Ponty was writing in the late 40's and 50's he wanted to reject mind-body dualism and think about consciousness as an embodied phenomenon. He regarded perception as, firstly, constitutive of human experience – the most foundational experiences we have are perceptual; when you come into the world the first thing you see is a jumble of shapes and sounds and as being intimately connected to the body.

“... the body is considered a constitutive or transcendental principle, precisely because it is involved in the very possibility of experience.”

(Gallagher and Zahavi 2008, p.135)

This is something that is quite radically undervalued, at least by philosophers, and I should be interested to know whether you think dualist misconception is still very active in medicine.

A phenomenology of illness tries to remedy this bias, and to move away from the causal, solution-based thinking about disease processes to thinking about how patients experience their disorder. If the solution-based thinking would solve all our medical problems I would quickly be out of business, but unfortunately this is not the case. There are huge numbers of people living with chronic conditions for many decades. So it is very important to attend to and try to understand the experience of somebody with impaired mobility, impaired vision, impaired cognitive abilities and so on, to help to think about and choose appropriate interventions that might be useful to ameliorate some of the effects of the illness.

Phenomenology is then a very different business from medical business, assuming an image of medical business as a 'doctor-I've-sprained-my-ankle-here's-a-bandage-thankyou-goodbye' sort of thing. This is a very different kind of thinking about how people assign meaning to their illness and illness experiences, and in what ways those meanings impact on how they live their life more broadly. I want to try to capture the notion of disorder being embodied, and enacted in the sense that with every action that somebody takes, like going to the corner shop to buy milk. If that person has depression or MS or a broken leg each one of these experiences will be vastly influenced and changed by the disorder, and finally situated, in the sense that

the biopsychosocial model has made very prominent, that people's social perceptions and life opportunities radically impact on the experience of their illness.

For an admittedly extreme example of how illness might shape, limit or sculpture one's existence in a most radical way we might look to locked-in syndrome as described by Jean-Dominique Bauby in *The Diving Bell and the Butterfly*.

So how can phenomenology help to enrich the understanding that people in health professions have of their patients? Firstly it offers an interesting way of thinking of patients as people in general, as *being in the world*. 'Being' includes the physical embodied dimension, and 'the world' includes, for better or for worse, the social dimension, the geography of their world, that might be modified or restricted through having an illness or disability; and thinking about their relationship with their environment as something that is at the core of their illness experience. Some disabled people who have written about disability have made the argument that there aren't any disabled bodies, only disabling environments – the social model of disability. I don't think that's entirely true, but there is a definite sense in which the kinds of environment we provide for people can radically change their experience of disability. Illness and disability affect people's goals and actions and their general attunement to their environment, with loss of agency, productive function, social participation and financial status. Whether an illness disrupts a goal might be very critical to the person who is ill but this hardly ever features in medical consultations, unless they are specifically asked: what were you planning to do? – what has the illness prevented you from doing? So there is a much more existential appreciation of what it means to be a human being, especially one affected by illness or disability. If you think of illness as not just a disorder of the physical body that can be seen in terms of molecules or signalling pathways in chronic pain, and really try to understand it as a disruption of the lived experience of that body, that helps to uncover another dimension of the lived experience of illness. When we restrict people's physical possibilities we also limit their existential possibilities.

Another useful contrast that Merleau-Ponty proposes is that between the biological body and the lived body; or rather that our one body has two dimensions, the biological, and that which we experience from within. We can think about illness as something that removes the body's transparency and offers us a rare opportunity to perceive the gap between these dimensions. So maybe, while as a physician you may be attending to the biological body, the patient may be coming to you with their lived body experiences of suffering. In this situation you may find that objective facts cease to tally with lived experience. It is something like an eating disorder where we can see that regardless of how thin the objective body is the subjective experience of the body remains that it is fat.

So in broad terms we can think of the experience of illness as something that redefines our relationship to the world, and this change doesn't just take place for the ill person herself but also includes her family members and friends who experience this transition. Among the physical, psychological and social changes, illness affects people's sense of time: what they want out of life and what they consider it worth spending time on. There is an element of adjustment in which people adapt their creativity to come up with new solutions and ways of achieving things. While by no stretch of the imagination can I say that illness is a good thing, there may be a potential positive secondary consequence of being ill which is often overlooked but well worth thinking about: that people's self-respect and dignity can be very much enhanced by feeling that they have succeeded in achieving something in spite of bodily limitations.

Illness and dis-ability, breakdown and homelessness

Returning to the idea that illness dis-ables us, that it takes away the fundamental attitude towards existence which is one of being able, Heidegger has a nice existential definition of human lives as almost pure possibility. He says what differentiates human beings from a tree or a rock or a badger is that we have the freedom to choose what to do to exercise our choices (with obvious constraints – I can't choose to fly or to breathe under water), to pursue life as a series of possibilities and have the freedom to choose whether to take them or not. Merleau-Ponty enhanced Heidegger's view by saying yes, you're right – as an existentialist he thought freedom was absolutely fundamental to the human being - but we have to also remember that possibility includes the physical ability to perform actions in the world, so if somebody wants to be the fastest 400m runner in the world they need legs (although Oscar Pistorius's participation in the Olympics may oblige us to revise that!) But what Merleau-Ponty wanted to point us to was that performing actions in the world, having effective agency, very much depends on the kind of body we have. Young contrasts the way in which boys and girls throw balls [slide of a baseball professional and a beauty queen pitching] and makes the philosophical point that the man can not only throw faster but his use of space – his 'spatial comfortableness', using the vertical dimension, involving his shoulders and whole body in the movement, isn't simply a physical fact about him but an existential fact. If you think about social arrangements that restrict women: restrictive clothing in some cultures, or going out after dark, these are not just physical, aesthetic or moral constraints but they are existentially limiting for the women who have to adhere to them. Women's motilities, their comportment, their ease of being in the world, are modified by socially learned restrictions to their embodiment; perhaps that is something we as a society ought to address.

Another way of thinking about illness is to view it as breakdown. Heidegger's tool analysis refers to the way we are very happy with tools, the things we have ready to hand in our world, so long as they work: when the pen writes or the car starts they are inconspicuous and transparent; they enable us to do things but don't actually play any conscious role and they aren't in the forefront of our minds. But in situations of breakdown tools become conspicuous. In an analogous way health can be regarded as transparent in the way we take our bodies and our abilities to do things for granted, but in illness the body becomes conspicuous and cumbersome. You might say the body is not a tool like a pen or a lawnmower, and that is true, but in some respects the analysis is both applicable and interesting, because it can help us think about types of bodily breakdown and the ways in which we can compensate for those.

A third way that phenomenologists have thought about illness is as homelessness. The Swedish philosopher Svenaeus suggested that in illness one becomes alienated from one's body and disoriented not only existentially but also physically and mentally. This disorientation is something medicine should tackle, and enable people to find a way back to a home-like way of being.

The patient/physician²⁰ interface

Going back to the question I opened with: how do we go about evaluating people's lives? This is probably a question you grapple with on a daily basis in your professional lives.

²⁰ This of course includes all pain practitioners.

You might take someone like the late disability activist Harriet Johnson and think it must be terrible to be confined to a wheelchair, suffering back pain, but here is what she wrote a couple of years ago:

“Are we ‘worse off’? I don't think so. For those of us with congenital conditions, disability shapes all we are. Those disabled later in life adapt. We take constraints that *no one would choose* and build rich and satisfying lives within them.”

This is a key point about thinking about medicine as something whose business it is to enable people to live rich and satisfying lives within their physical or mental constraints.

So how does this apply to the patient-physician interface and the interaction in the clinic? The potential for the breakdown of communication is very great. The stakes for the patient are very high and health professionals have huge time constraints and professional pressures. The terms under which the consultation takes place are less than favourable. You've got ten or fifteen minutes within which to make huge decisions with somebody else from any background, any level of education and sometimes with language barriers and so on.

It's worth giving a little philosophical analysis of the constraints. You might think that illness represents two distinct realities – two different worlds. In the world of the patient, there may have been months or years of experiences and stories they want you to hear; a huge build-up of emotionally loaded thoughts and feelings about the illness. The appointment letter may have been on the fridge for two or three months and he is constantly thinking; I'm going to see the consultant next month, next week, tomorrow... He may come to you with twenty questions and nineteen of them seem to be irrelevant, or with pages and pages of printout from the internet. But your professional world is going to be completely different. Maybe you're running behind, maybe you've spilt coffee on yourself, maybe you have problems at home – all these things are in the consultation room as the consultation begins.

Phenomenologists have described this meeting as involving a decisive gap between the patient's experience of illness and the physician's view of disease and the biological processes involved.

How can phenomenology help to improve the physician-patient relationship? Phenomenology discloses how individuals constitute the meaning of their experiences, so we might say that it brings us to think that illness is not an objective entity, but something that is determined by how it is experienced by the patient, their family, friends and their physician. This is not to deny that there is a disease; it is simply setting it on one side and focussing on the illness and the radically different ways in which it might appear to patient and physician. So the physician might construe the illness as 'disease state', but the patient encounters suffered illness as well as the disease. The patient also encounters the body as painfully-lived.

So all this leads to different explanatory models and different systems of relevances. You might be interested in diagnosis but the patient wants an explanation: why did it happen to me? – why did I end up by having lung cancer? - I never smoked - and similar questions. You may want to suggest treatment but the patient comes with the very clear objective of a cure. You might be able to offer a prognosis, but the patient doesn't want statistics, they want to know what is going to happen to *me*. So the

demands on you are great, although your ability to provide the information or the cure that people are after is in some cases extremely limited.

The patient seeks validation of their experience from you but without always explicitly stating what their values are, so you have to tread extremely carefully around issues such as gender, race and culture. In short, a phenomenologist would say that patient and physician do not share a system of relevances.

The essential characteristics of illness

What then are the essential characteristics of illness? I want to suggest that these transcend particular features of different diseases, and that they constitute the meaning of illness as lived. So what do alcoholism, bulimia, flu and kidney failure have in common? What kind of general phenomenological insight can we glean?

S. Kay Toombs summarises the eidetic ²¹ features of illness as: loss of wholeness, loss of freedom to act and loss of the familiar world. With bodily impairment there is a profound sense of loss of total bodily integrity and the body can no longer be taken for granted or ignored. It thwarts plans and impedes choices, rendering some actions impossible. The disruption of the fundamental unity of body and self results in seeing the body as other than me. There is a loss of faith in the body which comes to be seen as a threat to self. We suffer a radical loss of certainty: with loss of control come unpredictable, apparently capricious interruptions to our lives. With inability to carry on normal activities comes a sense of isolation from the familiar world. The future is truncated. Toombs concludes:

“What the phenomenological approach is concerned to show, however, is not simply that the patient’s experience should be taken into account as a subjective accounting of an abstract ‘objective’ reality, but that the patient’s experiencing must be taken into account because such lived experience represents the reality of the patient’s illness.”

(Toombs, p.236)

This is the real shift that the phenomenological approach requires of us, from thinking about the subjective processes of an objective reality in abstraction to thinking about it as having a primacy of its own.

Personal experience – good and bad

One of the most distressing experiences I had when I was diagnosed [with lymphangioleiomyomatosis (LAM)] was having undergone a CT scan looking for abdominal masses caused by lymphatic obstruction, I heard something about the radiologist having reported that something was wrong with my ovaries and when pressed I was told ‘they think it’s ovarian cancer’. That happened at 4 o’clock on a Friday and the following week all I could learn was that my respiratory consultant (who had ordered the scan) was on holiday but had left me a message saying ‘this has nothing to do with your lungs’. I was given an appointment with a gynaecologist in three weeks’ time but thanks to the intervention of my respiratory nurse who rang him he saw me the next day and assured me that the scan report was wrong. It’s this kind of small mercy - the nurse’s kind gesture - that becomes so enormously important in a situation like this.

²¹ Relating to or denoting mental images having unusual vividness and detail.

I want to conclude by reading a short passage from my book (*Illness*).

“Empathy. If I had to pick the human emotion in greatest shortage it would be empathy. And this is nowhere more evident than in illness.

The pain, disability and fear are exacerbated by the apathy and disgust with which you are sometimes confronted when you are ill. There are many terrible things about illness; the lack of empathy hurts the most.

I am in the respiratory department for my breathing tests. I begin preparing several days before the test. I always brace myself for a decline, telling myself: you *know* it will be worse this time. A further deterioration brings with it a further shrinking of my world, fewer things I am able to do easily, or do at all. Every month, as my breathing deteriorates, I wonder what will go next. Will I have to give up my electric bike? Will we have to install a downstairs toilet? Will I be able to continue practising yoga? Seeing your capacities diminish, your world becoming smaller and harder to negotiate, is never easy. Most people experience decline over decades. But seeing your abilities shrink at a terrifying pace at the age of thirty-five is horrific. Nonetheless, I know I must have the breathing tests.

A lovely nurse, Simone, is usually there, chatting to me, telling me about her boyfriend. But this time she is not there. Another nurse, sullen and unfriendly, leads me to the test room. She sets up the machine without saying a word, hands me a tube and tells me to blow into it as hard and as fast as I can. I take a big breath and exhale into the tube. I blow hard. My face goes red, my body tenses, my shoulders quiver with the effort. I want good results. I want the same results as last time. I want to be stable, oh, how I want to be stable. I blow until I feel like fainting. I want to be able to blow the same meagre 1.4 litres of air out of my lungs as I did last time. (This test is called FEV1, the forced expiratory volume expelled in the first second of exhalation. A normal result is about 3 litres.) I blow. My lungs are empty and I feel dizzy from the lack of oxygen. But I keep blowing, as hard as I can, stretching the beleaguered membranes of my lungs well beyond their capacity. The needle, unresponsive, barely shifts. It crawls upwards, marking the diminishing amount of air I exhale. I sit down, panting. I've done my utmost. I've blown myself away. But I know I failed. I know I declined.

I ask her for my result. ‘1.1’ ” the nurse says, with no trace of emotion in her voice. I try hard not to cry, but panic and despair get the better of me. I choke on my tears. Crying involves a lot of breathing at the best of times; with respiratory illness, it is downright difficult. I sob quietly, bitterly, the way defeated people cry. I lament my helplessness, my body's betrayal. I can't do it. I can't breathe properly. I cannot breathe. All those hours at the gym, kick-boxing classes, strength training, runs — all to no avail. My illness is stronger than my body, stronger than my will. I've lost 300 precious millilitres of lung function over the past three months. The equivalent of what a healthy person would lose over a decade. I look at the nurse. She stands there, stony but for her slight impatience. Now I'm crying and can't do the other tests. I'm spoiling her day, getting her behind schedule. I collect myself; ask her for a glass of water. A sulkily hand presents me with a dripping paper cup. She doesn't look at me or say anything. I am alone.

I later reflect on the encounter with the nurse. What sort of training has made her able to stand there, saying nothing, offering no word of comfort or distraction? Does she do this every day, to all her patients? Does she feel anything but annoyance towards me? Is this exchange sanctioned by the National Health Service? Does she think of me as a person? I can't ask her these questions. She probably won't even remember me. I know I failed the unwritten law of the medical world, where everything is impersonal, where news of deterioration and terminal illness are to be met with dry eyes and a steady gaze. And within this world, my human failure will be held against me, while her failure to be human does not even have a name."

(*Illness*, p.37)

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Joint Discussion of talks by Havi Carel and Raymond Tallis

The thing that hit me is that here we are trundling along in this evidence-based, randomised control-based, population-based, impersonal medicine trajectory and on the other hand seeing the patient as a person, an individual – and both of your talks emphasized the importance of the latter.

The last two days we have talked a lot about vocation and care. In [Ray's] talk there was no mention of care. I am the man the palliative care team or the hospice call in when a patient is in agony they can't control. I have never yet met a patient I can't manage. But the second talk made me realise that I am a phenomenologist. I realise that when I see a patient I don't see a disease, I see a patient with a problem, and I am trying to work out that problem. So maybe there is a shortfall in the way we do medicine: perhaps we have a limited kind of treatment algorithm and if a patient falls outside it I am sometimes horrified to hear doctors saying I can't help you. I will never ever say that; I will always try to find a way to help them. So I am very much pro a vocation of care which involves doing everything you can for a patient to minimise their suffering. But that doesn't involve killing them.

(RT) First of all about vocation. I have actually written a book about medical vocation called *Hippocratic Oaths*, in which I deplore the reduction of the medical profession to people who form contracts rather than deliver under covenant. So to punish you for your opening accusation that I don't really care and are more into killing you would have to read *Hippocratic Oaths* (which would be a terrible punishment for anyone!) I am very much into medicine as a vocation, and I believe that when medicine loses its vocation it actually loses its soul. I don't think I need to be reminded of this; after 37 years as a doctor particularly looking after old people with incredibly complex problems where if there was ever a case for the phenomenological approach it was for them. I made some awful crass mistakes precisely through not entering the totality of the patient, sometimes because I was busy and harassed but that's not an excuse. That answers your general point but you followed this with an extraordinary empirical statement that you've never come across a patient that you couldn't help, presumably enough to satisfy them. I think you are the first palliative care person I have come across who has actually made that assertion. I have worked with some really first-rate palliative care people for many years and we brought in end-of-life care in our geriatric wards very early on. Both parties agreed that there were always patients who were in an irredeemably appalling situation who you knew wanted to die and were denied that option. A small minority but the single patient matters. So we are disputing on empirical experience. Even with first-class palliative care, the assertion that there is no patient who would not benefit from assisted dying is one I couldn't sustain.

I should clarify my position – I am not a palliative care doctor, I'm a pain specialist and they call me in when they can't control pain ...

... but pain isn't always the main problem. If you read about Ann Macpherson's death: she was totally disintegrating. This wonderful woman was ending up as a bag of pus for the last three weeks of her life. That isn't going to be solved by pain treatment – she was begging to die. It was a disgusting death ...

... but if my say so that is your judgement looking on her...

... no, it was hers and her daughter's and her husband's judgement ...

... but I have seen patients in hospital dying apparently disgusting deaths and they go into a hospice and the reverse happens ...

Hang on ... Ann Macpherson was probably the best-known GP in the Oxford area where there is the best palliative care and she would have had everything possible. Both her husband and daughter are doctors. She wasn't missing out on some magic remedy – her body was disintegrating. Her daughter annotated this with great care and personal cost and I actually cried when I read it because I knew her well.

I have also sat round the beds of others including my mother whose last few weeks of life were absolutely appalling and again it wasn't the pain. Pain can be difficult to manage but it wasn't the most the most difficult problem – it was total body disintegration, total lack of control, being reduced to basically something that is utterly alien to you.

The only thing is that these cases of failure of palliative care are still relatively rare and it may be asked whether we can we justify a change in the law for the benefit of so few ...

... as regards the numbers: in the Oregon experience about 1 in 500 people actually had assisted dying. But another 100 times those discussed the possibility of assisted dying with their doctors. The benefit of knowing that that is a possibility restores your sense of control. And a sense of control is one of the key factors in determining the bearability of things. But I come back to the feeling that a minority isn't unimportant. We extrapolate from the Oregon figures that about a thousand people in the UK might be in a situation to justify assisted dying. But we don't have an epidemiology of horrible deaths, and this is something we urgently need. I suspect that the figure is rather bigger than we physicians like to think. We do bear other people's suffering quite heroically.

We had Bobby Farsides to talk to this group a couple of years ago and she was discussing the limits of tolerance in the context of Lord Joffe's proposals. I would like to read a few lines from the transcript:

"Lord Joffe told the House of Lords in the final reading of the Bill, at which it was defeated, that patients should not have to endure unbearable pain for the good of society as a whole ... [We had talked about things like female genital mutilation where we have no problem with banning something which is acceptable to some people and part of their culture, to prevent suffering] but In this case we have people telling us that they have unbearable suffering and asking for the law to be changed in order to allow them to be relieved of it; and going back to Joffe's claim, unbearable suffering is suffering the ending of which it would be a humane act. But we chose through our legislatures to reject that argument. So what have we in effect done? I would say we have asked the people who claim to be suffering unbearably to tolerate that pain in the interests of a society which feels that there are important reasons to take very seriously any proposed change in the law that moves towards medically assisted dying. So we have actually turned the issue on its head and said that in the instance of FGM we will not tolerate pain and suffering, but in this case we have to tolerate a certain level. Can a society faced with this example choose to tolerate what a small minority of people tell us is their unbearable suffering in the interest of protecting those people and others from harms they do not recognise or acknowledge? Should those who claim to be suffering unbearably be expected to tolerate their suffering in the interests of defending moral principles they see as inappropriately applied in their case,

*protecting society or in order to avoid the harms others believe would follow on from giving them the right to seek assistance in ending their lives? Now I'm not making a judgement on these issues. All I hope I have done is shown you how by using some of the conceptual frameworks we use quite happily in other areas we end up with what we might think is a slightly uncomfortable reversal of asking people to tolerate their own pain and suffering in the interests of society.'*²²

That's a very good analysis. One of the cornerstones of our ethical principles in Western Europe is that you treat each person as an end in him or herself. To subordinate someone's suffering to the greater good is to instrumentalise them and this is one thing you should never do to anyone let alone a dying person.

I want to contrast the situation in palliative care where we may, perhaps complacently, think we are doing quite well, with the situation twenty or thirty years ago in surgery when it was assumed by surgeons that nobody got postoperative pain after an operation by me, and we've spent twenty years tackling this.

There is only about 16% of the population that have access to hospices. I wonder why we put so much energy into [?killing patients? - inaudible] instead of making hospice care more available, and the care of dying improved for more people.

That again is an empirical assertion and one has therefore to look at international experience. The Oregon experience is I think decisive. Two things you need to know: one is that out of the 50 states they have the second best palliative care services and yet they have need for the Dignity of Dying Act and it is used. Secondly since this act was introduced the number of people dying in hospices – which must be a good indicator of availability of palliative care - has doubled. If you look at the Belgian experience you find that investment in palliative care was ahead of an assisted dying bill because they felt they had to take up all the slack first. There is no conflict between palliative care which is a huge thing and assisted dying which is of course, thank God, a smaller thing. They are all part of the same picture of ensuring that people live well and die well.

I think that you're right in your assertion that knowing it's available reduces the likelihood of its being used because it returns control, which is almost more important than pain relief. Mostly, if not always, if people are in the right place we can make their pain tolerable, although too many people don't have access to that; but it's the humiliation and degradation that came across in the account of Ann McPherson's death; the loss of her sense of being a person, not only for her but for her knowing her family were seeing her like that – that her children would forever have that imprint on their brains – that's phenomenally important..

Her children were very badly damaged. As Tess said, it is a great privilege to care for someone you love but not when that person is desperate to die.

The community has changed. I come from Norfolk where it used to be very difficult to get any palliative care drugs including morphine out of hours because you might have to travel 40 miles to find the pharmacy that was open and they didn't always

²² 'Tolerance, Pain and Suffering: The responsibility of sufferers', Bobbie Farsides, Transcript of 2010 meeting of Philosophy and Ethics SIG 'Culture and Pain'. The quotation is from p.60 but the whole talk is worth reading in the context of this discussion. Copies of the booklet are available from pwgorman@btinternet.com or can be downloaded from a link to the SIG page in the BPS website.

have enough stock to last over a weekend, so families had to travel up to 80 miles to get medicine for someone who was dying.

They have now introduced boxes with a set amount of drugs, which can be prescribed by the GP, and which stays in the home with access to anyone who needs it. The big problem was overcoming the fear that it might be abused. But this never happened in hundreds of cases and people were enabled to have a dignified death, and the knowledge that it was there abolished the fear of loss of control which might have prompted a request for assisted dying.

After I retired six years ago from specialist palliative care I went back to work for the Marie Curie Foundation. There has been a rolled out programme throughout the country to take good palliative care into GP surgeries, as well as care of dementia, heart and respiratory failure, neurological disease etc; at least 50% of Marie Curie's work is now with these sorts of things rather than cancer. The box Bernd referred to is standard practice and it is very reassuring knowing it's all there and will have been topped up as need be before a weekend. Things have improved. That gives the family a great sense of relief.

Advance directives

May I ask both speakers about the concept of advance directives? I'm surprised neither of you mentioned them.

(HC) I think they're a great idea. The worry that people sometimes have about this is that when they are healthy and well they may tick all those boxes saying that if they've got X,Y and Z they want to be allowed, or even helped to die; but they fear that once they are in that situation they might think: it's not too bad actually and I've changed my mind, but may be unable to express the change in their position. That is something that needs to be addressed but in principle it's not so much the autonomy; it's really the sense of control. Not in the sense that I rationally decide, but the sense that if things get really horrible and I get to the point where I am no longer rational I can still make it stop and nobody can force me to stay alive under these circumstances.

It's a bit of a cliché to say that for a lot of people death is to the twenty-first century what sex was to the nineteenth: it's a taboo and people aren't comfortable talking about it. It's true that it's an incredibly difficult topic to discuss. There are a lot of decisions to make about organ donation, advanced directives about assisted death and so on, but as we move into an understanding that these things are part of life these conversations will have to happen more. If you ask people about organ donation then 90% will say yes it's a good thing, but less than a third actually manage to sit down with their families and have the required conversation. So there is a difference in these situations between the lived experience of something and the abstract understanding of it.

(RT) I'm very much in favour of advance directives. Dignity in Dying, which is affiliated with Healthcare Professions for Assisted Dying, has a great push on providing a very simple advance directive. It's all about choices, and the all-party parliamentary group that is supporting assisted dying is in fact called Choices at the End of Life, because it's not just about assisted dying, it's about getting what you want and deserve and so forth.

The problem with advanced directives arises when, as Havi was indicating, you become mentally incompetent, or when a situation you expected to be intolerable turns out to be tolerable. There is a story of a famous mathematician who told his wife that if he couldn't do mathematics at the highest level he didn't want to be alive any more. He became demented and his wife noticed two things: first of all he never looked happier, and secondly for the first time of all he was tolerable to live with! There is a whole philosophical question about personhood. If I at 55 decide about myself at 85 am I the same person, and if I become so demented am I another person? Then what is the situation? Can I assume a future self, as Hume would say?

So why didn't I raise the subject of advanced directives in the context of assisted dying? It is because with advanced directives you can only state the treatment you don't want; you cannot requisition treatment you do want. You can't requisition assisted dying (a) because it's illegal and (b) because of the general principle that you can't requisition ... you can't even state, as the Leslie Walsh case indicated, that you want to be fed and watered till your heart stops. So unfortunately although advance directives are a very important part of choice and respecting what you wish and individualising treatment they don't address many issues in relation to end of life.

Assisted dying and assisted living

As a priest I don't subscribe to the absolutist propositions that you were attributing to some of my colleagues, because I don't think Jesus was that kind of absolutist. As a GP I think I could technically be said to have participated in assisted dying in one sense or another. The thought occurred to me first when I read your article in the BMJ that I wanted to relate assisted dying to what I have come to call assisted living. I think what Havi has been talking about in the context of the lived experience of illness is medicine's failure to provide assisted living. When I quoted from her book in my talk earlier in the meeting I referred to James Markum who has talked about the fragmented body divided into its component parts, the standardised body which is made to conform to some abstract concept of what is proper, and the alienated body. These were all examples of the sort of thing you have been describing where medicine has failed to assist the person to live within the constraints of the illness and within the reality of the lived experience of the illness. I think if medicine was better at doing that we would be less troubled by the issue of assisted dying; our understanding and approach to dying would be enhanced, and our fear of dying would be diminished. This applies to the profession as a whole because generally we are very bad at confronting the whole issue of dying and death. So if we better understood our responsibility toward assisted living we would find it easier to handle assisted dying.

I thought you were unnecessarily scathing about some of the 'miracles' people who are about to die experience because we have heard in the course of these conferences examples of people in hospices and other circumstances such as Chris Chisholm described yesterday [in her talk on Jumbulance holidays for people with serious or terminal illness] who have been given the opportunity to rediscover the joy of living and some quality of life, and this does make a difference to their perception of their approaching demise.

That is my GP perspective but as a priest I would also say that assisted living needs to include a spiritual understanding of what is happening, which is often lacking in healthcare. I see a continuity of life through the process of dying. For some people, the need for assisted living needs to accommodate the understanding that they can be helped through the process of dying whatever their concept of what lies beyond it.

(RT) I think we are in agreement. Assisted dying and assisted living are part of the same package. 99% of the time medicine is about assisted living – getting people better, or at least working with poorly people to help them feel better. But there is that 1% where assisted dying is the way ...

... of course, but Havi was also saying just how bad some people can be at that. People in this room may not be, but generally speaking ... The sanctity of the lived experience actually propagates our attitude to dying ...

Traditional attitudes

I'm not sure if I should be saying this and I think it's going to confirm my outsider status. You're talking about something which is very specific – very much a twenty-first century first world problem. I come from a very large Welsh farming family. I want to ask you, a hundred years ago when most people died at home what do you think they died of – do you think they just slipped naturally away? If you do you are wrong. If the matriarch of a family was dying at home from a hideous ghastly disease and she wanted to die, I think her eldest daughter would have seen it as her moral duty to help her on her way and would not have allowed any punishment, be it imprisonment or eternal damnation to stand in the way of her duty to show love and compassion for her mother. I would not like to say what I would do if my husband were in hospital dying of a hideous disease; I'm not sure if I could stand by and see him suffer for three weeks. I'm not a doctor, I'm not bound by the Hippocratic Oath, I'm just a human being. I feel so much for you because you're being asked to act as paid executioners, which is morally and legally wrong. There is this huge gap between what you have to do and the lived experience of the patient and the patient's family, and I don't know how you can bridge that gap.

(RT) There are plenty of examples from literature – remember Paul Morell in *Sons and Lovers* who bumped his mother off. When it was reviewed there was no outrage about that, although there was about the sex. It's because this is no longer possible and because we have such a paranoid society we have to put the thing in the framework of law and regulation. Historically I completely agree with you. But in the real world ... if I am asked in a radio interview if I have ever bumped a patient off of course I say no because I don't want a visit from the nods the following day, I've got my life to live. But a lot of medical practice amounts to assisting patients to die, of course, but it does need formalisation.

I live in a rural community surrounded by dogs and horses and cattle. Not one of my farming or veterinary friends would hesitate to put down their best horse or the dog they'd gone hunting with for years if they were in great distress which they couldn't relieve.

(RT) That brings back a terrible experience I had at the BMA: after I gave my opening statement someone who was supposed to be on our side said 'if it was a dog I wouldn't hesitate etc. ...' So the opposition leader thought 'the lord hath delivered him into my hands' and the next person said 'well, my patients aren't dogs or horses' to a great round of applause from the serried ranks...

... for many of my patients their dog or their budgie is their best friend and they care for them ...

... it's an argument I have sympathy for but don't entirely agree with, and it's probably politically a very dangerous argument. I knew we'd had it when that chap brought it up – I suspect he was a plant.

Depersonalising patients

Can I bring the discussion back to Havi's experiences – not so much yours as your husband's with earwax. It's sort of laughable but you highlighted an incredibly important point: that is that that note sits on your fridge for weeks and the patient is really psyched up by the time they get to hospital; they are going to see The Consultant who is going to give them The Answers. En route they have to see the frosty receptionist and sit in the waiting room with serried ranks of people who have become completely depersonalised, and then the outpatient nurse will come and shout out their name, all of which are phenomenally depersonalising experiences, especially if your problem is a relatively trivial one in which no-one is much interested. Your experience is bad enough but presumably people are at least excited about your problem because it is so rare. An awful lot of our pain patients are in that unexciting category.

(HC) There are some constraints that are given, like the big system. He will know that if he's going to some big clinic like ENT outpatients they won't know him. In his case it doesn't matter so much because all he wants is for someone to remove the wax, advise him how to prevent it happening again and send him home. These are the kind of paradigm examples of where the disease is important but the illness is trivial. There are bigger burdens in the other cases where there is an ongoing relationship - and I must say that as time goes on things do become less impersonal. It's hard to say what is medically exciting – perhaps a double lung transplant or delivering triplets.

My consultant always comes out of the room herself and comes up to me and says would you like to come in now – there's no shouting of names. But I see a lot of other patients seeing other physicians. The experience is so multidimensional - the architecture of the Bristol Royal Infirmary is not great, it's very functional and makes me feel I would like to get in and out as quickly as possible. The real skill for you guys is identifying the points at which stepping out of the scripted role is going to make a real difference. The thing that upsets me most is when you sit with groups of patients there is very often a complete denial of the fact that you are human beings; you may have had a rough day, perhaps with someone dying. You say you get called in for difficult patients ... I usually think of a difficult patient as someone who doesn't comply or is aggressive ... but you have to assess something subjective ... I'm thinking of Elaine Scarry's book *The Meaning of Pain* where she talks about your pain as a paradigm example of absolute certainty – you can't mistake it for anything else. But another person's pain is a paradigm example of absolute doubt. It's incredibly difficult for any engagement to take place. Patients are like kids – they don't want you to have a bad day or take things personally, but to have 100% attentiveness to their needs. So there is a kind of pastoral role that has been eroded in the profession in ways that don't allow the development of that kind of attunement.

It's so important not to think physically. What I try to get out of a patient is what is causing their distress, and it's not always physical pain. Suffering is a paradigm that involves pain but there are many other facets; relationship problems, family problems etc. that hospices are very good at sorting out. When I am called to see a patient who is in distress part of my role is to work out how much is physical and how much is existential and you have to try to work with that particular patient in the best way

you can with the help of others. I always think we should have that in all chronic pain clinics. It strikes me that we are deficient in so many ways. You describe the impersonal nurse – my wife had the same sort of experience. It comes down to what has happened in medicine and nursing in the modern age: we have lost the ethos of caring. Normal interactions with other human beings seem to be disappearing.

(RT) One thing is that there is so much business to transact now. So much illness is framed in ways that is unliveable. For instance my serum potassium of 6.4 isn't a kind of thing I can live. There is so much content of illness which is as it were in the keeping of documents. We want to get the documents right and if someone has a potassium of 6.8 we want to get that right.

I have to say that Havi's book is fantastic: everybody in this room should read it. It seems to me that even the relatively trivial earwax thing illustrates an asymmetry between the doctor and the patient. For the patient it's that special day; for the doctor there may be 25 people in the waiting room and the nurse is saying come on, speed up ... There is this asymmetry and it's a very difficult one to cope with, and everything you say has a huge potential payload for good or ill.

Pressure

I read about a guy who decided he didn't want to be resuscitated, so he had a tattoo across his chest saying 'not for resuscitation'. When he subsequently changed his mind he couldn't afford the laser thing so he wore a big Elastoplast patch over the word 'Not'!

It worries me that people may be pressurised into making that choice: they are in sound mind, you've done all the right checks and asked all the right questions, but they've been made to feel guilty because they are still around and people want their inheritance or to be relieved of the burden of looking after them.

(RT) That's been a preoccupation of people on both sides of the debate. It's an empirical expectation that needs to be checked. If you look at the Oregon data assisted dying is more often opposed by the family than you would expect. People who want assisted dying often do so in the teeth of their relatives' wishes. They don't want to lose their Mum or Dad. There is very little evidence of pressure. Of course you have to have checks and constraints which is why any law has to be framed with safeguards: the primary doctor must be sure the medicine is right, independent doctors to be sure that the whole thing has been thought through and a properly witnessed signature with legal input etc. There is a point however when endless checks and regulations can get in the way of the person achieving their aim, so there is a balance ...

Were the Oregon people more in the higher socio-economic bracket with health insurance or are we talking about the whole vista including people without insurance or living in trailer parks – who were they?

(RT) The typical portrait was middle-class, rather feisty, towards the top of the socio-economic scale, used to having their own way. Also their average age was younger than that at which people normally die by non-assisted means, which of course makes sense, because the older you are it becomes easier to die than when you are biologically robust and death is particularly awful. So the portrait of the vulnerable, unable to speak for herself recipient of assisted dying is not born out in practice.

So should I assume that the people down at the wrong end of society weren't in hospices?

90% of those requiring assisted dying did it within the context of a hospice, so they'd had the full whack of palliative care. Margaret Batten has done a wonderful breakdown of ten years' worth of the Oregon data – 600 patients a year ...

... I've got patients who I am sure might be pressurised...

Anybody could be pressurised into anything – giving their money away, or moving into a cheaper home – there are all those evil pressures around. But I am sure you can produce enough safeguards to make sure that people can be relieved of appalling experiences without being as it were obliged to undertake assisted dying when they are not ready for it.

Illness as homelessness

One of your [HC] slides [Illness as homelessness, quoting Svenaeus] used the lovely expression 'helping the patient to find a way home' – could you say more about that?

(HC) The basic phenomenological premise is that what really destroys people isn't the biological disease process. As Ray was saying if I knew that my white blood cell count was whatever or my kidney function tests were abnormal etc. none of these things would matter to me until they got translated into my own experience. So in some ways the point of medicine isn't to fix diseased bodies, it is to make people live longer and live better, and that's a core point for Svenaeus. There is a lot of interesting stuff about this experience of being homeless or disoriented or alienated from your own body which is extremely compelling because ... people ask me about breathlessness and ask 'is it like running fast, or walking fast uphill, or like being at altitude?' and I have to say 'no, it's not'. I have had all these healthy experiences before I was sick but there is nothing that comes close to the feeling that your body is doing something really weird and you don't know what it is because you've never felt it before. Going back to this idea that in health the body is transparent, there is something very obtuse, something obvious in your face, it puts a stop to everything else. It's not like if you have cut yourself or you've got a bit of a headache and you can continue with what you are doing, it's kind of all consuming in that way. Another way of looking at it is to go back to the idea of freedom: if you think about your actions as normally being framed in the context of ... say you feel like stretching your legs after lunch you just go for a walk, and you walk as long as you feel like it, or have time for, and you come back. So in effect you have walked without limit so the thing that guided your experience was the project, to go for a walk. If I want to go for a walk the whole experience is defined by the restrictions: will I have enough oxygen, will it be hilly, what if I need the loo, what if I get too tired. And the whole nature of the experience turns from a natural unreflective experience to something artificial and planned, so you feel kind of homeless in that sense; you are placed in a world from which you have been dislodged in a way.

In the context of the chronic pain clinic, fibromyalgia sufferers with chronic widespread pain and often other medically unexplained symptoms are people whose lives have stopped. Some of them come from a demographic where their lives weren't great in the first place; I was thinking about helping them to find the way home, but the place from which they came may have in large part contributed to the

way they are now. They are people who never had much autonomy or control; they've often been the victim of circumstances from early onwards till now when they are the victims of even bigger and worse circumstances. So rather than trying to help them to go to the home where their problems may have originated we may need to find them a different place ...

But can that be a different home? I was just thinking about my own experience. You are on this trajectory, highly successful, doing all this stuff, and then your chronic disease process [bipolar syndrome] takes over and bang it stops. One response to that is to just say I've had enough, commit suicide, another to say – well, I'm just going to sit at home now, but yet another is to find a different direction and go to a different home. I know I'm fortunate, I'm bright, well educated and financially secure unlike your group of patients, but even in their context could they not find different homes?

But home isn't a place – home is your body ...

But your body exists in a context. If Caroline's patients go back to being beaten up by their husband and having no money, their body is in that home, but I'm going back to the same home but in my head it's a completely different place. Maybe they do have to go back to that physical home but ...

(RT) My main area of interest was stroke and stroke patients. In a way stroke transforms your world. Suddenly you have to make your home in a different world. The body that you take for granted as the presupposition for all your behaviour is now something that has to be argued with – when you've had a stroke you don't just walk, you do walking. Your legs become tools, and obstinate tools at that. To remind us that the human body on which our whole lives are presupposed is in itself terribly human. It has lots of properties we never have any awareness of until we have it go wrong. I've never had any relationship with my kidneys, I've never had a good or a bad word with my spleen, I've hardly colonised most of my body. An awful lot of it is terribly alien and I'm quite happy that we can get along with each other fine so long as it doesn't get its own ideas. When it suddenly starts producing an immune process or something, suddenly the presupposition of your world is lost, and the world is changed with it. And you suddenly have to find your home in this new world. A minor thing like putting your socks on becomes the day's work.

Isn't that home a metaphor for meaning in this context?

Lévi-Strauss said man is a creature that makes his home in the world, and this seems to be the primary achievement of growing up from this blooming buzzing confusion of infancy and then suddenly you've got to start all over again.

(HC) The question of life opportunities is obviously inseparable from the other considerations you have to take into account. Anna Luise Kirkengen writes about how earlier experiences and trauma are inscribed into one's body, and how a lot of illnesses later on, particularly depression can be traced back to those, so if you don't deal with those you are treating the symptoms but not the underlying cause. She was suggesting various ways in which you can reconfigure our understanding of the way in which human beings are made up of a mind and a body and unified way of understanding how inseparable they are, and how we have to take into account not just physical but also psychological, familial and social situations. The thing I always find a bit grating about the biosociopsychological model is that it seems to say all you have to do is add them up all together then you won't leave anything out. And recently I've ended up with biosociopsychological-spiritual! What you really need is a

metaphysical transition not just to say human beings are these things put together but all of these things taking place at the same time with complex interactions between them, and then work with that. I don't envy you your jobs!