

Dilemmas in Pain Management

Scargill House June 30th to July 3rd 2003

Introduction

There can be few branches of medicine which throw up so many apparently irreconcilable paradoxes as pain management. Some of these are relatively intellectual problems, such as the difficulty of combining a reductionist approach to analysing problems with a holistic one to finding their solutions. In the first two meetings of what has become an established group of people with a common interest in exploring this sort of thing, our discussions have perhaps sometimes been rather cerebral and detached from the real world of the consulting room, theatre and laboratory. The theme for this meeting was therefore chosen to try to speak to bring our feet down to the clinical ground and to face some of the many ethical and clinical dilemmas which we so often encounter, but so rarely find the time to talk about in any depth.

The Place of Intervention in the Treatment of Chronic Pain.

Colin Peters

I will try in this talk to answer three questions:

1. How did anaesthetists come to be in charge of pain clinics?
2. What is my present approach to interventional treatment?
3. What have I learned from our previous meetings at Launde Abbey and Scargill which has changed my attitude to this?

The earliest endeavours in modern times to treat pain other than by drugs were virtually all interventional, and most involved destroying neural pathways between the source of pain and the brain. Most the earlier procedures in the first half of the twentieth century were surgical, but anaesthetists, with the skills and anatomical knowledge required for local anaesthetic blocks, soon became involved. It was apparent from the beginning that despite their undoubted value such procedures had limitations and many failures and complications, and demanded greater understanding of the workings of the nervous system. John Bonica, the founder of the IASP, whose interest in pain dated from his appointment to the Madigan military hospital in 1944 with special responsibility for the treatment of pain, soon came to realise the limitations of his knowledge and skills in treating the terribly difficult and complex problems that presented themselves and acknowledged the necessity of combining the skills of different specialists; and founded the first multidisciplinary pain clinic in Seattle in 1960. The first pain clinics in the UK began to appear in the 1960's. Treatment of cancer pain formed a large part of the work, most of which was intervention based, and Sam Lipton's book, "Persistent Pain – Modern methods of treatment" which was largely devoted to this, became a standard text. Although Melzack and Wall's gate theory was first published in 1965, advancement in pain theory and its application to treatment was relatively slow until the 1980's since when enormous advances in understanding of the mechanisms of pain have been seen, especially as regards plasticity in the nervous system and phenomena such as "windup-up". In particular there is better appreciation of the reasons why destroying

peripheral pathways rarely brings long-lasting relief (and conversely why temporary interruption often provides relief long outlasting the block). Another factor which diminished the importance of pain intervention was the emergence of the hospice movement and the realisation that most cancer pain can be effectively relieved by adequate doses of opioids.

McQuade's 1997 systematic review of Effectiveness of some Common Treatments concluded that there was good evidence of effectiveness for some common treatments, some were ineffective, and some lacked evidence either way. In general since the 1990's we have seen a swing away from intervention towards a genuinely multidisciplinary approach including cognitive- behavioural therapy and alternative medicine. The Pain Intervention Special Interest Group of the Pain Society, dedicated to increasing knowledge about intervention and teaching the necessary skills was formed in 1997, perhaps as a reaction to the apparent erosion of enthusiasm for such treatment, and the perception that incorrectly performed procedures would give it a bad name.

So why do we persist with intervention? There would seem to be at least two very good reasons for this and others perhaps not quite so good. Firstly there is no denying that some procedures, mainly for cancer pain, can be extremely helpful. Secondly, procedures such as lumbar chemical sympathectomy can be of use in conditions in which pain is not the primary problem. However, it has to be admitted that a placebo response, fuelled by the patient's desperate need for relief (and the therapist's to provide it) may lead us into a not altogether unbiased impression that our treatment is working. And it should perhaps also be acknowledged that anaesthetists temperamentally have an innate urge to "do something" and enjoy intervention.

What then is my current policy and philosophy regarding Interventional treatment? This is founded on four guiding principles:

1. Intervention must be based on sound anatomical knowledge.
2. Intervention must only be used when there is a firm diagnosis e.g. Trigeminal Neuralgia.
3. Intervention must only be used when there is no other alternative treatment.
4. Intervention must only be used when benefits outweigh potential unwanted effects.

The blocks I do can be divided into four categories:

1. Those used for treatment of non- painful conditions:
 - Cervical (surgical) sympathectomy for hyperhydrosis.
 - Lumbar sympathectomy for limb salvage and ulcer healing
2. Treatment of chronic pain:
 - R/F lesioning for Trigeminal Neuralgia.
 - Cancer pain blocks:
 - Intrathecal phenol
 - Coeliac plexus blocks
 - Cordotomy
3. Simple local anaesthetic blocks with or without steroids for musculoskeletal pain:
 - For costochondritis
 - Trigger point injections
 - For chronic postoperative pain
 - For osteoarthritis of the hip.
4. Blocks I continue to use despite lack of evidence to support their efficacy and a probable

frequent placebo response:

I/V Guanethidine

Epidurals

Root blocks

Facet blocks.

I do *not* do:

1. Blocks in neurogenic pain.
2. Blocks in somatisation syndrome.
3. Sacro-iliac injections and sclerosing injections for back pain
4. Repeat epidurals for back pain.

- all because of lack of evidence for efficacy.

Finally, what have I gained from our previous meetings? There has been much but in the context of intervention the most important thing is that I no longer feel guilty that I do not have the magic injection that is going to cure every patient, and feel I have the strength to say to both patients and colleagues that injections are not the cure for many problems, although I still believe that there is a good case for interventional treatment in some situations. I have begun to wonder, however, whether an anaesthetist is necessarily the best person to lead a pain service.

In discussion the question posed in the programme: “does intervention simply put off the evil hour of accepting pain” was alluded to but no conclusion reached. It was suggested that although doctors have discussed the subject *ad infinitum* there never seems to have been any systematic attempt to find out how patients feel about it, and a survey of the opinions of those who have undergone procedures in the past put forward as a study worth considering.

In discussion of the suitability of the anaesthetist to be other than an interventionist, it was pointed out that he or she only sees the patient during a relatively brief episode out of their lives, whereas the GP has a relationship lasting perhaps for years, and is thereby better placed to attend to “spiritual” needs.

How do we manage the demanding, manipulative patient?

Diana Brighthouse

I have increasingly felt that medicine is going the wrong way. This all goes back to Descartes and the concept of mind and body being separate, with which I profoundly disagree. About six years ago I did a Master's degree in Comparative Spirituality which included philosophy of religion and existentialist philosophy. This led me on to training as a psychotherapist and now I divide my time between managing chronic pain and working as a trainee psychotherapist. In dealing with the demanding patient (and I'm not sure that I would acknowledge that there is such a thing) we shouldn't tinker around at the periphery but look at the whole patient and recognise that they have an inner world as well as an external one, and our job as health care professionals is to integrate the whole patient. My husband is a vascular surgeon and he is thankful that there are people like us around to deal with the “heartsink patients” but thinks we must all be mad!

I believe in what psychotherapists call the therapeutic relationship. We in the pain clinic labour under the illusion that psychotherapy is CBT. CBT is about problem solving. Psychotherapists feel that CBT has hijacked all psychological therapies in the NHS because its a short-term thing – you can send someone for 8 sessions of CBT and measure outcomes, and show short term benefits, but it doesn't address causes, and like epidurals the patient may be better for 3 or 4 or 6 months but has to keep coming back for more, and we are seeing this with PMP's. So we need to ask some more lateral thinking questions and come at the problem from a different perspective. I still do epidurals etc but think of them as only a small part of pain management. When a patient comes for their first consultation they come with a whole lot of expectations: a whole lot of preconceptions as to what they've come to, who you are, what you offer; and they have hopes, fears and anxieties. They will typically have been through a large number of other doctors en route to you. They have often been multiply rejected: each person they have seen has done some investigations, looked at some problem-solving, failed to solve the problem and moved them on, giving the message that there is nothing they can do. By the time they get to the pain clinic they have pretty much got the impression that they are going to the last refuge of the destitute – the centre for lost causes. Even the psychiatrists have begun to send patients! They come to you with all that baggage. Psychotherapists talk about “transference “ and “projective identification”, and believe that in the here and now of the consultation a big unconscious dialogue is going on. Themes in both the patient's and your unconscious are being acted out between you. So the patients are projecting onto us huge amounts of hope, fear. and anxiety. We are receiving that; we may not realise this unless we have been trained to look for it. We may react in unexpected ways such as developing antipathy and dislike of the patient, or sympathy and empathy, and we have to be aware that that is to a greater or lesser extent because the patient is projecting these emotions into us. My approach to patients has changed a lot since I've been practising psychotherapy. I now start to examine my response: why are they making me aggressive or angry? - because they have elements of that in them. Demanding behaviour is a way of acting out your inner fears; the patient who comes in aggressive and uptight is highly vulnerable, very insecure and desperately anxious that you are going to fail them too. We need to be aware of these things, and that we are not seeing the patient in isolation, but with all the other people interacting in their environment: their family, friends and the other doctors they've seen, who may be giving them quite different messages from yours. There may be people pushing them into the sick role, such as a spouse who is conniving in this. They may have low self-esteem and feelings of worthlessness and act this out by becoming the demanding child to your parental figure: like the child at the checkout who says “I want some sweets mum” the patient is saying I want the scan, I want the injection, I want the drugs – I want you to do something, and it is very easy for us to get pushed into the parental role and connive with that, which merely perpetuates the demand from the patients point of view because you are not meeting the demand. What they really need is to be led by us into an adult relationship; if we keep them in the child role it precludes any possibility of their taking responsibility for themselves, and I see a lot of my role as a pain doctor as enabling patients to take responsibility for their own lives, and their own decision to get better or not. Some patients don't want to change and are apparently comfortable with the sick, chronic pain role, which affords them more benefits than disadvantages. I don't have a problem with that if the patient comes to an understanding that that's what they are doing. In this understanding you may offer the patient the scan you don't think is necessary or the injection you don't think may help much as they may be necessary to move the patient on. Sometimes I write on the MRI form that it is “therapeutic”: I know it will be negative, but when the patient is immovably convinced that they have a tumour or “something in the spine” it may be the only way of allowing them to move on; and this may be a reasonable use of medical intervention.

I want to tell you about a couple of patients who may illustrate the points I have been trying to make.

First is Jane, a 48 year-old divorcee with one grown-up daughter who has been coming to see me for about three years. She was referred by the rheumatologists with a diagnosis of fibromyalgia and was being treated with opioids. She had also seen the general physicians, the orthopaedic surgeons and several partners in her local general practice. She is an articulate woman with a degree in sociology who had worked in social services for most of her life. She was a classic “heartsink” patient who came with lots of information from various self-help organisations such as the ME society and from the internet, and a written list of questions. She was still working when I first saw her, but took medical retirement shortly after. She came with a very medical model-focussed way of being ill and expectation of treatment. This had been reinforced by all the people she had seen. She was very resistant to the suggestion that there could be any psychological factors influencing her pain. For about a year I saw her on a fairly regular basis just allowing her to talk and reflecting back to her some of the things she was saying – any manager looking at outcome measures might conclude that I hadn’t earned my salary. But over a year she started to talk about other issues in her life. Various things have emerged: firstly she is living in a Lesbian relationship with a woman 20 years younger than her – about the same age as her daughter. This has lasted about 7 years; a previous one lasted for 8, and she is having troubles in this relationship, with lots of rows with her partner focussed in her illness and consequent huge anxiety. Her daughter is a single mother as was Jane herself. More issues emerged over the ensuing months: Jane was adopted and had been abused by her adoptive father. Her mother became ill at this stage and she was faced with going back to her. And as all these things came out, so did the medical model of her illness start to shift; although she still wanted to try this and the other medication, she began to acknowledge more and more that these other things might be influencing her pain, and actually asked to be referred for psychotherapy rather than any further intervention.

The second patient is Dawn, in her 40’s with a fifteen year old son. She came from a pain clinic in a neighbouring trust where she had fallen out spectacularly with the consultant: the letters of complaint to him were riveting! The referral letter described her as a nightmare, difficult and manipulative. She is a large and physically formidable woman, with several medical diagnoses including a connective tissue disorder, systemic lupus, hypertension and diabetes. Her son has multiple physical disabilities. She spent the whole of the first consultation saying she had no faith in the medical profession and my colleague in particular, whom I know to be a charming and caring man. She came demanding to be put on a PMP, which was not very practicable given that she came some distance and the programme is an outpatient one. I offered to refer her to INPUT; she accepted the long waiting list but asked to see me in the meantime. In conversation it emerged that she was quite a frightened woman: it seemed that the rheumatologists had told her that sooner or later she would finish up in a wheelchair and she was worried about how she would look after her son, about her job and income. As these fears have been dealt with gradually her attitude and demeanour has changed.

Gladys is however a patient I am getting nowhere with and wonder whether I will simply have to discharge. She is 74 and has had chronic headaches for nine years. She has been investigated by the general physicians, the neurologists, and the rheumatologists, without any cause being identified, although she has cerebrovascular disease with several small strokes from which she has made a full recovery. She has a chronic anxiety state for which she has seen the psychogeriatrician who says he can do nothing unless something is done about her headaches. I find her impossible: I’ve sat and listened and listened to what sounds like a record endlessly going round and round: “there must be something causing these headaches, doctor”. She is very anxious, and her anxious husband comes with her and colludes in this ever increasing spiral of illness behaviour and focus on the headaches. I have repeated the scans which are of course normal but nothing will shake her conviction that “something is

being missed". I am simply going to have to discharge her as I cannot move her on and it seems that after nine years of anxiety the search for a cause for her headaches has become her only *raison d'être*.

So: three different patients and three different outcomes. The way I view patients has shifted radically, and I now look for my response to the patient: what emotions are engendered in me and what does that mean about what is going on in the patient. I am firmly committed to the idea of the therapeutic alliance and notion that healing can go on in the relationship that develops between you and the patient. The problem with that is the same as with non-CBT psychological management in that it is not seen as very sexy by managers: it's long (and indefinite)-term, doesn't have any neat outcome measures, doesn't lend itself to evidence-based medicine, and therefore doesn't attract funding. But that doesn't mean it isn't valid.

Discussion:

There is a difference between the cognitive behavioural techniques used in PMP's (including problem-solving) and CBT psychological therapy; we do use CBT therapy individually in some patients before they come on the programme

Yes this does have place but isn't it quite different from psychodynamic psychotherapy?

Yes but projection and transference are all there in CBT: we do deal with emotional issues in pain but not in a psychodynamic way.

CBT is only a small part of pain management which is all about holistic intervention;

But most psychologists in this country are CBT trained

Not necessarily and most concede the place for psychodynamic therapy in some patients

There a lot of half-baked psychotherapy around available from so-called counsellors who have fixed ideas of how to interpret everything and upset patients by suggesting that their pain is caused by childhood trauma etc.

Is there any way can influence the way in which patients are encouraged by their GPs into biomedical thinking about their pain by all these referrals?

GPs feel forced into a medical model by the threat of litigation, by constraints of time, etc ; but if we constantly feed back to them the biosociopsychological approach we use they will feel supported in trying to get away from a medical one. They appreciate long and detailed letters which are perhaps the best way of educating them.

We are being pushed into a surgical pattern of outpatient consultation lengths –

One thing we have jealously guarded is time as we feel that it is the most important thing we can offer our patients

Can you prepare your patients for coming to a different kind of clinic?

We send them a leaflet before their first appointment. They see that we work in a very integrated way with each other and our nurses and psychologists

Some patients “need” their pain and part of that is “needing” their clinic contact; “I go regularly to pain clinic” is part of their identity

Yes this is a major problem and we are beginning to think that for logistic reasons we will have to be brutal with them and tell them they can’t come any more as it’s stopping other people getting seen.

Harnessing the placebo response

Peter Wemyss-Gorman

Can we discriminate between the use of a potentially powerful therapeutic weapon and dishonesty or quackery?

First of all there seems to be some confusion as to where the term comes from but it is almost certainly derived from “Placebo dominum in regione vivorum” (I will walk before the Lord in the land of the living), the opening words of the vespers for the dead which people once paid priests and friars to sing, and which came to be known as “placebos”: Mounting cynicism about the value of these led to derisory use of the word placebo to mean telling the listener what he expects and wants to hear rather than the truth, and came into medicine at the beginning of the 18th Century.

The placebo response is a fascinating subject which seems to go to the heart of the mysterious relationships between mind, brain and body which have preoccupied us much in our previous gatherings, but since I want us to concentrate today on the ethical aspects of harnessing it rather than going into its possible mechanisms in any depth, and in any case these remain very little understood – least of all by me! Furthermore many of the doctors and psychologists among you will already be familiar with much of the literature on the subject. By far the best summary in my opinion is the chapter by Pat Wall in the 1999 edition of Melzack and Wall’s Textbook of Pain. So I’m just going to summarise what little I do understand, which is mainly a question of dismissing all the things we know that placebos are not!

First of all, the placebo response is not a “purely” psychological phenomenon; as well as subjective symptoms including pain, “physical” symptoms such as swelling of the jaw after tooth extraction has been shown to be reduced by placebo, as well as arguably partly psychosomatic conditions such as asthma. There is good, but inconclusive, evidence of a biological substrate for the effect of placebos, through opioid mechanisms and other things like cholecystokinin, but these of course only explain their effects on pain, and don’t seem relevant to other manifestations of the effect.

Other widely held false beliefs about placebos include: first the suggestion that they can differentiate between organic and mental disease or “hysteria” – dismissed by Wall as “cruel and dangerous nonsense which flies in the face of overwhelming evidence to the contrary”; secondly that a placebo is the equivalent of no therapy and that effective drugs have no placebo effect of their own; thirdly that there is a fixed proportion of patients (usually quoted as 30%) who respond to placebo (the actual range is from 0 to nearly 100% in different studies); fourth that placebo responders have a special mentality or personality type

– they haven't., although it probably is true that there may be a somewhat greater placebo response in neurotic anxious or dependent subjects . Lastly, and perhaps somewhat counterintuitively, there is evidence from some very clever experiments that placebos can reduce the actual intensity of pain and not just affective dimensions such as unpleasantness.

As to explanations of how placebos may work (other than through neurochemical mechanisms) there are others here much better qualified to talk about this and I hope may be able to help us later. The first, that they do so by relieving anxiety may be partly true on occasion but is clearly incomplete. The second, that they work through cognitive mechanisms, notably expectation, is demonstrably true but quite how they work in this way is still a mystery at least to me. The existence of conditioning mechanisms (like those classically described by Pavlov and his dogs) would seem to be suggested by experiments showing anticipatory responses to drugs in animals, but remains a matter of controversy when it comes to humans. Finally Wall proposes that the placebo is not a stimulus but an appropriate response to pain defined as a "need state", like hunger and thirst which like pain show a poor correlation with any objective stimulus, and can be terminated by "consummatory" action.

So much then for a quick gallop through the background, except for pausing for a moment to consider the question – do placebos "work" at all? A major meta-analysis published in the New England Journal in 2001 set off a storm of controversy by seeming to suggest, if not prove, that they have no effect whatever, at least in the setting of clinical trials. The conclusion of the debate seemed to be that most people accepted that they do work, at least some of the time in some people. I would doubt if there are many here who would not agree that they can often be a powerful therapeutic weapon, and of course they were with a few exceptions the only weapons available to our medical forefathers up to barely a generation ago. In view of the very limited benefits most of our conventional medical interventions have in chronic pain states, it would seem foolish, if not negligent, not to avail ourselves of anything that might benefit our patients, apparently without any risk of adverse effects, and perhaps we should all be working harder at adding to the therapeutic effects of our interventions by "selling" them with more confidence and enthusiasm. I suppose I never gave the matter much thought until taken to task many years ago by a young colleague for failing to present treatments more positively. I tried feebly to defend myself but have remained in some confusion about the subject ever since.

So why was I then, and to some extent remain, somewhat diffident in the way I present treatments? I don't dispute the value of a good rapport with patients and being seen to be interested in them and their complaints, having a confident and reasonably authoritative manner, and so on not just in themselves but as part of the therapeutic process. But I do have rather an obsession with being strictly honest with patients – perhaps as an over-reaction to the many sad stories our angry and disillusioned patients tell us about Mr X and Dr Y who have assured them with irresistible confidence that their wonderful (and sometimes very expensive) operation or intervention is bound to cure their pain – and subsequently seem to suggest that it is the patient's own fault when it fails, or that their continuing unabated symptoms are "not genuine". I should perhaps hesitate to label such an approach as quackery as of course these things do work sometimes, but I do wonder sometimes if these people are not the modern equivalent of the Quacks of yesteryear, with the essential difference that their "remedies" have much more potential for harm than coloured pills and nasty tasting potions. But I'm sure some of you will argue that these are extreme examples of doing things badly, and you have devised ways of harnessing the placebo response in all sincerity, and I would be genuinely grateful for some tips. I suppose what I try to do is give people justifiable hope rather than unrealistic expectations, remembering always that many probably have an indefinite future of living with pain to look forward to, and that I am trying to lay the foundations, so to speak, of what may well become a long and

difficult therapeutic relationship. I think most people who have learnt to distrust doctors and get no relief from any pill do appreciate honesty, and probably wouldn't respond with the expectation of benefit which is a major component of the placebo response anyway. But I'm not at all sure how often I get the balance right and I would dearly love to hear how other people approach this dilemma..

Just a little further speculation: do things like the placebo response and hypnosis demonstrate the power of the mind over the body to an extent that suggests a way through the apparent therapeutic impasse with which we are faced which might lie in learning to identify and understand this power and exploiting it honestly and scientifically?

Don't ask, don't tell? Revealing placebo responses to research participants and patients. *Pain* 135 (2008) 213-214.

The Placebo Effect – An Unpopular Topic The ethics of placebo-controlled trials.

Philip Cartwright

I stole this title from a lecture given by Pat Wall which I had on video and showed to our department. Some of the audience were as enthralled as I was but others left in disgust as it is indeed an unpopular subject. It seems threatening to many doctors as it seems to fly in the face of the biomedical model they were taught at medical school.

The earliest published placebo-controlled trial I can find was a comparison of Sanocrisin and distilled water in the treatment of TB published in 1931. Between 1950 and 1980 there were 986 papers about placebo research. In 1953 Prof Gaddam wrote: "Dummy tablets may of course act as placebos, but if they do, they lose some of their value as dummy tablets. They have two real functions: one of which is to distinguish pharmacological effects from the effects of suggestion, and the other is to obtain an unbiased assessment of the result of the experiment". In 1992 Patrick Wall wrote about the aura of quackery which surrounded placebos, especially if money was involved, and caricatured the common attitude to them as a tiresome and expensive artefact which complicates "true efficacy", and the very mention of which is taken as a hostile questioning of validity of the logic on which a therapy is based. He also acknowledged the way in which they could undermine someone's trust in their sensory experience if at the end of a trial they were told that they had responded well to a placebo.

It is necessary to debunk 4 widely held false beliefs about placebos : firstly that placebo responders have nothing wrong with them in the first place and are suffering "somatic hallucinations"; secondly the 33% response rate, based on a misreading of Beecher's studies which showed a range of 0% to nearly 100% , with 33% merely an average of these; thirdly that placebo responders belong to a particular personality type – neurotic, introverted, suggestible etc.: almost anyone can respond and the same person can respond differently in different circumstances: and fourth, it is patently not true that giving a placebo is the same as

doing nothing, as placebos can have lasting physiological effects. (or it might be more accurately observed that the placebo response may entail lasting physiological effects).

Placebos can have prolonged effects, not just brief and fading ones; they can effect not only subjective variables eg angina and pain , but also objectively quantifiable ones, e.g. swelling, ECG changes, CRP , and opioid-like side effects like slowing breathing. It is generally accepted that they can have powerful therapeutic effects and were indeed almost the only weapons available to our medical forefathers. It has been said that surgery has the most powerful placebo effect that can be exercised in medicine, and in general invasive procedures are more powerful placebos than oral therapies.

Many authors of clinical trials fail to make the distinction between “placebo” and “untreated” arms of a trial, but these are not the same.

How do placebos work? It has been said that the response depends on largely subconscious interactions between the doctor, the treatment process and the patient: it is the form of a treatment without its substance. William Osler famously observed that “the greatest placebo is the doctor”. Possible mechanisms include relief of anxiety, that of expectation leading to a cognitive readjustment of appropriate response , and a classical conditioned Pavlovian response.

Ernst pointed out that the perceived placebo effect in a clinical trial is made up not only of the true placebo effect but also other factors such as the natural course of a condition, the tendency to regression towards the mean, other time effects and unidentified parallel interventions which must be subtracted from the perceived effect to identify the true placebo contribution. Conversely not only the true placebo effect but also the natural course and so on have to be subtracted from the perceived treatment effect to arrive at the true treatment effect.

The placebo effect further needs to be distinguished from three similar effects, viz.. the Hawthorne, Halo and John Henry effects. The placebo effect can be characterised as the experimenter telling the patient to believe in the intervention (explicitly or implicitly, and sincerely or deceptively) In this case intervention has no material effect, but the belief by the participant does. The Hawthorne effect is defined as an experimental effect in the direction expected but not for the reason expected, i.e. a significant positive effect that has no causal basis in the mode of the intervention, they are missing but due the effect on the participants of knowing themselves to be studied – an effect which will return to baseline after the study. The Halo effect, something we often see in medicine and particularly in pain intervention, is the effect of uncontrolled novelty: the participants think the technology is wonderful and that belief, rather than the experimenter as in the placebo effect, is the real cause of raised outcomes. The John Henry effect is the opposite to this and is seen when the control group participants who see that the technology make an extra effort to get the same effects or results. Thus the placebo effect is evoked by the participant’s possibly false belief in the efficacy of the treatment whereas the Hawthorne effect is effected by the response to being studied and the human attention this involves, a common confounding factor in trials of pain interventions. In both cases, the experimenter may be deceiving the participants, or mistakenly sincere, or neutral with respect to the effects of treatment or intervention. In general, the experimenter’s apparent belief in the efficacy of the treatment is more often important to the placebo than to the Hawthorne effect. Both however are psychological effects produced by the subject’s perceptions, when the material interaction had no effect.

There are transatlantic differences in attitudes to clinical trials. The FDA insists that new drugs require placebo controlled trials whereas most ethics committees in the UK require RCT’s with new drugs compared against best available treatment.

The WHO Declaration of Helsinki states that: “*the benefits, risks, burdens and effectiveness of a new method should be tested against those of the best current prophylactic, diagnostic and therapeutic methods. This does not exclude the use of placebo, or no treatment, where no proven.....treatment exists*”. This was revised in 2002 to allow placebo only where no proven treatment exists. The arguments are not going to be easily resolved.

Is there still a place for placebo-controlled trials? It can be argued that using only active-controlled trials may lead to a reduction in the reliability of Phase III clinical trials. On the other hand, although active controls may not demonstrate greater efficacy, they may demonstrate better safety, tolerability, and side-effects etc. The use of placebos may also be justified where no irreversible harm can ensue from withholding active treatment, (e.g. in conditions such as baldness which is frequently not treated at all) and it may be argued that trials that cannot produce reliable informative conclusions are in themselves unethical. If a placebo is necessary for scientific reasons, this constitutes an ethical reason to use them, although this may not be sufficient reason, and it can be argued that on occasion the use of a placebo may sacrifice ethics and patient’s rights to presumed scientific rigor; it is important to remember that what is being studied is comparison of the new drug against the active control, not the new drug against nothing. Active-control trials may on the other hand be open to the danger that they may expose more patients to harm as if the difference between new drug and active-control is, as is often the case, small, then a larger number of subjects must take part to achieve sufficient power.

Emanuel and Miller, in their New England Journal article entitled “The Middle Ground”, suggest ways in which the opposing camps can be reconciled. Both sides agree that trials in which irreversible harm may be done by omitting active treatment are unethical, that placebo-control is ethical where no harm can result, and where an effective treatment already exists, there must be a compelling reason for including a placebo arm, such as where you expect a high placebo response, when existing treatment is ineffective or has serious unwanted effects, where the condition usually runs a waxing and waning course, or where its low frequency would mean that an equivalence trial would have to be impracticably large. Where a placebo arm is included there must be scrupulous precautions to minimise the possibility of harm, including the exclusion of participants at greater risk of harm, minimising the placebo period to that required for scientific validity, careful monitoring and the availability of rescue medication with explicit and specific criteria for withdrawal in the presence of an adverse event, and clear and informed consent to the rationale of the use of placebo.

Mithani, writing in Health Canada, sums up these arguments thus:

“We believe that the judicious use of placebo controlled trials to establish the efficacy of a new drug, together with a comprehensive risk management protocol and appropriate informed consent, is ethical. To use an inconclusive trial design when a conclusive trial design is possible, is unethical.”

Finally, the following provocative suggestions may stimulate discussion:

1. The gold standard for an RCT should be to measure the therapeutic effects of the study alone (including placebo, Hawthorne and Halo effects) and compare them with the effects of the study plus the active agent.
2. Genuine effect sizes can only be determined by covertly administering the active agent and covertly measuring effects without any one having any idea if any thing is happening at all

3. The more information is given to obtain consent, the more powerful its effects.

These last two might seem to be incompatible with the universally accepted obligation to obtain informed consent.

Finally, a story and a statistic: firstly the patient who was referred to a drug detox service some years ago by a new GP who discovered to his that his predecessor had been prescribing amphetamines for this chap for 15 years. On closer examination of the notes it transpired that the prescription had been for "Amphetamine SFA". Secondly, in the 1980's the mean purity of street heroin in New York fell below 1%, but there was no difference in the behaviour or drug-taking patterns in the drug community.

So the idea that anything – including placebos – does nothing, is completely wrong: the universe is not designed to let you do that! (see Schrodinger's Cat)

Discussion:

If you tell someone that one arm of an RCT is placebo you're not deceiving them as they may respond to it; the whole point of the trial is that you don't know if your new drug is any better than placebo. They may still feel cheated if they've had either the placebo or the old drug if they haven't had the trial drug, even if it doesn't work.

You can get over that if you promise that everyone will have a chance of an "ordinary" clinical trial of the new drug after the RCT.

It is important to distinguish between placebo used in a trial format and something that I as a doctor am deliberately using e.g. to promote my facet block or whatever, because a clinical trial is totally alien to clinical medicine – its wholly "artificial".

You're also addressing the whole question of faith.. This is something the clergy have lived with for years; for instance between being asked by a very powerful Reverend Mother to come and lay hands on a girl who thinks she is miscarrying. and doing it despite my misgivings and she didn't miscarry. How far this was a psychodynamic interaction or what the objective effect of these sacramental acts is has been an open question all my life, but we are actually committed to these as clergy. I take the sacraments round the wards of the hospital as chaplain and I believe that this is a helpful thing, but I wouldn't be able to offer any explanation which would satisfy a clinician – nor indeed me – but I still believe that it is a good thing to do.

Yes it's the whole belief thing that makes a placebo work – ideally the doctor should believe it as well

There have been trials where one group has been prayed for and the other not without either group being aware, showing an apparent effect on outcome – how do you explain that when there is no element of belief?

We all pay lip service to mind-body interactions and psychosomatic events and illness so why do we have a problem with somatopsychic events and cures? If there really is an interaction it must go both ways.

Why are so many doctors irritated by the whole thing?

- because they want certainty – they are worried by doubt

Animal experimentation:

Can inflicting chronic pain on conscious animals be justified?

Jason Brooks.

The title refers to conscious animals and pain but the debate goes much wider than this, including the whole subject of animal experimentation in both conscious and anaesthetised animals, and also relates to animals that have been killed to remove tissues or organs. It also relates to the deliberate infliction of pain typified by experiments involving ligation of the sciatic nerve to produce a neuropathic pain for as long as we choose to allow the animal to survive. So it may be more useful to talk about animal experimentation in general rather than focussing on pain.

Fundamental to our concern about suffering is the matter of animal awareness: whether the creature has knowledge of what is happening to it. Morality supposes that objects of our concern have feelings. Doubts have been expressed in the past about animal awareness. Descartes thought that animals didn't have awareness and therefore couldn't suffer. Some behaviourists have attempted to pass off apparent signs of consciousness and suffering as highly complex reflex behaviour. Even as recently as 1991 Peter Harrison argued that similarities in behaviour, physical structure and relative position in the evolutionary scale were irrelevant as evidence of consciousness. Nowadays however most people do accept that animals have a degree of consciousness. The level of this is assumed to vary from species to species, and Darwin thought that the occurrence of consciousness was in the form of a continuum parallel to evolution from simple creatures right up to humans.

Definitions of pain in humans usually include emotion and cannot therefore be applied to animals as we really don't know what animal emotion means. So animal pain has been defined (by the Universities Federation for Animal Welfare) as "an adverse sensory experience caused by actual or potential tissue damage which is accompanied by protective and visceral reactions and *induces change in behaviour* including social behaviour which can be specific for an individual animal". We know that there are many similarities between humans and animals as regards pain pathways and response to pharmacology etc. which seem to suggest that animals do experience pain and justify the use of animal models for pain research.

Is it possible that pain is in some ways worse for animals? Humans have an awareness of the future and can anticipate pain; animals live in the "eternal present"; they cannot conceive of pain to be suffered for a greater good (for instance the pain of a small jab which we know will alleviate the pain or that of an operation which will cure it), or appreciate its power to concentrate the mind. They have no ability to anticipate the cessation of pain. We can deal intellectually with pain but for an animal it acts only as motivation to avoid it.

How can we measure pain in animals? We can for instance take a neuropathic limb and stimulate it with cold, and our end point is withdrawal, and we call this a pain response. There are other physiological parameters (biochemical and electrophysiological) that can be measured to suggest pain but they may not necessarily be pain. It is even more difficult to assess the severity of pain. The parameters prescribed by the Animal Scientific Procedures Act refer to suffering and are classified as mild moderate and severe, and if they exceed certain levels the experiment has to stop. The sort of indications of suffering you look for are piloerection, responsiveness, posture and vocalisation, and if for instance the animal is unresponsive, hunched with coat bristling and vocalising spontaneously (which you hope not to see) it is imperative to stop the experiment, whatever its importance.

Next to consider is the matter of animal rights. These have been promoted by the animal rights movements, who take a lead from the writings of Peter Singer who maintains that animals have an “equal consideration of interests”, echoed by the American philosopher Tom Regan, who argues from marginal cases: if the young and mentally ill have rights then so do animals. It may be asked at what level animals acquire rights – do amoebae have them? Regan’s response is that they have rights if they have a “unified psychological presence” but it seems very difficult to know what that is or draw a line where it starts. He equates “speciesism” (considering animals as below us) with sexism, racism and slavery. Many people accept that animals have a right to life and a right not to be caused suffering, and see that the two are inextricably linked. Others however would maintain that the concept of rights only applies to human society and cannot apply to animals. Rights go with duties, so as animals have no duties they cannot have rights. It is claimed that there is a basic distinction between humans and other animals such that only rational, autonomous and self-conscious beings can deserve full rights, and that only humans can act morally and so earn rights.

What rights could animals have? They can have legal rights, defined as “an interest recognised and protected by law, respect for which is a duty and disregard is a wrong.” Since animals cannot observe this it can be argued that there is no justification for animals having rights. There is however in English law a concept of trust to benefit animals which gives them a legal right to protection. What about moral rights? These have traditionally been drawn from religious authority but nowadays are perhaps more a matter of individual conscience: a personal awareness of correct behaviour or sense of duty. There is a general feeling that if you exploit something or somebody you take on a moral obligation towards it. We exploit animals all the time: we eat them, we make them work for us, and we do experiments on them; do they thereby acquire moral rights? This concept has been embodied in legislation for many years, for instance that protecting farm animals. Perhaps we have an obligation even to animals in the wild, as we keep altering the ecosystem. Natural rights are even more ambiguous: they are said to arise from the nature of things as they are or as they are thought to be. Natural law seems to give ready justification for the contention that we are obliged to give animals sufficient freedom to allow realisation and expression of their nature, and satisfaction of their needs. These rights would seem to include a right to natural life, a right to well being according to their nature, and a right to be immune from wilful infliction of suffering. It has also to be asked if those rights can be overridden for the good of nature as a whole.

There appears historically to have been little consideration and little written about animals and their rights until relatively recently, although Leonardo Da Vinci predicted that one day experimentation would be judged a crime. Aristotle thought that plants exist for animals and animals exist for humans. Descartes wrote that “animals do not speak, therefore they do not think, and therefore they do not feel”. These attitudes seem to have been little challenged until the mid 18th century, and Dr Johnson was an early critic of the use of animals in experiments. The first legislation to protect animals, Martin’s Act, was passed by Parliament in 1882., but was a controversial measure. The RSPCA was founded in the same year. In 1831 powerful group of men including Darwin, Jenner and Thomas Huxley came together to sign a petition calling for legislative control of animal experiments. (Darwin deplored animal experimentation but conceded that “a ban on it would be a great evil”) All this culminated in the Cruelty to Animals Act of 1876, which despite attempts to add more stringent controls remained in place until 1986 when it was superseded by the Animal Procedures Act. There have been many pressure groups involved in this struggle ranging from the moderate right up to the animal rights militia who do not hesitate to use violent means to achieve their aims, and their aims if not their methods reflect a general view in society that the protection of animals is important.

There are indeed several disadvantages in using animals for experimentation. First of all of course no one likes causing pain and suffering. It is also very expensive. Animal allergy is quite common and some researchers are no longer able to go into the laboratory: others have even been subjected to violence. There are inherent sources of error: variations associated with experimental animals, distortions imposed by the experimental conditions which are not like "real life", and most importantly the problem of extrapolation of results from the animal model to the human.

Inevitably the arguments for and against animal experimentation are coloured by sentiment, defined as thought or reflection coloured by emotion. Sentiment tends to influence opinions and moral judgements by basing them on feelings and emotion rather than reason and logic. Sentiment often overrides other arguments, such as setting the sick child, rather than the old woman in a home, against the "fluffy bunny" or dog rather than the rat or snake. Sentimental arguments are often misinformed, inconsistent and illogical. For instance no one is much concerned about the 20-100 million birds and small mammals killed annually by domestic cats - compared with the 2.7 million killed in laboratories.

So can animal experimentation be justified? We have to look at the benefits versus the costs: the benefits in terms of the importance of the objectives of the experiment and the probability of achieving them, versus the cost to the animal in terms of suffering. Our ultimate aim should be to provide the greatest happiness for the greatest good – remembering that the greatest good also means doing the least harm. We must weigh the future evil of intended animal suffering against the present evil of unrelieved human (and animal) suffering. We have already talked about the costs, but what are the benefits? There clearly have been profits in terms of medical progress throughout the ages from Aristotle and Galen via Harvey, Pasteur and Jenner right up to the present day. It is much more difficult to estimate future benefits: we don't even know for certain what benefits the work we have just been doing will have in the long run: knowing what progress the future will hold is even more difficult.

So how do we strike a balance? Many complicated cubes, questionnaires and algorithms have been devised to try to determine the justification for a particular project.

Are there alternatives? The key words are replacement, reduction and refinement. The Animal Procedures Act demands that you must show that you have done everything possible to *replace* methods using conscious living vertebrates; either relative replacement involving humane killing of them to provide material for in vitro studies, or absolute replacement using life forms presumed less sentient, using computer models, films and videos, or relying on human and epidemiological studies. Such techniques also require validation. But animal experiments will always be necessary as the sum of the parts is always much greater than the individual elements: for instance if you test a drug on a bit of spinal cord it will never be the same as using it on the whole animal. *Reduction* of unnecessary or reduplicative research can be avoided by good communication, (not always provided by drug companies) using an ideal model and good experimental design. *Refinement* consists in using only methods which alleviate or minimise potential pain and suffering, and enhance animal wellbeing. This necessitates proper expertise, anaesthesia and analgesia, good postoperative care and the choice of humane endpoints.

In conclusion, it must be acknowledged that use of animals in experimentation is not desirable, but there may be a case for regarding it as acceptable. We can, arguably, regard restricted animal suffering in research as a lesser evil than continuation of suffering which

could be prevented by medical science. There does seem to be a place for compromise but this can only be determined on a case by case basis.

Discussion:

There is a Rabbi who writes as a contender for theological animal rights on the grounds that we do bad things to ourselves by treating animals in a way that doesn't honour them.. There is a theological struggle which carries over into things like GM crops – it's like sticking your finger into creation. It reminds me of the hedgehogs in Uist which we introduced and found that they proceeded to eat all the eggs of the rare birds which breed there, so that they either had to be culled or trapped and removed by animal rights activists at a cost of about £800 per hedgehog!

Which is a good argument for honouring creation.

Had it been rats we would just have got the Warfarin out, wouldn't we? When we torture people we dehumanise them first – do we “deanimalise” animals before we experiment on them? I would have great difficulty experimenting on cats as I tend to “humanise” my own cats.....

It's natural to want to look after dogs and cats more than rats – that's the way we are.....

We use the greater good argument all the time – we kill the rats in our barn so they don't eat the chickens. Another thing which animal right activists seem to forget is that some animal research is done for the sake of animals.

I disagree that it's necessary to “deanimalise” rats to experiment on them;; when I was doing research involving rats I actually became very fond of them

I did too – they're very nice animals.....

Unlike mice which are very aggressive – a good animal experimenter will handle I animals well - you don't want people in laboratories who don't – apart from anything else it will ruin your experiment. I totally disagree that it is ever necessary to be cruel.....

Except that of necessity some experiments seem to be unavoidably cruel: you didn't mention autotomy.....

That's not allowed any more, as that was indeed deemed to be unacceptably cruel. No – the animals that had the nerve injury appear to be completely happy – you know if you work with animals every day if they're happy or not.....

This raises the question as to whether the results of these experiments can be transferred to humans – we wouldn't be happy.....

They're not happy when you test sensation in the neuropathic foot - for that moment they aren't happy – but they are happy again when you put them back in the cage, so they aren't suffering for long periods – but admittedly transferring results to humans is always a massive problem.

You expressed some scepticism on your presentation about animal emotion and now you are talking about animals being happy and unhappy. Are we only talking about sensation and behaviour? This is a crucial distinction because the issue of cruelty only arises if one is concerned about , as it where, the place of pain in the animal's life – what the animal's attitude to the pain is – not just the pain.....

Perhaps happy is the wrong word – attributing human emotions to an animal– the animal just seems to be behaving quite normally.....

But I suppose that is what I'm questioning: I'm wondering if we have to be so restrictive about our application of emotional words.....

But as with my dog I've no way of knowing whether it's happy or not other than from its behaviour.....

It's only in fairly recent history [in Nazi Germany] that it was deemed acceptable to experiment on mentally handicapped people.....

And only very recently that we have accepted that newborn infants have pain.....

And the other day we heard that even fish may experience pain.....

May I ask out of pure ignorance what developments in the treatment of pain have arisen directly as a result of animal experimentation?

In fact there has been twenty years of “hard-core” research mainly by drug companies looking for analgesic agents for which there is a clear need and the only ones to have come directly out of animal experimentation have been the COX 2 inhibitors – and perhaps indirectly Gabapentin. Apart from that it has been only a question of improving old drugs.

And you can't say that has benefited animals as apparently I can't give my dog COX 2's

It's regrettably true that there has been so little spin-off from pain research in terms of treatment but at the outset it was reasonable to expect that understanding the ways that the nervous system works with regards to pain would enable us to learn to treat it, and it is still reasonable to expect that one day this may be the case, but it is beginning to look increasingly unlikely and I wonder whether the time is approaching when we are going to have to concede that we may have been looking in the wrong direction all this time.....

And research may well tail off as drug companies begin to withdraw funding if they can't find the magic bullet – and it seems unlikely that there ever will be a magic bullet as the more research we do the more we realise that there are so many factors involved that the expectation of finding one drug that will relieve all pain is quite unrealistic.

Are animal rights campaigners particularly concerned about experiments in pain research?

Apparently not – they seem to represent a spectrum of belief from those who are against any animal research to those who are even against farming animals but none specifically against pain research.

One of the advantages of talking about rights of animals and for that matter humans is a negative one in that it sets a limit to utilitarian calculations of the way in which something or somebody is subject to utilitarian calculations: so if I have a right to life then it doesn't matter how much the rest of you benefit from my death, you are still not allowed to kill me.. I am sceptical about animal rights but I understand the advantage that animal rights people get from talking about them.

It has been said that if you have rights you must also have duties.....people are beginning to talk about rights in fatuous situations: "I have a right to have my hernia done in a year" which seems to trivialise the idea of rights – if you expect more than basic rights such as the right to live you must be prepared to contribute to the society that affords you these rights.

We must also consider cultural differences in attitudes to animal rights.

You seemed to imply that sentiment should always be subservient to logic when discussing these things...

Oh no – emotional considerations are always important and may on occasion override logic.

Private Practice

John Wedley

The question has been posed: can we justify treating some patients in a few weeks while others have to wait months and this brings up the subject of inequality of access to health care. This raises two major issues: funding and choice.

The funding of health care is a problem not only for this country but world-wide: how do we ensure that we adequately provide for the sort of treatments that we think we should be making available. One thing that nobody has been able to overcome is the difference between providing health care on a mass basis for everybody and the industrialisation process. We have been able to make so much progress in the last 200 years because of industrialisation: if you come up with a better machine or a better product and can mass-produce it you can bring down the unit costs. If like John Charnley you devise a technique for replacing worn-out heads of femurs, the unit cost is the same if you do a thousand as if you do ten. Increasing the number of procedures in medical care, especially complicated ones, does not reduce unit costs, although you can try to do this to some extent by introducing day surgery as most of the costs of hospital care are those of hotel provision.

At this stage I want to look back on what our health service is and how it has developed and how this problem of unit costs have been addressed, which will lead us on to the second major issue, that of choice: the need to not only provide adequate health care for everybody

but we need to allow choice its providers and its recipients. 1948 was a period of gross austerity in this country. There were shortages and rationing of fuel and food and even if you had the money and the coupons the stuff just wasn't there. The government of the day came out with two grand concepts which were to revolutionise society: a health service which would be universally available to everybody and free at the point of contact, and universal free education which would be of different types with equal access to it and "equal parity of esteem" – for everybody regardless of the type of education they had received. The problem with education became apparent fairly quickly and arose largely from lack of provision. If you were fortunate enough to live south of the Mersey on the Wirral and passed your 11-plus, 60% of secondary education was provided in grammar schools. If you lived north of the Mersey in Liverpool the figure was only 16%, so people passing the 11-plus had totally different opportunities for further education. Because the NHS was such a great advance and people were so grateful for it, it took rather longer to recognise inequalities in health care. But to give due credit to the politicians, they did recognise the difficulties and tried to do something about them. The first attempt to improve the health service was the 1971 reorganisation undertaken by the Wilson government. Problems arose because they reorganised the health service and local government at the same time. A concept beloved of civil servants at the time (and since) was "co-terminosity": that all the authorities that deal with you (your health authority, your local authority and your district council) should have co-terminous boundaries. Unfortunately these boundaries were drawn on maps by civil servants which gave rise to some very strange anomalies, for instance if you lived just west of the Surrey-Hampshire border near Frimley Park hospital you had to drive 30 miles to Basingstoke for your health care. In order to have a sufficiently large population unit, if you live in Cumbria (with only 65,000 people) you are lumped in with Newcastle and have to drive over the Pennines in the middle of winter to get your cardiac angiogram. The answer to that was to create area health authorities; these only lasted four or five years before they were taken away and we were left with district and regional authorities. At the same time there were changes in the position of the teaching hospitals: prior to the 1971 reorganisation they were tertiary hospitals; your doctor could refer you to any hospital in the country if he felt they had the necessary expertise. In 1971 the university hospitals lost this status, for which they had been centrally funded, and now came under the local health authorities, and had to take on a local function and be responsible for their local population. They thus became secondary referral hospitals – like super district general hospitals. This was obviously unequal as some district had a large teaching hospital, and others small DGH's with limited facilities. The government of the day realised that one factor in creating inequality was the fact that we had too few doctors, so they created new medical schools – in Southampton, Cambridge, Leicester and Nottingham – to increase the number of doctors qualifying. They were aware that there were inequalities in training and introduced structured specialist training programmes. The 1974 reorganisation which got rid of the health authorities didn't make a great deal of difference but the person who probably had the greatest influence in making the health service as we now know it was Margaret Thatcher. She being the daughter of a shopkeeper thought the best way to deal with the inequalities was to put people into competition with one another and to allow people to pay for what they received, so that the people who were providing a good product would prosper and those doing badly would go out of business. And it worked! – I built my pain clinic at Guy's by doing procedures no-one else in the country was and got lots of money from the Trust who encouraged us to expand and develop, and at St. Thomas's they got a huge grant from the King's Fund towards developing INPUT. The same happened with the cardiologists and anyone offering something specialised and different - doctors are pretty good at manipulating whatever system they find themselves in (*murmur of dissent!*)

So where are we today? We live with a mixed economy, with a system of central funding, which needs to provide some sort of equality of care, and to ensure that standards of care are equal throughout the nation. This has led to the National Care Standards Act, which has

been in force for about two years, and for the last year or so has been implemented by the National Care Standards Commission. This is intended to be applied to every clinic, and every department in every hospital, private or NHS. The first chairman of the Commission soon realised that he had an impossible task and resigned after one month. This didn't deter the Government at first but they disbanded it after six months – at least it was officially disbanded but as the organisation which was intended to replace it doesn't yet exist it has been asked to carry on, so they are continuing to go round inspecting hospitals and putting the fear of God into administrators. The other body responsible for standards of care delivered to your patients was the Commission for Health Improvement (CHIMP). replaced by the Commission for Health Audit and Improvement (CHAI) which (as it apparently wasn't doing its job forcefully enough) is itself to be replaced by the Committee for Health Care Advancement (CHA) Anyone can apply to get a full-time job on one of these bodies. Note the importance of words here: "health" has now become "health care" (like I always say "independent practice" – never "private practice"!)

One of the recently appointed health ministers has no other responsibility than looking after CHAI. But it's not all these bodies that have caused so much grief to hospital managers – it's been the "performance ratings" that have been imposed upon them.

Before we leave our present situation let's have a look at the much-maligned NICE: the National Institute for Clinical Excellence. They are trying to do something the Americans have been doing for years. Clinical trials and meta-analysis can tell us about efficacy – *can* a treatment work. When we put it into clinical practice, however, no one checks up on whether patients are taking their tablets as prescribed – *so does it work in this setting?* But the remit of NICE is to look at the question: *should* we be using it? – what are the implications of using it? In this they have come into conflict with the public, for example the Multiple Sclerosis Society over the matter of Interferon, as although there is some evidence that it may work in a small proportion of MS sufferers it is too expensive to give to everybody. Lastly there is the matter of nasty doctors who have been doing post-mortems on patients and taking bits out, leading to hospitals such as the Alder Hay being pilloried for doing this to babies. This and unfortunate events in Bristol and so on have led to loss of public confidence in and reverence for health professionals. This in turn has led to the reform of the GMC who are now insisting on regular reappraisal of doctors as a prerequisite for continued practice, with regular revision of licence to practice every five years.

So we now have not only central funding but also a very large element of central control. Mr Milburn saw this as a potential problem, and thought of ways to return control to the periphery. Foundation hospitals are intended to take many of the responsibilities now held by central government. But these have been opposed by many within his own party on the grounds that the good hospitals will attract more patients and therefore more money – but less good ones are going to get less money and get worse, leading to greater and greater inequality. Mr Milburn counters this with the promise of pouring money into the struggling hospitals and moving successful managers into them. So it may be that foundation hospitals will give more equality and better choice for patients. Standards will remain the responsibility of central government; the diminished influence of the Royal Colleges on standards and training has been perceived as part of a general attack on the profession.

But the problem remains that this country is at the bottom of the European league as regards the percentage of our GNP spent on health care. To be fair the present government has spent more than any before to try to correct this situation and by 2005 up to the European average as it was two years ago – of course by that time Europe will have moved on and we may still be near the bottom. But where is this additional money going to come from? They don't want to take any more directly from the taxpayer, and this is where the independent sector comes in, and has been perceived by this and previous governments as a very good way of getting more money into the system. This is paralleled in the education

system where the Church of England provides 30% of primary school education in this country. People are already paying for education through their taxes but if they want to they can pay more. It's a way of getting more money into education and similarly can be used to get more into health care.

So is there a moral problem? What about all these rich people? Well, they are paying their taxes and National Insurance for their health – in fact more taxes than other people – but they still have a lot left over so is there a moral issue about what they spend it on? – is it morally wrong to spend it on health care, or should they spend it on fast cars and foreign holidays? What about the people who work in independent practice? They are making a profit out of the suffering of other people – but then we are all making a living in this way whether salaried or privately.

Are there alternatives? We are the only country in the world that funds our health service in this way. One proposition being considered by the Tories (who might just possibly, if not probably, form the next government) is to allocate central funding to each individual to allow them to reach a certain standard of care. After that you will have total choice: if the standard of care at your local hospital is not to your satisfaction you can take your money anywhere else in the country or abroad, as long as it is within the European Union. This is not dissimilar to the position in other countries where you have state health insurance topped up, if you choose, by private insurance. Is there a moral issue with health insurance? Should I spend my spare money on alcohol or with BUPA who are a non-profit organisation who plough millions of pounds per annum into medical research via their foundation. Which is ethically a better decision for both the nation and me and my family? Should top-up funding be compulsory? In Ireland you must have insurance which is either with the state organisation (as do 85% of the population) or with BUPA who negotiate rates and benefits both with the government and the medical profession. Should there be a tax base to facilitate private health insurance? Isn't National Insurance supposed to be paying for the health service? That was the original idea in 1948 but it has been corrupted; in the same way that road tax doesn't pay for roads so National Insurance doesn't pay for health care, and has been dubbed a "stealth tax". They have taken your National Insurance contributions and put them into the coffers and general running expenses of the state. When Robert Maxwell did the same thing with his pension fund it was called embezzlement!

The question is then: who controls the controllers? Everybody agrees that we need better funding; we need more money to be put into health care. We need somehow or other to provide adequate resources both for the receivers and providers of health care. Standards need to be maintained and the greatest protector of standards is training, and the Royal Colleges need to be supported and maintained rather than sidelined as they have been in recent years. But the worst blind spot of the present government is their failure to appreciate that for so long the health service has relied on the goodwill of the people who work in it and of the population who have been willing to put up with its imperfections. We need inclusivity. We need to involve staff who need to know that the work they do is valued. Local involvement in decision-making is important but we need to know who is making decisions and on what basis – are they just responding to central government dictat? Lastly people do want choice and this is not an unreasonable proposition.

It's easy to knock governments but they have appreciated these problems and done their best to overcome them. If you know a better way of doing things this is your time to speak up!

Discussion

So basically what you are saying in answer to the original question is that what is needed is to level up rather than level down?

That's always been the argument in education – but the problem with education has been that if you allow people to opt out you remove the people – the articulate middle class - who provide the most incentive to improve it, and the same applies to health. In America they spend four times what we do as a percentage of GNP on health, and if you are at the rich end of the spectrum its very good but if you happen to be at the bottom its very very bad.

The question occurred to me when I was doing locum sessions in a hospital trust where the waiting list for procedures is at least six months unless people go private when they only have to wait for two or three weeks – and somehow it just don't seem right

This was one of Alan Milburn's major problems when he came to office as he perceived consultants as lazy people who didn't pull their weight in the NHS. How could he have come to that conclusion? Could it possibly have anything to do with the fact that his partner is a psychiatrist? Let me tell you about psychiatrists: They retire at 55 and 21% of them are in full time private practice –

And the reason for that is that most of them feel that they can no longer practice the sort of psychiatry they were trained to do in the NHS because its so grossly underfunded

Can I give you an Australian perspective as we have a much bigger mix of private and public provision: let me give you two examples of how it can work well and when it doesn't work well. My wife came off a push-bike and hurt a rib. If we had gone to the public hospital we would probably have had to wait for hours but in the private one she was in and out in twenty minutes including X-ray. Where it doesn't work well is in Cairns where there are two plastic surgeons who are so busy with private practice that they don't do any public work at all, so if you need plastic surgery and can't afford private you have to fly a thousand kilometres to Brisbane. Once you introduce private you have to be careful because it becomes part of the ethos of maintaining..... and people demand as of right that they can have private health insurance and now our government funds it to the tune of - a tax break of 30% of all private health insurance and some people have argued that if they had put that into the public health system you wouldn't have had to do this in the first place. Once you introduce something you have to be careful because people come to expect it – I don't know what the answer is ; I don't think any country has got it right – certainly not Australia.

But Australia is recognised as one of the countries that have got it more right than most others –

Well, it depends were you live – if you're in a major city you are probably happy because you have choice but the huge geography of Australia has big implications.....

We know there are clear links between poverty and chronic ill health and that probably includes chronic pain, and chronic illness is something the insurance companies aren't keen to take on.

My secretary spends a lot of time dealing with insurance companies as patients (especially elderly ones who have had the same policy for years and years) usually think they are covered for everything but there is huge diversity in types of policy in this respect: the worst offender is AXA who refuse tell subscribers what they are covered for and what they are not in their policies. By the way, AXA is a French company that runs the German health insurance system – partly topped up by the government – and that's what they want to do in this country.

Or they may pay for your treatment for some time and then turn round and tell you you're on your own

And as soon as you have been classed as terminal they won't pay any more – for instance if you're in a private hospital and need a coeliac block the question is: will it make her better to which the answer is of course no so they won't pay and you then have the dilemma: do you take her away to another hospital - it's not ideal....

Most people in the West Midlands with private insurance are covered by company policies so they have even less idea what they are covered for

Actually most group policies are administered by BUPA who administer a fund on behalf of the employer and it's usually much better than individual policies, with greater flexibility.

We have to concede that lots of money has been poured in but most people including me have the perception.....we don't perceive much change on the ground – I mean where the money goes to.....

There are changes on the ground: two months ago the number of administrators in the health service passed the number of beds!

There has been an escalation in demand for treatment of chronic pain....

partly fuelled by the internet where if you go worldwide you find pages from the US advertising procedures from private hospitals and selling them as something that will work....

You've got to expect people's expectations to go on escalating year by year – this isn't something to be afraid of.....

We still do see instances of patients seeing consultants in NHS outpatients and having the treatment they are told they need in the private hospital. Managers should make clear that this is simply not acceptable.

Relieving Suffering – Euthanasia or Palliative Care?

Teresa Merino

The first thing is to be clear about what we mean by suffering. This is difficult to define: it's very personal, and depends on culture and circumstances. To find its meaning we need *knowledge*. We must try to employ scientific rigor when we to assess pain, nausea and vomiting and so on, but investigation is very difficult in palliative care. To start with we don't want to use treatments that might not benefit someone who is already heavily burdened with illness and the proximity of death, and if we start a study our patients often die half way through it. But we must still try. It is a *learning process*; (palliative care is a very young speciality) and the people who have taught us most about suffering have been the patients. They need to be given permission and indeed asked to tell us what it is like for them. But to learn from them we need to employ *the friendship of the heart*, which means that when a professional is with a patient and really wants to help, a little bit of the inner world of that professional needs to be laid on the table. That's what makes it difficult – it would be easier to be in a hurry and only have so many minutes per patient, or to say we'll talk about this next month (when next month they may be too ill) so time is very important. Some of the things that make us face our own mortality and suffering may remind us of very personal losses. These three things are the basis of the hospice movement: knowledge, the learning process and the friendship of the heart .

The concept of *total pain*, first suggested by Cicely Saunders, is also of fundamental importance in palliative medicine. It is furthermore very practical; it refers to the physical pain, which people are very frightened about, and psychological pain often resulting from what the patient imagines is going to happen next. This may sometimes be our responsibility if we have failed to explain things properly, or have been in too much of a hurry, or perhaps instead of admitting we don't know enough about a particular problem and promising to look it up and come back later we have made something up and made things worse. Socio-economic pain must not be forgotten; the young person with a young family who doesn't know how he can continue to pay for his children's education. Then there is the stigma associated with illness, which can be a big social burden.

Lastly there is spiritual pain: the search for meaning. People ask us –why me? Why is this happening to me? They really want and expect answers; sometimes there are partial answers but the overall answer is way beyond us and they need to know that we too struggle with this.

So suffering is not just a concept, it is a mystery; there is a whole world of suffering. In our society there are many professionals dedicated to this world and in British society we have got it right in terms of the resources and the professionals available for dealing with all its aspects, compared with many societies, even just across the water, where physical suffering may be adequately addressed but it is left to families and lay people to deal with the rest of this suffering and distress.

There are several other concepts we need to examine: such as integrity, dignity. We need to work out what we can give the patient, little by little, of what they can take by way of solutions remembering that these solutions are always partial and something else is always going to happen: ultimately, death. Then we must look at what we want to do as a society and as a community, and professional and medical intervention.

We must analyse what really happens when a person (who may not yet even be a patient) asks for euthanasia – why does someone come to that? This does happen even in hospices and some hospice staff will refuse even to discuss the subject. It can however be a very useful discussion because people will only come to this when there is a real authentic reason to do so: their suffering has become unbearable or they anticipate this. This can be for many reasons, some unrelated to the illness: for instance it can be because of culture problems when people find themselves far from home and familiar landmarks and find this all too much to take, and may need someone from their own ethnic background to help. It could be the illness itself or their personal history. We have to bear all these possibilities and more in mind when trying to find out why someone is so desolate that they want to end their lives. The concept of personal perception from previous experience is very important in the contest of illness. Sometimes we don't realise what we say to patients: for instance "we'll fix this for you this time" with the unspoken "but next time....." left hanging in the air, so when the next time does happen the patient is absolutely petrified. Also the nature of the illness: a sore throat that a week later is bleeding and another week later is a huge lump, so the patient cannot escape knowing that this is something very serious. We have all seen old ladies with huge fungating breast tumours who have been hiding them until the time comes when they must show them to the doctor who says "if only you had shown this sooner we might have done something about it" –thus only adding to their sense of hopelessness when it is precisely because they didn't want to face the situation that they had been hiding it. The social context of illness may be very important as typified by something we hear all the time: "I can't afford to be ill", be it for financial reasons or perhaps because of children. Lastly there is the support network. One of the rewards of my job is when I go to see a patient with advanced illness who says "I know I'm very ill and I know I'm going to die but my father died in this hospice and I know I'm going to be fine"

What about our professional focus in relation to the illness? How committed are we sometimes? We see patients who have previously seen fifteen other specialists who have told them at various stages that there is nothing more to be done, (which may be unavoidable) and they come expecting us to say the same thing. Professional realities have to be recognised: if you have a target of so many patients to see in a month you are going to have limited time to give to each patient, although I am sometimes amazed that some doctors do somehow manage. In an age of computers we often see patients with inadequate information, and communication between professionals is not always good. There may be differences between the patient's and the professional's concept of illness which lead to misunderstanding. How "holistic" is the professional approach?

We need to find a balance between professional focus and personal perception. But then more things come into the equation to make it even more complex such as religion, culture and ethnicity: the person's vision of their own integrity and dignity; the experience of suffering at a personal level. How often do we hear a patient say

“the problem is not the illness – the problem is I’m encumbered with something you haven’t even dreamed of thinking about”.

Personal history is very important and is much more than social history. We must avoid oversimplification. I would need much more than being categorised as a “white European Female” – you would have to know that I am Spanish and that I have lived here for so long and I have these likes and dislikes etc.

We need to assume the deepest connotations and the beliefs that we have got in our own context. We need to be aware of the state of personal relationships: we tend to assume that people will want to hear bad news together but sometimes when we see the husband sitting next to the patient and ask if it’s all right to talk it becomes apparent that the wife doesn’t want him there. We must listen with attention and give time but sometimes it is better to keep going back with shorter consultations, and to go back and check that what has been said has been understood, and that facts and data are allowed to be framed within that individual personal context.

Our society is not homogeneous and stable. There are lots of influences from different cultures. We can no longer expect when we go to the doctor to see the same one as we have for fifty years, but now you don’t know who the people in the health centre are or if you’re going to see a locum or a trainee; if you think you might have cancer you may be tempted to keep quiet about it and hope it will go away.

I always worry when people start talking about dignity: “if I have cancer I want to die with dignity”. Do we understand what they mean by this? Is there a difference between this and the use of the term as in “a dignified person”? A concept I have found very helpful in this context is *integrity*. Integrity is something the person can build – something to work with. It is susceptible to attacks and modification, to distraction and even destruction. It is like a protective barrier; it has its boundaries; it is about quality. It seems to be a concept that has been rather lost in this last half century and people no longer use it. But I am beginning to understand that when people say “that would go against my dignity” what they really mean is *my integrity* – the barrier that I have built around myself. When they say I would struggle with not being able to get up and go to the toilet without help they seem to be protecting something else. So I work now on the premise that people really mean integrity when they say dignity and like to challenge them about this; and often their response is: you really mean that even if I am in bed with a catheter I can still protect something of myself – to which the answer is yes: even then we must help you maintain your integrity. But what about dignity? Dignity is an intrinsic value with which we cannot negotiate. It is the most human of all values – even more than the value of life because life has a beginning and an end whereas dignity comes the moment we are born and is preserved after death in the manner in which our bodies are treated. It is not something we can work with: it doesn’t belong to me and that is what makes it so complicated; I know what my dignity is but I can not – unless I am given a good atmosphere – say what would affect it. It is what remains when a person has been robbed of everything else. We have all seen someone who has been battered by life both physically and emotionally but when you sit with them at the end of it and you can still see the spark and know what they were all about.

The last concept I want to talk about is that of chaos. This is not the same as disorder but a mathematical concept, meaning lack of linearity. When you see a patient for the first time they are often in a chaotic situation; you ask them what is the worst thing that concerns them and all this anguish comes out. But when you leave them, even if all you have done is listen, allowing them to order their thoughts, ideas, fears and hopes, even if they are not exactly happy at least they feel more in control. And that is very important as if you are in a hurry and don't give them enough time you leave them still in chaos with the added burden of the doctor who didn't have enough time or didn't seem to understand.

So what makes us suffer? What makes us go to the brink of these situations is fear: fear of illness, and often more the implications of illness. This may become compounded by misunderstanding resulting from inadequate or absent explanation. Language difficulties may contribute to this and is a huge problem in central London especially. There may be professional insensitivity to transcendental issues. We must be aware of cultural differences: for instance I must remember that it may be difficult for a Moslem man to talk to me as a woman about some things. Stereotyping must also be avoided. When we give a patient a diagnosis in medicine we often think we have achieved something but this is no help to the patient if all we have done is give them a label.

The problems of loneliness and isolation and lack of visitors have been aggravated in recent years by difficulties relatives have in taking long periods off work without affecting things like their pensions. Insensitivity to cultural and religious differences and even overt racism among NHS staff have also contributed to these problems.

Suffering can be looked at through the concept of anguish. Anguish is frequently due to fear that the situation will inevitably get worse. We can often help when such fear is based on misunderstanding, such as the worry that if morphine is started too soon there will be "nothing left when the pain gets worse". This is at least a rational if unfounded fear but sometimes people want the option of being "put out of their misery" for irrational reasons that they cannot express.

Judge Rochester has expressed the opinion that it is not up to the doctor to decide how much suffering another human being must bear. Sometimes we are not very good at admitting that we are failing to relieve a patient's anguish and need help. So what can we do when the request for euthanasia is addressed to us? We can send the patient to Dignitas in Switzerland or to Holland – or we can stay and listen. Sometimes there is a long silence before the patient starts talking and challenging us. We must then try to understand what this person is going through that is so unbearable. It is unusual for this to be unbearable physical pain. We must help them in their search for this which often involves respect as patients can come up with the most weird ideas as to what is going to happen next. The problem is to really believe them; if we laugh they may laugh with us but they may still be afraid. Their need is not just for information but also to know that we will keep company with them in the most difficult of times. They need to know that in all the phases of their illness in which he or she will need support, information, tolerance and respect, they can rely on us. When this is done properly most patients will say..... OK I didn't really want euthanasia – I just wanted someone to listen to me. That is not to say that palliative care is a panacea and can sort out all problems. I remember a patient who asked me every single day for "the pill" despite the fact that we had relieved his pain, nausea and postural hypotension and he was generally feeling much

better. He was an army officer with no family save a daughter with whom he could not even begin to consider living with (or she to have him) because of the relationship between them that had developed over the years. One day he again made the same request and I asked him why when he had only moments before in the twenty minutes I had been with him he had been laughing and teasing me. He said something I will never forget in my life: “yes doctor, but now I have twenty-three hours and forty minutes to get through before you come back.” I was the only thing that made him smile – it wasn’t me: I was just the only person who had been there with the idea that I *could* do something, although he was in an expensive room in an expensive private hospice. We found him a place in a nursing home which seemed ideal but he knew better: he died the day before he was due to move.

Discussion:

Most of the publicised cases where people have demanded euthanasia and have perhaps sought it abroad have not involved cancer but Motor Neurone Disease and this seems to be a peculiar and almost separate issue.....

Yes, that is a very great challenge. But in some of the publicised cases there has not been a hospice involved. I’m not saying that MND isn’t a very horrible disease...but what we try to do is to start helping early on, by taking the patient in for one week every month partly so the family can do other things, and the patient likes that.....We try to become involved as soon as possible after diagnosis for respite and these are not the patients who ask for euthanasia..... their minds are so bright..... you can think of ways in which they can interact in the day centre.....

The concept of dignity is one I’ve long wrestled with and have wondered if there is such an entity as dignity itself, or whether it is a state; and I went to the dictionary and found it defined as a state of being dignified by somebody else; you don’t own it, it is something conferred by others – and the best words I could come up with to describe it were being loved by those around you which confers dignity on you – which helped me because it implies that if you felt loved you would still be dignified however messy the situation – or (especially for a woman) however messy you felt..

Another definition which appeals to me as a practising Catholic is found in our catechism : “dignity is the print of God in you” – which is very much as you are saying: who cares if I cannot do anything for myself if I know I am loved but beyond that..... I love it when people say “you and the nurses are lovely and look after me so well but it is much more than that.....” One group of people in whom we often see destruction of integrity is young drug addicts.....

One highly publicised case which always comes to mind is that of Dianne Pretty and you always heard about Dianne Pretty and her husband; and you always think that the worst thing would be to die alone – that you need someone there – but I wonder if it might contribute to the need for euthanasia if you have a destructive other person there barricading them from and perhaps robbing them of love from other places or something.....

Yes – you have hit that nail on the head: Dianne Pretty was supposed to be under the care of one of the Liverpool hospices but apparently never attended any of the things which could have helped her such as the day centre. I have no proof but I have been told that both her husband and the GP had been approached by the pro-euthanasia society and offered a number of things.....and I know for a fact that the same thing happened in Spain with a young paraplegic and the society provoked a great deal of publicity.

How do you handle the situation where there is a destructive other person?

Funnily enough - in fact it's incredible! – that I have never in my life been in such a situation until last week. We have a patient with MND and her husband really treats her badly to the extent that several times when the home care nurse has visited she has found her lying flat in obvious respiratory distress although the husband has been advised about this many times. We have finally and reluctantly been obliged to call in the Elderly Abuse Team, but I don't know what the outcome will be as she doesn't want to be taken away from home.....

Everything we have spoken about so far has assumed that the patient has a functioning cerebral cortex but what concerns us especially as doctors, for instance in the active/passive euthanasia debate, is what we do when the patient has lost their brain.....

Although there may sometimes remain a question as to whether are not we are dealing with a sentient human being who may be suffering and feeling pain, the truth of the matter is that ventilators are switched off every day without any hassle. It is only the high profile cases that sometimes shake us like that of Tony Bland who was in a persistent vegetative state for years until a judge ruled that it was best for him that he be allowed to die of starvation. But what of the strokes and very advanced dementias? I personally think there is “something there” even when someone cannot communicate; I have looked after a number of very advanced dementias and I have no doubt, although I cannot prove it, that some of them are very frightened and there are ways of calming them down short of killing them. I don't agree with the notion that someone with advanced Alzheimer's is not a person. Hospices have started taking such patients, and try to make sure that families as well as patients receive the comfort they need.

A distinction is sometimes made between active and passive euthanasia. These terms have become obsolete from an ethical point of view; it is now accepted that for an act to be called euthanasia there has to be an *intention* and an *action*, so that not giving antibiotics is not euthanasia; it is simply not using extraordinary means in a situation where a response is unlikely. This causes a lot of confusion. Euthanasia must be voluntary – if it is “involuntary” it is homicide and even in Holland you can go to jail for it.....

Are you saying that there is no difference between active and passive euthanasia?

No – I am saying that there is no such thing as passive euthanasia. I can only think of one situation in which there may be uncertainty, that of the neonate with severe Down's syndrome and pyloric stenosis when the question is do you operate or let them die.

What about the vegetative patient with a tracheostomy whose tube becomes obstructed by a mucus plug and you have the decision to suck this out or let them die – isn't the latter course passive euthanasia?

This is perhaps a simple choice but if you remove the plug and withhold antibiotics the intention is not for the patient to die but not to overburden them.....

I would call this nature taking its course; and I have seen ITU patients in whom active treatment has been abandoned who have quite inexplicably got better.....

Yes I have seen people with apparently complete bowel obstruction whom I have been able to discharge home.....

Palliative care physicians are sometimes accused of using sedation as a form of euthanasia. There has been a huge debate about this and the European Society of Palliative Care has recently produced guidelines which suggest that when think you must let nature take its course, but it could be painful or distressing for the patient it is ethically acceptable to allow the patient to be less aware. As we have learnt more we find we can use smaller doses of drugs which are not going to cause death, although they might hasten death as the patient may be more prone to infection.....

It has happened two or three times in my career that I have anaesthetised a patient with bowel obstruction and then in theatre it has been discovered that there is total obstruction due to inoperable cancer; the surgeon has abandoned the operation and left me with an anaesthetised patient that I feel I cannot wake up only for them to die in agony, for the two days or less.....

But what if that patient is expecting to wake up and has unfinished business..... I would call the palliative care team and make sure that they take over..... I have found it possible to use smaller and smaller doses of drugs as I have learnt which drugs to use in different situations and how best to use them. Palliative care teams are very underused in general hospitals; we are a supportive resource and want to be called whenever the doctor needs someone to talk to about some awful problem – not just to take a patient over. Nurses are much better at calling their palliative colleagues and this may be a way in for us but doctors are only asked in desperate situations or when the family is already screaming for us.

I still have a problem with this passive thing... if it's passive you say it's not euthanasia, OK it doesn't conform to the definition of the word euthanasia but in effect the same thing happens: the patient dies.... I'm still not entirely clear that there is a difference..

The thing is intention.....

Yes but..... that may make us feel better about it, but does it make any difference to the patient?

Yes; if I am the patient and I have beliefs..... and I want to have two or three days to do things..... it does make a difference

I too work in palliative care. We are incredibly honest with our patients and they with us as the relationship develops. I see patients progressing towards death who may be diminishing physically but growing in a way which is hard to describe and you couldn't imagine if you didn't see it. We offer respite at an early stage when they don't have so many problems – I think it's very important to get in early. At some point along the way the question of living wills arises: not everyone wants to do that but many do and I think this gives them a feeling of control at a point when they feel they are losing control.

A living will is a document by which someone explicitly describes the care and treatment he wishes to receive when he is no longer able to express himself, and can also nominate someone – a relative or lawyer perhaps – to represent him in such circumstances. This can be very useful but three years ago there was an attempt to get euthanasia through Parliament “through the back door” using the Mental Incapacity Act: we were very close to legalising euthanasia enforced through living wills which are not now legally binding by making them so, so that when a patient is no longer able to let us know that he can reason the doctor (or the Trust) has the last word – it's as dangerous as that. We have to be very honest and specific about what people want; if for instance in MND because they know that there will come a time when they have difficulty with coughing things up. If they say that at this stage they want their days to be shorter and their nights longer that's not euthanasia – that's just reducing the hours of awareness. The problem comes however when they say they don't want any active treatment – you have to be very clear what they mean by this. For instance, you may ask them that if they are still able to eat, and choke on a piece of chicken, do you just want us to leave you?

As they progress and learn that many of their symptoms can be controlled things that might have seemed very frightening in prospect six months earlier can be dealt with, they do want to move the goalposts.....

I get the impression that it is less physical symptoms than emotional distress that “pushes them off the shelf”.....

It's a mixture of both – and anxiety: if we are slow in answering a patient's bell we may find them crying and wanting to die.....

I must also mention spiritual distress and spiritual growth: a person continues to grow spiritually right up to the moment of death and it is a great privilege for those of us working in palliative care to observe this. It's a real joy to sit and listen to someone who is getting things into perspective in this respect. It's fascinating to see how as the physical body deteriorates the spiritual comes through. People who “haven't believed in anything” for years allow themselves to start asking questions and want to talk.....

Hospices are devoted to giving people a “good death” – but in hospitals the opposite seems to be the case; I despair sometimes when I see how bad a death can be in hospital. How can we change this? How can we change the culture? No-one seems to want to take responsibility – not even the consultants people are supposed to be under.

I think it would help to have a working group of professionals with a common interest in dying patients including palliative care. Then if we work even in a huge

hospital we will have built up such a good relationship that you will scarcely need to call us, remembering that palliative care is a supportive service and we have much more time than you.....

But some consultants never do ward rounds and no-one takes responsibility for deciding if a patient is to be resuscitated, so it is left to the nurses who have to ring the bell and put on the paddles.....

If you involve the palliative care team in the induction process for all junior doctors, they and the nurses will call in the team when necessary, and I have no compunction in calling the consultant who is looking after the patient and suggesting we go and see the patient together.

In this meeting we keep coming back to the issue of education – of changing people's perceptions, for instance that death is a matter of the doctor's failure. But how much is it that we are unable to cope with dying – as human beings watching another human being dying. I was interested in your story of the chap who decided it was time to go and died an hour later: there is a Buddhist notion that there is a time to go for everyone, and there is a dignity in deciding when that is for oneself. How much of a problem is the lack of education of our society about death – we are frightened of it and don't even want to talk about it. The churches have been far too slow to pick up on this. We have this great hope that we will be kept alive as long as someone will foot the medical bills, and that the doctors will do the right animal experiments to enable them to get this right.....

But do you think we are frightened of death or of the dying process.....

I'm not convinced it's just the process.....

I'm not afraid of death as I believe that in some way that's what I'm here for and I look on it as an exciting adventure but I wouldn't like to die in hospital!

Do you think there are people who are less attached to life because they realise their moment has come; they are not looking for meaning and their intellect is not damaged but they are just ready to go – do you feel that's OK?

Yes, the process of dying is a very personal thing - if we can help that's fine but why is it a medical thing? The challenge to me is not primarily as a doctor – we can control most of the symptoms to an acceptable level – the demands it makes on me is when I realise that I've got a good relationship with this person so I must stay with her and listen to her right up to the end. It happens often that I find the relatives round the bed and they and the patient are distressed and crying; I take the relatives away for a moment to find out what is going on and I might learn that the patient is not letting go because of unfinished business such as an unresolved family conflict from many years ago – you need to tell them that it's all OK now and that they can let go. And it's the most unselfish thing a relative can do is to say that they will be fine even if they are left behind and that the patient can let go.

But can we really control the hour of our death in this way?

I don't really know but I have seen people hang on until the arrival of a relative from Australia allows them to let go.

My experience is more in acute medicine and intensive care but I am convinced that the great majority of people don't die until they are at peace with themselves – it may not be until the last nanosecond but they do not die until they are ready to mentally.....even with an aortic aneurysm something seems to happen and they die at peace.

Absolutely..... for instance only last week we had a patient who was so angry with the nurses and horrible to them.... we just showered her with all the things we usually try to find out what was troubling her to no avail; then suddenly last Saturday she suddenly chose one of the nurses to tell her that before she was married she had several abortions and that was the only problem. She died in peace the next day. If we had sedated her or worse resorted to euthanasia when she was so distressed and angry she would never have had the chance to come to terms with something that had troubled her all her life ; I feel it is a real privilege to have the opportunity to help people in this sort of way

Where do you find support both as a professional and as a person?

This is a very personal matter and is different for everybody..... some have a faith, some have a life and family outside the hospice and so on; clinical supervision is becoming more and more in fashion; the first time I was offered it I nearly had a laughter attack but it was amazing - I found it really helpful. But the really important thing is that in palliative care you simply have to be part of a team and support each other – it just doesn't work otherwise. But apart from that we all have our own coping mechanisms..... If people just say thank you I feel I have achieved something.....

Some hospice patients were asked to rate the most important aspects to them of palliative care and at the top of the list they all put "being listened to". Then second was that we would stay with them right to the end .

Prescribing drugs of potential misuse or diversion – ethical issues involved.

Willy Notcutt

Dependency, diversion, discomfort, distancing and downright bad luck.

I want to look at some ethical issues in pain that we haven't started to think about in the world of pain management at all – clinical ethics in general in UK hospitals has only recently taken off and tends to focus on such things as end-of-life issues and fertility rather than the more mundane issues that arise in everyday clinical practice.

I have been involved on some research on certain plant products and I want to concentrate on that but I recognise that there must be ethical issues in psychological treatment, in intervention, in whether we should try to treat a patient or leave them alone, in use of resources, in research and other areas.

My interest in this sort of thing was aroused last year when I was approached by a local senior GP and member of the PCT stating that there was far too much opioid being prescribed in Great Yarmouth compared with other districts in Norfolk and what were we going to do about it? Was it contributing to our drug problem in Great Yarmouth? (which is incidentally among the top 10 most economically deprived areas in the country) We looked at the other town we serve, namely Lowestoft (which is in Suffolk) and noted the same trends, which suggested that they must be led from our clinic. It began to worry me that the interesting plant product we were prescribing as a part of our research programme might find its way from Granny's fridge to grandson and his mates on a Saturday night. Issues of diversion are arising and cannabis may be even more of a problem in this respect than opioids.

I have sat for some years on the James Paget Hospital Clinical Ethics Advisory Group – nothing to do with research, and we have set ourselves up as a clinical ethics forum; not an ethics committee which like in the US has an executive role, acting as judge and jury: you present the evidence and they tell you what to do. Clinicians bring us problems which we can discuss aside from the patient and give them suggestions which may help them to make decisions themselves.

This group is made up of clinicians, lay people, the hospital chaplain (but not an ethicist) what I want to do is put you in the audience in this role –forget that you're a doctor, nurse, psychologist or whatever – and look at number of real cases that flag up some ethical issues. You will need to take into consideration such things as concern for personal wellbeing, the need to be trustworthy and honest, compliance with the law, basic justice, not taking advantage, doing good and preventing harm, professional matters such as impartiality, openness, confidentiality, diligence, responsibility, and conflicts of interest. Are there areas in which we must treat everyone the same or where the common good is implicated?

Case 1

A 56-year-old woman with back pain and sciatica who had been through the pain clinic mill at St Elsewhere's and eventually had an epidural catheter and port implanted. For a year or two she had been injecting herself with diamorphine through this and it had worked well for her. Eventually however it became infected and had to be removed. It was not replaced and she was put on 5mg diamorphine i/m twice a day. She had been on this for over a year when

she changed practices and her horrified new GP sent her to us. She averred that she had tried all other opiates and found this the best, and felt it would be better if she had it three times a day. I have never prescribed this in twenty years of pain practice. I did however discover somewhat to my horror that the BNF advises diamorphine for chronic pain by mouth, *ilm* or *s/c injection* regularly every four hours. Should I continue this, or even increase it? The dose is a reasonable one even if increased; she seems a very respectable middle class person and the question of diversion didn't seem to arise. (Would I have felt differently had she been Social class 4 or 5?)

What would you do?

The first obvious thing would be to explain the drug kinetics and try to persuade her to change to an oral preparation.

We did but she insisted that she had tried all the orals and none helped.

Is it fair to her to stop?

We none of us like the idea of injecting even 5 mg but we might be quite happy about prescribing 120mg orally

This regime doesn't make pharmacological sense.....

I agree but she still insists it works for her....

Is this a placebo response to an ilm injection?

When she injects herself she gets a "buzz" so this is controlled addictive behaviour: pain is not the issue as pharmacologically she is not treating the pain - she probably got the same buzz when she was injecting epidurally – what she wants is the buzz.....

You can't say that! You can't say she isn't treating the pain because she is content that her pain is under control.

People can choose to be addicts but they shouldn't be coming to a pain clinic with an addiction problem, not a pain problem.....

Surely it's both

Is she functioning normally?

Yes, she's active and quite happy with the situation provided she gets her injections. This is an evolved situation – they had tried everything at St Elsewhere's and this is the only thing that works for her and she is happy with it. She is however asking for more and I am bit worried that if I agree she will be back in six months time asking for it four times a day

A lot of patients come to A and E with dubious pain complaints and insist that only injections will help; they often end up being admitted and then you have the problem: do you send them home on this regime? Or say no and mostly we draw the line at this point and eventually they give up trying. In this situation you have to draw the line and perhaps refuse to let her have more....

Yes, perhaps I should draw up a contract with her.

If she were less obviously a respectable lady you might be more concerned with psycho-social issues – has she had a psychological assessment?

No , and perhaps this suggestion should be carefully introduced as the next step.

On the subject of contracts, we had a patient with a previous history of addiction who came to us asking for Diconal which was the only thing that worked; we contracted with him that the would get it four times a day but never more in any circumstances and five years down the line there is still no problem with this.

I knew a doctor many years ago who used to prescribe a mixture whose contents were unknown to the patient, and when they came asking for more he would write a prescription that might or might not contain an increase in the active drug - that was the contract: he had promised to respond if they were in trouble but they wouldn't know how – and it worked!

Case 2

A woman with a progressive neurological disease: (Shy-Drager syndrome which may involve either cerebellar and Parkinsonian symptoms or both, and a poor prognosis with increasing autonomic dysfunction, many other unpleasant symptoms including progressive dysphagia and probable death from respiratory failure in a year or two) She suffered painful muscle spasms for which she was on a trial of cannabis. Later in the open trial phase she admitted that in the evenings she was taking a bit extra to get high and help her to escape from her wretched existence for a few hours. Is there any harm in this – getting a bit euphoric on our medication in such a desperate situation?

In terms of treating the whole patient in the situation she finds herself I have no problem with this

But the problem of chronic high doses of cannabis is that they have a chronic effect which is undesirable and possibly dangerous and very much to be avoided if someone is going to take it for twenty years but if she's only going to be on it for a year and it helps and there is no evidence that its going to do her any harm then its OK..

I think we agree in this situation but what do we think in general about allowing our patients to have a little euphoria - perhaps in the evenings to provide a little escape from the misery of back pain

But it's not being taken to relieve the pain but something else.....

But this may be emotional pain? – perhaps we can justify this.....

There are other strategies people can use such as relaxation.....

This particular patient couldn't do this. But I want to press the general question of providing more than pain relief

We might be a bit worried from the legal point of view but we make this sort of clinical decision every day: we prescribe mood-improving drugs such as Prozac but if this sort of thing works better what's the difference? – at least in the short term.

To act as Devil's advocate: if its OK to make the patient high, how big a step is it for them to make their friends high?

Diversion is another issue.....

But to bring us back to treating the whole patient and their psychosociological situation , we have a duty of care towards all of these and not just her pain, and we have to make the same risk/benefit analysis as in any other clinical situation....

And in any case we can only advise – the patient has to make the choice. Its an adult-adult relationship ; we aren't her parents and we can only give them the information to make the choice

Let me take you on to another situation which arises from time to time as a result of my well-known interest:

Case 3

A fit 75-year old with spinal arthritis who gets pain on walking and particularly at night which keeps her awake so she is always tired during the day. She has been through the usual physical therapies without success, has worked her way through analgesics up to opioids which make her intolerably nauseated and constipated. One day she arrives in the clinic and from her handbag produces some herbal cannabis she has obtained from her grandson, and says she wants to try it. What do you do?

I have had a very similar situation: the patient went away and smoked it and said it was magic and I have told her if it comes to it I will support her: I don't know if this is right or wrong.....

Remember this is an illegal act

Not if it's obtained over the internet – but I've discussed all this with the patient, she knows its illegal but she insists it's helped her like nothing else and I feel quite comfortable with supporting her should the need arise

I've had several patients tell me they are using cannabis and I have never told them not to.....

cannabis taking is not without risk.....

Yes and of course I discuss this with the patient as with any other drug

Nevertheless it is illegal - do you document this in the notes?

Listening to all this it has struck me that it is often quite difficult to make logical judgements based on moral rules and I find myself wondering how I would feel – how I would react - if faced with these situations, and reprehensible though it may be perhaps we're going to be sometimes inevitably forced back into intuition to make these decisions , and let our hearts rule our heads

Yes this is an easy thing to do but nevertheless these are ethical matters which we must have thought about and we need to be able to stand up in court and justify our decisions. This is why I always make notes and record what I have said and what information I have given. This will provide both me and the patient some protection.

Won't it make things easier if the supply of cannabis is legalised, so 75-year old grannies won't have to involve their grandsons as suppliers

Another consideration is what happens if said Granny falls over and breaks her hip after taking cannabis*but this is the same with morphine.....*of course but this is illegal, which makes it all the more important to document the advice given.

Another difference is that if you prescribe morphine 10mg you know exactly what will be dispensed but this is not the case with cannabis.

(There was insufficient time to discuss the remaining cases but they are presented here as food for further thought)

Case 4

An ex heavy manual worker of 45 with chronic back pain and sciatica has had a wide range of treatment without success. He is taking 200mg of morphine daily and has been on a stable dose for two years, which controls his pain well enough to allow him to move well, although he is not working. He is resistant to suggestions of reduction in the dose and although he is not asking for an increase his GP is worried that he may be passing some of his medication on. Despite a spot check of his urine showing morphine metabolites I share this suspicion. What am I to do? Should I accept him at his face value? Should I demand that he reduces the morphine and put him on a weaning programme? Or should I accept that a little diversion into the recreational area is likely to do little harm over all. At least the users will be getting pharmaceutical grade morphine in a form not easy to use.

Case 5

A 50 year-old man has been a patient of yours for several years. You have struggled to help him with his back pain. Eventually he has told you that the only thing that really works is to smoke some cannabis. He finds that half a joint three times a day and a whole one at night controls his symptoms sufficiently to allow him to get out to work and even drive his car.

One day he contacts you urgently. The police have discovered that he is growing cannabis at home, have seized his plants and are thinking of charging him with supplying although he denies this. Since stopping the cannabis his symptoms have got much worse: he sleeps poorly and is unable to do his job.

What would you do? Have you documented his cannabis use in the notes? He asks for Nabilone which is not licensed for treating pain and is very expensive – should you prescribe it?

He asks you to attend court to support him if his case gets to trial – should you agree?

Case 6

Another man found by the police to be growing cannabis for his own medicinal use. He was 50 and had used cannabis for many years to control the pain associated with MS. His wife died about a year ago in tragic circumstances, and he lives alone, unable to get out much. He

has been on a clinical trial of medicinal cannabis which he finds of some use but not as much as the cannabis he grew himself. He knew that he should not take illicit cannabis while he was on the trial, and that to do so would be to break our rules and endanger the trial and the other participants, but if I kick him off it he will now have no other source. He has to resort to morphine which makes him feel very ill. He is covered by our Home Office licence,

What should I do?

Case 7

A man has been arrested for importing 5kg of cannabis to provide for patients who attend his herbal shop. He is above board and there is no evidence of supply for recreational purposes. He was arrested last year on a similar charge but the trial was abandoned. The defence ask you to appear to give information on the possible medical benefits. Should you agree?

Multidisciplinary team working.

Ian Yellowlees

I want to look this morning at the ways in which we relate to each other as therapists rather than how we relate to patients.

Communication is a really complicated business. We all recognise that even in the simple situation of a tissue injury all sorts of factors come in to it including events in the CNS, genetics, experience, context of the injury, intellectual and physical characteristics of the patient – culture, age, gender etc: all these things go into the expression of pain. Then you have to add in the observer in whom the same sorts of things are going on. Our relationships with other professionals can be equally complicated.

The ways in which we interrelate involve both professional and personality issues.

Turf wars are an all too common way of relating. When I was setting up an acute back pain service in the Borders I found myself up against a turf war with the physio department. Now how many of you regard acute back pain as a "Pain" issue? – how many as a "Physio" issue? How many of you subscribe to CSAG guidelines that you should consider biopsychosocial issues after six weeks of an unresolved back problem? Do physio's consider biopsychosocial aspects? Would that be regarded as part of mainstream physio? Could you run an acute back pain service without any backup from the pain team? We have some problems here! And who is going to be boss? It's usually a consultant – why? Is it any more than history and tradition? We nearly all subscribe to the idea of multidisciplinary teams, and feel that the contribution of each member is of equal importance. So why is the consultant paid £70,000 plus and the physio £20 -something? – *the consultant takes ultimate clinical responsibility* - but what does this mean? *Someone with whom the buck stops, who has to carry the can for the actions of the team and relate to outside agencies such as management; will managers listen to*

anyone else than doctors? – there has to be a leader – but does this have to be the consultant? - he has many other duties and responsibilities – but so do physio's and does it justify this pay differential? But the disparity between grades is a much bigger issue than pay; shouldn't we be thinking in terms of levelling up rather than levelling down?..... What about secretarial support for a start?

Do we just accept the status quo? How can we change things? Let's look at the typical team of doctors, physio's psychologists etc: we acknowledge that each brings a special skill but these tend traditionally to be very compartmentalised. But there is a huge amount of overlap, and most of us could do large parts of each other's jobs, and we aren't working in a compartmentalised fashion day-to-day. So this brings us on to the concept of generic working.

Anybody who has been involved in any aspect of pain management for any length of time will have developed "generic" skills: we can all give advice on simple analgesics and simple exercise programmes, and listen reasonably well to provide a "sounding board" at a basic psychology level and so on – and we all do it.

I tried to develop these ideas when I was working in the NHS but the NHS is seriously resistant to them! Since I left the NHS I have however been able to pursue them. One approach we have tried is to categorise patients into three "levels". A Level 1 problem is one that can be tackled by any member of the team, such as one requiring simple drug advice or suggestions for exercise. Level 2 patients might have something requiring a little more specialist input from one or other team member but still with a good deal of "crossover". A level 3 patient definitely has a serious problem that can only be dealt with by one or other specialist. Recognising and using these generic skills is important because it allows you to make the best use of the resources available, and certainly speeds the progress of the patient. It enhances each specialist's position as it formalises the recognition that there are key members of the team who have something special to offer and you know whom to turn to in a difficult situation

But there are potential problems. To define the differences between these levels you have to have trust between team members and each has to acknowledge the limits of their skills, and this may not always be easy. Crossing of professional boundaries may present major difficulties. And then there is "jobsworth" – perceived legal difficulties: "I can't do that because if something went wrong I wouldn't be covered legally".

These sorts of working relationships can surely only evolve with time as people get to know each other – you can't just decide you are going to change your whole way of working next week.....

Well, we have decided to formalise them "upfront" and assign patients at the initial assessment to one or other level, and decide whether a particular team member is needed to deal with level 2 or 3 problems. It's a much more structured and efficient approach to planning a patient's treatment.

I want to move on now to the other area of potential difficulty in working in a multidisciplinary team, that of interpersonal relationships. We are all different: we've all got different experience of life, of working in teams; we've got different degrees of confidence both to let go and to delegate, and to accept others might be right; many of us have chips on our shoulders – including money; and many of us have a view of role within the team which others might not share. I feel that if you address these issues and spend time thinking how your team works with the people you've got in it, then it works much better. One approach might be to apply Belbin team scoring, which is designed to identify characteristics and

aptitudes which are helpful or unhelpful in the context of a team, or to form a team with complementary strengths and weaknesses