

# Suffering, Change and Choice

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This was the fourth in a series of meetings devoted to discussion of philosophical and ethical issues associated with pain medicine; it is intended to create an SIG dedicated to this in the near future. Numbers were small this year, despite wide dissemination within the Society, and some surprise expressed that so few people seemed to think that this sort of thing is important. Perhaps there is an impression that our discourse would be cerebral, intellectual and far removed from everyday experience in the pain clinic. This is emphatically not the case: we are all nearly all clinicians and our discussions are firmly rooted in the problems that arise in our work, both in our patients and ourselves, but that we rarely find the time to ventilate. Despite, or perhaps because of our small numbers, the quality of discussion seemed even better than usual, and although we may have found few answers to a ever-increasing array of questions, I think we all went away more than ever before with a sense of refreshment and renewed vigour for our work, a better ability to cope with its demands, and better appreciation of its rewards.

## Pain and Suffering

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### **The topic**

Pain and suffering occurred to me as an interesting topic last summer when I attended a conference of pain managers. There is a tension between two groups in the pain management world: “the cutters and burners” as some of them like to call themselves, whose practice is based primarily on physical interventions, and those who take a more general psychotherapeutic approach. Against this background one of the speakers, a director of a hospice in London, drew a distinction between pain and suffering and claimed that, at the hospice, they attempted not just to control the pain of terminally ill patients but to address their suffering. She understood suffering to involve the whole person and to be, somehow, a function of their sense of themselves.

My philosophical mind wandered to a major topic in moral philosophy, to Utilitarianism which says the rightness or wrongness of actions depends entirely on their consequences. It goes on to insist that the consequences of actions be understood in terms of down-to-earth, empirically determinable effects. The original Utilitarians reached for Hedonism to provide an account of these consequences. So they ended up saying that the rightness or wrongness of actions depended on

whether they maximized the pleasures and minimised the pains of the greatest possible number.

One of the main objections to Utilitarianism is that it doesn't give the person a central role in morality: individual people count only in so far as they are recipients of pleasures and pains. What struck me was the analogy between this philosophical criticism and the pain managers' discussion. It seemed clear to me that just as I instinctively warmed to the hospice director's point of view encapsulated in the distinction between pain and suffering, I instinctively rejected the hedonistic base to ethics and for the same reason. It isn't pleasure we should aim at, but producing people who are fulfilled and happy; and what we should avoid is not pain episodes but suffering people. This shift makes a difference in moral philosophy – it undermines the ambition to reduce morality to calculation and technique. I wonder whether it makes a more practical difference in how we should care for people.

I am going to make some remarks about the distinction between pain and suffering and then raise a few questions under three headings

- Useless suffering
- Fantasies of suffering
- A place to suffer.

### **How are pain and suffering different?**

I want to talk about 5\* suffering. We often use the word suffering when we mean something much less than the 5\* variety. There is, for example, a sense of suffering which means no more than undergoing or experiencing. To *suffer* a setback in business is not in itself 5\* suffering, though it could cause suffering. Closer to home, a person may be suffering from a disease and be unaware of it. Another use of the word 'suffering' misses what is distinctive about 5\* suffering. We talk about suffering pain when we mean nothing more than that we are in pain. We do not mean to add anything to the idea that the person is in pain when we say they are suffering pain.

It may well be that the most familiar cases of suffering are those that are caused by or accompanied by pain. But they are different and not only as ideas but in reality. This is not to deny that some pain may be so severe that it is inconceivable that anyone could experience it without suffering. But we can be in pain and not suffer. The injured rugby player may be in pain and yet be exulting in victory. Equally, we can suffer and not be in pain. Psychiatrist must regularly see patients who are suffering severe distress and yet are not in pain, though their suffering may be so palpable that we want to talk about mental pain.

### **What is suffering?**

It isn't easy to say what suffering is. Suffering is not a sensation like pain: it is not localised in the way pain is, nor does it begin and end in the way pain does. Pains have causes but not reasons. If you get burnt, the burn is a sufficient explanation of your pain. The burn causes the pain more or less independently of how you take it. But suffering has both causes and reasons. For example someone's death can cause you to suffer, but there must be something about your beliefs and emotional response that makes you suffer? The death does not cause suffering more or less independently of how you take it. You could give reasons why you are suffering.

In this sense, suffering is more like an emotion than a sensation. Emotions also have causes and reasons. We have reasons for being, for example, frightened. But there is an important difference between emotions and suffering. Suffering does not have an object, at least not in the same way as an emotion. Emotions, such as fear or love, have objects: your fear or love is directed at the feared or loved person or thing. But we cannot ask: what is the object of your suffering? It is as if, though suffering has causes and the person who suffers has his reasons for suffering, suffering is a more self-orientated state than object-orientated emotions.

So what is suffering? I think my hospice woman was on the right track. Pain manifests our physical vulnerability as animals; suffering is the result of our psychological vulnerability as persons. Suffering is a protracted, deeply unpleasant experience; it is an experience that people go through. It is undergone. Suffering is the helpless revulsion and rejection that we experience when we are overcome by the unbearable and the unavoidable. It is what we experience when we are faced with something dreadful - death, hopeless illness, loneliness, abandonment - that threatens to dismantle what we take to be the core of our personalities. It realises itself in despair, depression and anxiety.

### **Useless Suffering**

Does suffering have a function? A central purpose of religious belief has been to give meaning to suffering. Theodicy is that branch of theology which tries to explain the place of suffering in a providentially governed world. The word was coined in 1710 by Leibniz, but it is an expression of an older, deep-rooted way of thinking: we cannot accept the sheer uselessness and meaninglessness of suffering. In the religious traditions from which we have emerged suffering is explained in terms of the Judaic Diaspora and Christian Original Sin.

There are secular attempts to rationalise suffering. Sometimes suffering is represented as the inevitable price of achievement - the “no gain without pain” school. Some robust pedagogues no doubt think that there can be no education or discipline without suffering. There is something right about that: there is no gain without effort; and no effort without pain of sorts. But what’s that to do with suffering?

We no longer think that suffering should be inflicted even on criminals. Capital and corporal punishment have been abolished. We imprison people instead. Punishment is meant to consist in the removal of freedom and nothing more. Convicts are not expected to like prison, but neither are they expected to suffer there. If we were more honest, we would ask ourselves why so many of them commit suicide. None of these attempts to give some sort of social function to suffering appear plausible or even decent nowadays.

Is there an evolutionary explanation of our capacity to suffer? To give an evolutionary explanation of something is to show how evolutionary pressures could lead to its emergence in the biosphere. A particular feature is explained if the animal that possesses it gains a reproductive advantage. For example, camouflage. However, some features are explained not because they constitute an advantage but because they are collateral to some related feature that does constitute an advantage. For

example, human beings are prone to back problems. This weakness in itself is nothing but a liability but it is the collateral damage consequent on standing and walking upright which do have evolutionary value. Finally, there are some aspects of activities for which evolutionary explanations should not be sought at all. For example, there is surely an evolutionary explanation of play among animals; but there is no evolutionary explanation of soccer – though it is an appropriate form of play for bipedals like ourselves; and even more clearly there is no evolutionary explanation of soccer's offside rule. You may like to run a similar line of argument about morality. Social Darwinism looks for evolutionary explanations long after we should have dropped them.

What about pain and suffering? Feeling pain has obvious evolutionary advantages. It warns us of damage or illness. It was bad news for the brontosaurus if it did not know its tail was on fire because it did not feel pain in that remote part of its body. Not each and every pain shares this useful function. The pain of terminal cancer is an unfortunate and useless spin-off. But generally speaking pain has a function in providing an insistent warning system to the state of the body.

Suffering has no evolutionary advantage. It is essentially dysfunctional. It looks as if useless suffering is the incidental price we pay for knowing so much and becoming so refined and sensitive. In a sense this story trivialises suffering by representing it as a useless by-product. But, just for that reason, it makes it even more important than we might otherwise think to avoid suffering ourselves and avoid causing it others. There are dangers in thinking that suffering has a meaning or a function. If you think suffering has a redemptive value you may even come to believe, as the Inquisitors did, that you have a duty to further it.

### **Fantasies of suffering**

There is another potentially positive by-product of the dysfunctional nature of suffering: it allows unrestricted play to our imaginations. We endlessly fantasise our desires, needs etc. But functional desires, e.g. for food or sex, set limits to what our imaginations can do by way of weaving myths around them. At the end of the day food, whatever *Ready, Steady, Cook* does, has to be edible. Children have to be conceived and relationships maintained, whatever the eroticists get up to. But if suffering fulfils no objectives, our imaginations can roam untrammelled. Christianity is in large part a fantasy on suffering. Tragedy is a dramatic genre that depends on the satisfying horror we experience in the face of suffering. Can I modestly suggest that sadomasochism is an erotic fantasy on suffering, not on pain?

One account of suffering that avoids offensive rationalisation can be found in the philosophy of the wonderful Emmanuel Levinas. He has a deep and subtle meditation entitled "Useless Suffering" in which suffering has a fundamental moral role. [Emmanuel Levinas, "Useless Suffering" in *Entre Nous*, The Athlone Press, 1998.]

He writes: the suffering of others "*solicits me and calls me...my own experience of suffering, whose constitutional or congenital uselessness can take on a meaning, the only one of which suffering is capable, in becoming the suffering for the suffering...of someone else*". "*It is this attention to the suffering of the other that...can be raised to the level of supreme ethical principle...*" (p. 94) but which "*cannot give itself out as an example, or be narrated in an edifying discourse*" (p. 99).

This is not a moral theory that a serious social thinker like Aristotle or Hume or Bentham could advocate. It is a moral fantasy – I use the word non-pejoratively. But perhaps it is either this heroic response or nothing, if we find ourselves, as Levinas did, in a concentration camp - a place where suffering had become the dominant mode of existence.

### **A place to suffer**

To say that suffering is useless is not to say that it is unimportant in human life. It has the massive importance of being the state we most want to avoid. We need to do something about it. Are we doing enough and are we doing the right things?

One question that occurs to me is: where do we go to suffer? The very idea of an institution whose mission is to provide a place for people to suffer in sounds creepy. What about hospices? The hospice movement started because Cicely Saunders realised that people need a place to die. Hospitals were not keen even to admit that people died in them. Death meant failure. So new institutions were needed that were committed to palliative care rather than cure. If hospitals found it difficult to admit that their patients die, I imagine, they would find it even more difficult to admit that their patients suffer.

Although the hospice movement is based on the idea that death must be acknowledged, its attitude to suffering is not so clear, despite what the hospice director said at the pain conference. Hospice literature is marked by frankness about death and pain management but is less forthcoming about suffering. I did not come across the word 'suffering' once in the web pages I visited, though the word 'distress' is used. Perhaps that is not accident: the focus of the Hospice is to make death an experience we can go through without suffering.

A characteristic passage from their promotional literature reads:

*The driving force behind hospice, or palliative, care is the desire to transform the experience of dying. Still in the 21st century in the UK people die in avoidable pain and distress. In hospices multi-disciplinary teams strive to offer freedom from pain, dignity, peace and calm at the end of life.*

Anyone who has achieved *freedom from pain, dignity, peace and calm* isn't suffering. As death is seen as a failure by medical practitioners who are focused on cure, suffering is seen as a failure by the hospice which is focused on making death a positive experience.

Perhaps that is inevitable. Maybe we cannot do for suffering what the hospice helps to do for death – make the idea of a *good death* a possibility. Perhaps there is no room for the idea of good suffering.

Nevertheless we can do something. The appropriate response to pain is alleviation; to suffering consolation and comfort. Do we need a place where consolation and comfort are available? The ideal of an asylum, a place of safety and support for the vulnerable, comes closest to being a place to suffer. I wonder whether you think of your own hospital here as fulfilling that role.

# Suffering and Choice

Michael Bavidge

## Introduction

A few years ago I heard a paper given by a Czech philosopher. He began by saying that the most serious philosophical question is: could one be free in a cell that measured 8 feet by 6? He had spent months in such a cell after the failure of the Prague Spring. So, coming from him, the question had a seriousness that we comfortable academics who were listening could not match. You can imagine answers ranging from “Of course, intellectual freedom is all that counts” to “Of course not. Intellectual freedom is an illusion, if you have no freedom of movement and your future is determined by alien, malevolent powers”.

There is a question which is analogous to that: can someone who is suffering be free? And analogous answers ranging from “Of course, you are at least free to accept suffering, to take up some positive attitude to it” to “Of course not, suffering is a sort of undergoing; not a sort of action; it is the very opposite of choice; the dysfunctionality of suffering emerges in our lack of choice”.

The suspicion is that in both cases, our attempts to claim freedom, in the most restricted of circumstances, is wishful thinking and self-delusion. And another suspicion is that our self-delusions are deeper in the case of suffering. Even someone who thinks that spiritual freedom is possible for the incarcerated is not likely to think that imprisonment is itself a positive thing. But people have thought that suffering has a unique spiritual value. And not just Christian theologians who attribute a redemptive role to suffering; Victor Frankel wrote “Only under the hammer blows of fate, in the white heat of suffering, does life gain shape and form”. Is this hot air or is there something in it?

## Types of choice

We can distinguish two types of choice – there may be many more. Consumer choice and what I am going to call the choice of commitment.

Choosing a washing machine is a case of consumer choice. The shopper knows roughly what she wants; she informs herself what models are available at what prices; she is competent enough to organise the finances and complete the various chores that are required to buy the item she chooses.

Consumer choice in general presupposes

1. an array of pretty well defined goods
2. displayed in a reasonable stable field of choice
3. a consumer who is reasonably well-informed
4. who pretty much knows her own mind
5. who has a fair degree of executive competence in satisfying her preferences.

A paradigm case of a choice of commitment is getting married, or choosing a career, or joining a political party. A person thinks of their lives as having a trajectory over which they exercise at least some control. They think of themselves as people with

an open-ended future which, whatever difficulties lie ahead, offers opportunities for a worthwhile life and self-fulfilment.

A choice of commitment in general presupposes

1. a set of ambitions or hopes or ideals which, while unspecific, can be characterised in general terms
2. an open-ended field of choice
3. a person who has a reasonably realistic view of themselves and of the world they live in
4. who has at least a minimal level of hope or expectation or optimism
5. who has a reasonable level of self-confidence in their future.

If we compare the numbered points we can see significant differences in all these elements of choice:

A choice of commitment does not involve specific, delimited objects of choice as consumer choice does. We don't choose our spouses from the array on the shelf. The vicar asks the groom "Do you take this woman to be your lawful wedded wife...?" He doesn't mean "Is *this* the woman you have chosen from all the available ones. Are you sure? Wouldn't you perhaps prefer this one?" He means "Are you really committed to marrying this woman?"

What I call "the field of choice" determines what the person takes to be the available lines of action open to them. Our choices are shaped by what is socially available. *Informed* choice presupposes *informed* choice. That is, before the chooser can make an informed choice, the options have to be informed by the social possibilities. This is true of both sorts of choice. But an important difference is that consumer choice requires relative stability in our fields of choice. You cannot make a sensible consumer choice if when you get the goods home they turn out to be already worthless. You cannot make sensible consumer decisions when the inflation rate is 200%. But commitment choice involves signing up to something whatever the future holds – for richer for poorer, in sickness and in health. It is open-ended and unconditional in a way that consumer choice is not.

The consumer has to be well-informed. She needs information. Information is made up of transportable items, storable, transmittable, objective. Information is what you have left when you take the personal out of knowledge. Commitment choice requires a much more general and personally engaged sort of knowledge. The enemies of commitment choice are not lack of information but failures of self-knowledge or self-confidence.

The ideal consumer has pretty clear objectives and she buys a product fit for purpose; the commitment chooser is not in the business of pursuing particular objectives but of giving a shape and direction to their lives. What this requires are not managerial or administrative skills but personal qualities that enable us to maintain some sort of positive orientation to the future.

Finally the consumer and the commitment maker have to engage with fields of choice; they have to see themselves as possible players, as counting, as having rights. The consumer sees herself as entitled to good service and fair trade. The maker of

commitments focuses not on contractual rights but more general values, such as human rights and the good life.

### **Suffering and Choice**

How does suffering affect these sorts of choices? It seems obvious that suffering has an adverse effect on our capacity to make choices of whatever kind. It cuts down the range of choice and undermines our effectiveness in making choices and putting them into effect. There are other inhibitors of freedom. Being poor, for example, seriously diminishes our capacity to choose - but in an external way. Suffering, on the other hand, undermines us from the inside. The suffering person has not got that ease and space in which we normally exercise choice. Suffering affects us at our core; it undermines our autonomy. It is a sort of undergoing, a passivity. It is the opposite of choice and action; it is dysfunctional because it inhibits normal levels of activity and choice.

I suggested earlier that suffering is self-orientated. A consequence is that the person who suffers is more likely to see their predicament in terms of commitment choices rather than consumer choices. "Here I am - suffering. What is to become of me? What am I to do to make my life liveable again?" What may appear to the non-sufferer to be a consumer choice becomes in the experience of the sufferer a commitment choice.

A friend of mine was recently diagnosed with prostate cancer. The consultant explained the disease to him and advised him about the various treatments available. He was told to think about it and make up his mind which course of treatment he wanted. The choice he made did not meet with doctor's approval. But what he found more upsetting than finding himself in disagreement with his doctor was that they were not on the same wave-length. For the doctor the problem was an objective one of calculating the line of action most likely to produce the best result. But my friend could not escape from seeing the problem in terms of "What am I going to do?" or "How can envisage living through these experiences".

I suspect that this is a general feature of choice for the suffering. Consumer choices are transformed into commitment choices. This may explain why some people are suspicious of consumerism in the Health Service – and not just for the political reason that choice for some means less or nothing for others, or that maximising choice may militate against other values we wish to retain in the Health Service, equality for example. People who are seriously ill or suffering don't need or cannot avail themselves of consumer-style choices. If we are talking about relatively minor medical interventions consumerism may capture the sort of relationship we want to have with the Health Service; but there is a gear change as soon as illness becomes a serious threat to our health or suffering threatens to undermine our viability as people.

So if we want to improve the lot of the sufferer we must try to maximise their opportunities for making commitment choices. It may be that without pain relief this is not a realistic possibility. All the attention and energy of the sufferer is taken up by his suffering. But pain relief is not enough. They have to relearn hope; and rediscover the assurance that, however bad their situation, there are things worth striving for; they must be able to feel that though their lives may seem to be severely restricted



they still have a say in the shape their life is taking, even if, *especially* if it is drawing to a close; environments are needed that allow this to happen.

### **Choice in relation to Suffering**

So far I have talked about suffering affecting our choices in general. What about our attitudes and choices in relation to suffering itself? Peter is going to talk about accepting suffering later, so I won't say much. The obvious thing to say about choice in relation to suffering is that most of us normally choose to be rid of it. We rightly regard it as one of things we most want to avoid. But not at all costs. We regularly choose pain or at least risk pain to achieve some objective. We visit the dentist; undergo operations, in the interest of health. For reasons of mere leisure and entertainment, we play rugby, climb mountains, ride horses. We less often choose suffering. But we do. We put ourselves in situations where we experience not just pain, but anguish and desolation. Some heroic souls have even preferred to be tortured than to be or collaborate with the torturer. But it is better to live a life of ease than be either torturer or tortured.

Nevertheless, people quite regularly choose to suffer. In these days of suicide bombers we are well aware of the appeal that asceticism & martyrdom have for some people. But even if we discount these as fanatical delusions, views like those of Victor Frankl, I quoted earlier, are commonplace. Suffering is widely represented as having a positive value. It forces us, or at least gives us the opportunity, to go beyond the trivia of everyday life; it makes us ask what is essential to us and what can be dispensed with. It forces us away from consumerism to fundamental thoughts about the trajectory of our lives. This shift follows the movement from consumer to commitment choice and helps to explain why some people believe that suffering has a value.

I cannot suppress a cynical thought about the recommendation of suffering on these grounds: some experiences are so dreadful that they can only be borne if they are thought to be wonderful. Just as some actions are so wicked that they can only be contemplated for the highest motives. There are less destructive and dangerous ways of cutting through trivia to the essentials of life. Suffering is not a positive experience even if by various stratagems we manage to draw benefit from it.

### **Stoic Acceptance of Suffering**

If embracing suffering holds no appeal and yet we cannot be rid of it, the next option is to accept it, to submit to it. The Stoic tries to make himself immune to the ills of the world by cultivating indifference to the vicissitudes of life. If we are living in a post-Christian age we perhaps have no option but to return to Stoic ideals.

The deaths of Christ and Socrates have often been compared. Both were executed by the State. But Socrates is presented in the *Phaedo* as choosing to die a good Stoic death. He accepted death and died without suffering. Christ, on the other hand, had a dreadful death which he prayed to be spared. He died after protracted suffering. The Passion is presented as Christ enduring total pain, physical, psychological and spiritual.

The images of the Passion, the values and the anxieties that it represents, are so inscribed in our culture and psyches that I am not sure that something as simple as disbelief can eradicate them.

## The privilege of hosting the Last Chance Saloon

Caroline Waterstone

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In fact I host two saloons: my individual patients and the other which is seriously 'last chance' – the PMP.

During the introductory talk of a recent PMP, in the course of what I hoped would be an accessible and coherent discourse on Pain Pathways: (you know this stuff – the difference between Acute and Chronic Pain, and also the difference between Hurt vs Harm; wind up; central maladaptive mechanisms etc, etc.) a youngish, slim, fit patient, James, interrupted me with "Is this the last chance saloon?"! Was I doing such a bad job with my explanation? How would the other eight patients react to this and how to reply? A colleague never at a loss for words, as I clearly was, responded with "No, James, the 1st"!

The truth is you can't currently participate in a PMP unless and until you have given up the search for a cure for your chronic pain and have metaphorically taken the pledge that you will seek no further biomedical interventions. This being a major referral criterion, we did have one referral from an out-of-area consultant who when sending the referral filled in the reason-for-referral box with "Last Resort"!

My previous physio jobs were all in neuro rehab. This is a model of treatment where I am clear and confident that I have the knowledge and physical skills to realise maximum potential of patients during rehab, whether the condition is due to a single event or is a progressive disorder. Where there is spasticity or rigidity I have tools and skills to improve that. If there is pain from these I can make a significant contribution along with medication to help alleviate that too. A positive contribution can also be made in helping these patients have a more comfortable death. It's true that these patients suffer from many of the things we talked about yesterday: loss of role within family, workplace, community etc; depression endogenous or reactive and indeed altered intellectual and emotional states can be features of all or some of these conditions at times.

The bottom line is though that within the limits of the degree of disease or event plus neuroplasticity, I have physical skills to bring which with follow through by the patient and carers can contribute positively to rehabilitation.

A chance encounter with two runaway horses and a carriage three years ago put paid to a full-time career in neuro rehab, and due to a serendipitous phone call here I am, in a new career in the field of chronic pain management – or rather self management.

This session is about personal growth and here is what I have learnt:

## Coping Styles

Chronic pain patients are predominantly female, suffering usually from back and neck pain, though they do sometimes present with pain in other joints or body areas with a pain duration of anything from two years to four decades.

They seem to be easily categorised into 2 groups determined by their coping styles:

- 'Withdrawn snails'
- 'Charging bulls'

The 'withdrawn snails' sense threat and danger in the world and are fearful of doing much. The 'Charging Bulls' are defined by what they DO, and continue to charge around doing what they have always done, thereby increasing their pain, decreasing their quality of life and ultimately being able to do less and less, with increasing frustration.

Neither group can imagine living differently without being overwhelmed by pain. These coping styles don't come from nowhere – we're back to family imprinting and cultural context, for instance if a patient's mother always took to her bed when she had a headache, leaving the children to sort themselves out, or if conversely she responded to a similar pain by using distraction, for example taking down all the net curtains for washing, or if as a child she was only ever shown affection and when sick, the patient already had a choice of styles to model.

So, clearly, finding out what lies behind these coping styles for dealing with r pain is important. We talked yesterday about how increasingly doctors are required to work to protocols and how this doesn't always fulfil patients' needs. Likewise, we need to know our patients well enough to work out from a choice of messages which is likely to be most appropriate, at least initially.

## Mixed and inconsistent messages from Health professionals

By the time we see our patients, they have been shunted from pillar to post seemingly forever between GPs – often changing GP practices when relationships with GPs break down – physios, orthopaedic surgeons, neurosurgeons, osteopaths, chiropractics, acupuncturists, Chinese herbalists and you could add your own several other treatments or practitioners to this. When consulting with each of these professionals the patients are receiving messages or instructions about the virtues or otherwise of exercise, rest, medication and other interventions. So by the time they get to see us they have been 'done to' by a plethora of professionals, none of whom has provided them with the magic bullet, yet still they continue to look for that elusive cure for their pain.

Lest the doctors among you think I am having a go, heaven forbid!, I would like to say that MSK physios have a lot to answer for in contributing to chronicity. They are anxious that if they do more than acknowledge yellow flags and open the can or cans of worms they won't get the lid back on again. They don't know where to refer the

patient (especially in view of the shortage of pain psychologists and so they stick to a their biomedical model of *doing to* their patients: in short, using an acute model of care for an increasingly chronic group of patients.

I am happy to report that we are increasingly doing joint working with our MSK colleagues helping to address their concerns – joint assessments with patients with identified yellow flags, joint treatments, and leading in-service training on aspects of chronic pain management. Some good things are already flowing from this – but it takes time - especially to help colleagues for whom there is still so very little psychology taught in their student training.

So: We have a group of patients whose condition is invisible – only their pain behaviours communicate their distress- a condition for which there is no cure, little public sympathy, who we the health professionals have ‘done to’ forever without positive result or may even have made worse. (Certainly the patient of ours who had back surgery seven times was not improved by surgical intervention) Many of them are suffering from decreased economic circumstances, relationship breakdown, increased isolation from their community, job loss and more and *then* it is suggested to them that from where they are now *they* might like to improve the quality of their diminished lives by adopting self management strategies! Those of us who are gainfully employed, supported by family and friends etc have trouble enough stopping smoking, committing to weight loss or fitness routines, so no wonder on day one of many PMPs we are met with aggression and anger at the suggestion that, since the professionals have failed them, they might like to have a go, i.e. “it’s down to you folks! We’ve got 30 hours: 3 hours for each of 10 Tuesday mornings for imparting information, enabling sharing and practice, but the outcome is up to you!”

What is it we do in this ‘Last Chance Saloon’?

As I said, I run 2 saloons:

Individual patients – I treat these patients because they are either too good for or don’t currently fit the criteria for attending a PMP. Alongside my input they may be seen by other PM team colleagues, OT, Psychologist, and Pain Nurse. They may be waiting for medical intervention, most usually epidurals or facet joint injections. Since there are waiting lists for these from 4-7 months, I get going first.

Often the first appointment is a time for unburdening and many patients express their gratitude to us for having the time to hear their ‘story’ and of their life with chronic pain. Sometimes, after just one hour’s appointment in which they have been truly heard, we can then get on with working out how they can begin to adopt appropriate self-management strategies to fulfil their identified goals.

Group

The power of the group is 2-fold: patients meet others suffering similarly and can share and compare their experiences of treatment, life etc; they see people better and worse off than themselves, and perhaps most important of all realise *they are not alone!* Then the multi-disciplinary team of psychologist, OT, PT and nurse, provides an energy powered by our belief in the programme we offer, which holds and supports the patients at this time of scepticism and downright disbelief,

tempered in some by a desperate hope this will work.

For patients in both treatment settings the topics addressed are:

- Continuing opportunities for questions, clarification and practice
- Exercise –*appropriate* exercise. My motto is ‘One is good enough’ - not g 10 of a set list of exercises. One of a few carefully chosen exercises once or twice a day and that carried out consistently is a base from which they can grow in confidence and begin to increase their routine.
- Relaxation
- Balance of activity and rest – covering pacing and baselines to discourage activity cycling
- Thoughts and feelings: understanding their impact on pain
- Medication
- Goal setting
- Flare-ups: we hope they will have one during the programme and they certainly seem to fulfil that hope by the 7th or 8th week of each programme! We want them to learn to use what they have learned on the PMP to deal with a flare up themselves without running to the doctor

Perhaps the most important thing of all is that we believe their pain is real. Being believed is huge for patients – acknowledging that it is not ‘all in their minds’ is an enormously important start and helps patients to move: these people who have so often been accused of malingering, waiting for litigation till they choose to get better, wanting early retirement from a boring- going- nowhere job etc.

Because we see patients so far down the line, not very many are making large shifts. But it can be very rewarding just to offer a hand, and having some patients take it and grow to trust that together we can get them to a place they have determined could be good despite persisting pain.

My most important lesson has been to learn to accept that people need to want to change and are ready when they are ready!

A kind OT colleague who shares our office and hears us despairing of tearing our hair out about some of our patients put this notice above the psychologist’s desk: ‘How many PM Team members does it take to change a light bulb? It could be one or all, but is the light bulb really ready to change?!

It’s taken a while for one who could fix so much in neuro rehab, and who knows a neuro patient who doesn’t want rehab, to be accepting when patients resist, reject and walk away, as James did, from self-management. I’m fine with it now. My new attitude was endorsed recently when two patients we had seen long ago and discharged rang in the same week, and the phone calls went something like this: ‘I know you were trying to tell me something when we met, but I wasn’t ready to hear, can I please come in and can we try again?’

## The therapeutic relationship

Could this be symbiotic? We have been discussing how our practice in chronic pain informs our own personal growth. Thinking about this, I remembered times when patients were sharing profoundly troubling spiritual pain, emotional trauma and physical distress that brought up pain from my own life. How are we in the face of our patients' pain? How can we use what comes up for us about ourselves to promote our own healing? Put bluntly: are we changing those areas of our own lives which don't work so well or are out of balance, while we are helping our patients to do the same?

Accepting the health professionals with whom it is my privilege to work, our patients and myself, and acknowledging that we are all doing the best we can with what we bring to our lives at this time, allows space for empathy and time for personal growth.

I came across this passage recently in the book *"Tar Baby"* by a black female American, Toni Harrison, the person doing the looking is an escaped black criminal

“Through the window on the ground below he saw the back of a man stooping at some cutting or digging chore. It was the black man he had seen off and on around the grounds. He stared at his back. Yardman, she had called him. That was Yardman's back. He knew backs, studied them because backs told it all. Not eyes, not hands, not mouths either, but backs because they were simply there, all open, unprotected and unmanipulable as Yardman's was, stretched like a smokehouse cot where hobos could spend the night. A back where the pain of every canker, every pinched neck nerve, every toothache, every missed train home, empty mailbox, closed bus depot, do-not-disturb and this- seat -taken-sign since God made water came (sic) to rest. He watched the angle of the old man's spine and for no reason that he could think of tears stung his eyes.”

# Ethnic minorities: do they get a fair deal?

Wendy Callaghan

Clinical psychologist, Leeds

I want to use this opportunity to share my observations with you and to hear about your own observations, to talk about the survey we are conducting, and to get some ideas about how to engage with people from the ethnic minorities.

Over the last 12 years I would judge that the number of people from the ethnic minorities that come through the door are not in proportion to the Leeds population. This is currently being investigated systematically by a clinical psychology trainee, using a simple survey initially. (You have to prove what you know!) Of those that do attend it is even more unusual for there to be a referral to clinical psychology or the PMP. Since 1997 I can only recall two black and two Asian patients attending the PMP. In my individual work I have only once had to use the language translation service.

Since 1992 I have probably only seen one dozen patients from the ethnic minorities.

With the recent exception of a young Iraqi woman, I have found myself feeling ignorant of the necessary details about people from other cultures. I have quite a lot of personal knowledge about Pakistan and Islam, but it does not help a bit in answering these specific questions:

- 1 What are their beliefs about pain?
- 2 What is their view of doctors, pain service, psychology?
- 3 What are their views about the treatment of illness?
- 4 What is the role of the family?
- 5 What does an expression of pain signify?
- 6 How is it received?
- 7 Are there differences between those born here and not?

I don't even have any meaningful or useful generalisations to call on.

There is, I believe, a prevailing view in the clinic that there is a mistrust of Western medicine and that traditional remedies, yoga etc. are preferred and that only physical treatments are likely to be welcomed. There is some anecdotal evidence for this in Leeds, but that is all there is.

What about racism? I recall a student nurse, in a teaching session, with the nurse tutor present, saying that Asians complain more of pain, implying that they were exaggerating their pain. This was said in a hostile fashion and sounded like a direct quote from trained staff on the ward. She was not convinced by my arguments about diversity. By the way, the nurse tutor was Asian! The other example was

closer to home (I am Jewish) and showed a clear belief on the part of the person concerned that Jewish people complain more about pain. In Leeds some Jewish people are easily identifiable by name, hence the belief, but what of the Jew married to a non-Jew who does not complain much. This person would be appalled to be thought of as prejudiced. This leads me to the question of that fashionable term – institutional racism. This is more subtle and harder to challenge, but we offer a one size fits all service. Clearly it doesn't!

We do use interpreters, but I have not heard chronic pain explained to them at the outset, nor do we even know if chronic pain is a concept they can become familiar with at the drop of a hat, so how does this affect the interaction?

We are not doing that well with the bulk of the population according to an article in the last Pain Society newsletter on “Barriers to Getting Effective Pain Management” in which the key points were : information, adequate resources, mentors with similar experience, social attitudes – so that will be with knobs on for those from different backgrounds.

### Points from discussion of group members' experience of engaging ethnic minorities.

- A lot of effort has to go into getting people from the ethnic minorities to take up the service. There is a need to identify where the block comes in the referral chain. Having staff from relevant backgrounds helps. Different groups need different arrangements. They provide an allfaith/purpose sanctuary.
- There is a need to provide information in different languages
- In one team, an Indian member of staff was readily able to make links to Indian women's groups.
- First generation members of ethnic minorities may be spokespersons for their communities - as they are immersed in both cultures.
- Someone said that Chinese people prefer Chinese medicine. I can think of one who doesn't want to imbibe the bits of snakes her mum was keen on!

### Suggestions about engaging staff:

- Provide something in exchange
- Contact specialist nurses in the oncology unit and see how they do it
- Make presentations at Grand Rounds etc
- Get on the GP training scheme
- Get community leaders to come and talk to us.



These will be followed up and I will report back next time we meet. In addition I have made a contact at Leeds University who is the Director of the Primary Care Research Unit, and whose special interest is in ethnic issues. I hope he will be able to help me formulate some questions for qualitative studies by further trainees, and give me further ideas about making contact with the relevant groups locally.

## Learning to accept suffering.

Peter Wemyss-Gorman

Consultant anaesthetist, Haywards Heath

Suffering seems to be an inevitable component of the human condition. It is universal, has always existed and presumably always will. Understanding it has been a major preoccupation of all philosophies and religions. It is indeed the major preoccupation of Buddhism. It has certainly been one of our main preoccupations in these meetings. Like Omar Kiyam we have “heard much argument about it and about – but evermore come out by that same door as in we went”. However reluctant we may be to admit that we may never understand suffering, we can in no way escape the relentless evidence that it is inevitable. But all the activities of you and me and thousands of others world-wide working in pain clinics, not to speak of all the scientists, and all the billions of pounds and dollars going to the drug companies and equipment manufacturers are predicated on the principle that pain and suffering are unacceptable. But however reluctant we may be to accept the inevitability of suffering, it seems that we must.

But of course it is not all inevitable. The fact that it is sometimes preventable and can sometimes be relieved makes acceptance of it all the more difficult. I would guess that for many of you, as it was – and still is – for me, the most challenging aspect of growing into this job has been learning to come to terms with our own limitations. When I first started back in the 1970’s interventional treatment was really taking off: Sam Lipton’s books and most of his long weekend course in Liverpool (practically my only training) were largely taken up with destructive techniques, especially cordotomy and facet denervation, which were going to bring in a new era of utopian freedom from suffering. The fact that in my hands cure of anything very infrequently seemed to result was depressing but I attributed this to my inexperience and lack of skill and hoped that if I persevered I might one day achieve the sort of results that the great and good in the pain world seemed to command. When I failed to make much progress, I attributed it to my terminal incompetence and got pretty despondent about the whole thing. Then as I attended meetings and got to discuss my problems with other ordinary mortals I began to realise that my expectations – and those I had encouraged in my patients – were very often unrealistic. But.....

both physical and pharmacological interventions *do* sometimes work. And surely one day all the huge amount of research that has been going on all round the world for the last 30 years and more and the enormous advances in understanding of the workings of the nervous system will one day bear fruit in terms of more effective treatment? Experience to date would hardly encourage optimism on this score but surely it would be wrong to give in to nihilism? There are so many things which make it difficult to accept the inevitability of suffering, but it would still – and indeed for the foreseeable future – appear to be necessary. But is acceptance simply shoulder-shrugging resignation or can it be something more positive?

## Acceptance

Lance McCracken has written extensively about the value of helping patients to accept their pain. He defines acceptance as “an active willingness to engage in meaningful activities regardless of pain related sensations, thoughts and feelings, and about not engaging with unnecessary struggles with experiences that often intensify the aversiveness of those experiences and intensify their life disrupting influences”. He stresses however that acceptance does not imply resigning oneself to all experiences of suffering, but does include facing some suffering when the choice to do so is the most effective means of moving in the direction most valued. “It is not simply quitting, but acknowledging reality and quitting efforts that are not working so that workable efforts can be pursued. It does not involve trying to think of pain as a positive experience, or even one that one can manage, but rather being aware of the whole reality of a situation and not just thoughts and feelings. Realising that thoughts and feelings may not serve as the best guides for action enables people to make choices influenced by results, between, for instance, simply avoiding pain or having pain present while doing what one values in life.” Acceptance is of course not incompatible with other pain management and control strategies, including “medical” interventions.

So much for patients accepting their own pain, but what about us? What can we learn from this about our acceptance of their pain? Certainly accepting it may guard us from the desperation to *do something* that may lead us to excessive or inappropriate treatment. If we allow ourselves to become distressed or despondent about their suffering, it will probably not help us to help them and may add to their distress. But we are human and are bound to react in this way sometimes; those of you who have ever been involved in the thankfully rare situation of the nightmare scenario that can arise in palliative care will know what I mean – should we always try to suppress this? Is the alternative detachment? This can be an effective way of protecting ourselves and ensuring that our judgement remains rational and objective, but if the patient perceives us to be detached, may this only add to their perception of having been abandoned? May it make them feel a little better if we frankly admit our frustration and openly share some of their distress? How do we achieve a balance between detachment and overinvolvement? Does acceptance mean giving up? – I’ve accepted his pain and told him he must accept it so that’s all right then? Can we expect patients to accept their pain if we don’t appear to?

I’m not going to attempt to answer these questions at this stage as I want us to struggle with them together.

First however I want to widen the subject a little to the apparent universality of suffering. Clearly pain is an inevitable consequence of the possession of a nervous system, and we discussed yesterday the extent to which this always implies suffering. When we look at the world beyond our shores poverty and hunger would seem to be at least as big sources of suffering as disease, injury and pain. And by our standards the treatment of these is often so woefully inadequate that millions of people would appear to be experiencing unrelenting suffering. But if your experience is that this has always been the case and apparently always will be, and if the possibility that anything could be done about it seems impossibly remote, or doesn't even occur to you, do you accept it? If people who share your culture appear to accept suffering, do you accept it too? If your religion teaches that suffering is the will of God or the inescapable consequence of your karma, does that help you to accept it? And does that make it easier to bear? Can you be happy in the face of poverty hunger and disease if you accept it? We often see pictures of people who certainly appear to be happy in conditions that we would find intolerable. Gordon Waddell pointed out years ago that the virtual epidemic of disability from back pain we have witnessed in affluent countries was simply non-existent in those where there are no unemployment or sickness benefits, and where you either work or starve; but that there is no reason at all to assume that there is any less back pain. Are there different standards of acceptability for us and for them?

Does acceptance of all the suffering in the world let us in the affluent part of it off the hook of our responsibility to do something about it? We may argue that the poverty, hunger and disease bit is the responsibility of governments and NGO's, but what is our responsibility in the pain world? The IASP have taken this on to some extent, mainly in the area of provision of opiates for cancer pain, but also in providing bursaries and other training opportunities for doctors from Third world countries, and opportunities for teaching visits and so on – but are we doing enough? I note that there is no mention of this sort of thing in the programme for the next World Congress in Sydney, though incidentally there is a session on ethics. This has been a bit of a bee in my bonnet and something I would like to cover more fully at a future meeting, and try to get someone with some experience of working in the third world to talk about it.

You may think that the last bit is somewhat removed from my original topic of learning acceptance in the context of the pain clinic, but I think the same potential conflict between philosophical acceptance of suffering and our obligation to do something about it pertains, and perhaps involves the same intellectual and emotional processes by which we learn to reconcile and cope with this and the many other paradoxes which face us every day. I suspect it's something we never completely learn but I would love to hear from those of you who feel they have come to terms with it and what advice they can give to those who are still struggling.

OED: acceptance – willingness to tolerate a difficult or unpleasant situation

- but also: the action of consenting to receive or undertake something offered.

