



THE BRITISH PAIN SOCIETY

Special Interest Group for Philosophy and Ethics

Suffering and Culture

Rydal Hall 28 June – 1 July 2010



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Introduction

There was an unprecedented level of interest in this meeting and a record number of applicants. This might seem to reflect a perception that the subject which is of growing importance in a multicultural society and an interdependent world has been relatively neglected in the pain literature, and rarely featured in conventional meetings; and for some of us, at least, an awareness of the inadequacy of our own cultural competence. Also, perhaps there was the fascination of discovering the importance of culture among the many factors which influence not only the conscious perception and tolerance – and intolerance – of pain, but even the physiological response to it. Others may have been drawn to the meeting by the implications of the subject regarding the acceptability of unrelieved pain in societies with inadequate medical resources, and yet others in the hope of finding something to alleviate their anxieties in dealing with apparently intolerable suffering. Whatever their reasons for attending, every one of the participants came away enriched not only by the insights provided by the speakers but by the opportunity to share their problems and concerns with others whose working lives are dedicated to the relief of suffering.

Peter Wemyss-Gorman, Outgoing Secretary,
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The anthropology of pain: Linking culture and physiology

Simon Dein

“When we talk about pain we talk not just about physiological response but the reaction to pain; its perception and how people deal with that, and that’s highly culturally elaborated.”

I’m a Consultant Psychiatrist but also an honorary palliative care doctor so I do work with pain control at a hospice in Harlow. I have a Doctorate in Social Anthropology. My main areas of research are in religious experience in mental health.

Ethnicity, culture and pain

Let me say first of all that it is only in the last twenty years or so that anthropologists have taken any interest in the area of anthropology and pain. To set the scene, I want to say a little about anthropology which is essentially the study of mankind in its wider social context. The area I have specialised in is medical anthropology which is looking at understanding illness, disease and their treatment in a cultural context. If there is anything universal in anthropology it is pain and today I want to discuss how culture doesn’t just determine the perception and expression of pain, but also has clinical implications because one of the most important findings in the health culture literature is the disparity of pain control within ethnic minority patients. I’ll say right at the beginning that in many cases the literature is extremely flawed to the extent that race, culture and ethnicity are often intermingled and vaguely defined: when we talk about high and low rates of pain control we have looked at ‘Afro- Caribbeans’ and not distinguished between people from Trinidad and Barbados.

Setting the Scene

The area of pain and culture goes back about fifty years to two sociologists, Fabrega and Tuma, who argued that pain is far from a purely physiological phenomenon. When we talk about pain we talk not just about physiological response but the reaction to pain; its perception and how people deal with that, and that’s highly culturally elaborated. Back in the 1950s researchers talked about the idea that how people expressed pain is determined by their attitude towards it. A study in the US looking at Dysmenorrhoea found at that time that very few women saw this as a medical problem. Very few were able to talk about it openly. Attitudes to it have obviously changed since then. The study argued that the very construction of Dysmenorrhoea as a medical syndrome influenced the women not just to discuss it but how they actually experienced the pain in the first place. As anthropologists we argue that cultural factors relate to the whole experience of pain. Generally we differentiate between private and public pain. It’s a truism to say that all pain is a private experience. Cultural factors determine whether that pain is elaborated, whether it is discussed and what people do about it.

Perception

Probably the most pressing topic today in terms of culture and pain is the area of perception. This is fraught with controversy. How do you begin to look at the various

ways in which people perceive pain? Experimentally this is done by inflicting pain in laboratory-based conditions either by applying heat or cold or by Ischaemia. Back in the 1950s it was argued that there is a strong cultural component in the perception of pain and that white people, women and the rich experienced pain a lot more than Africans or Afro-Caribbeans – a very racist idea. How has our thinking changed? A recent study by Williams in 2007 looking at temperature-related pain compared pain thresholds and tolerance in three groups in the US: Hispanics, African-Americans and white non-Hispanics. She found consistent differences in African-Americans compared to the other two groups with both a lower threshold to and tolerance of pain. (We have to differentiate threshold from pain tolerance – these are often mixed up in the literature) This is very clinically significant because we know that in the US the Afro-Caribbean population are generally prescribed much lower dosages of opioid drugs and scales of pain control endorse the fact that their pain is very poorly controlled.

Expression of pain

How does culture determine the ways in which pain is expressed? Pain is expressed verbally and non-verbally. Even from the non-verbal component it seems that some cultural groups are far more stoical in their expression of pain, particularly Japanese and Chinese people. Some years ago when I was a house surgeon [intern] in an Italian hospital being called to casualty [ER] to see a Vietnamese man with a perforated duodenal ulcer who was lying there very stoical among lots of other people who were screaming. It seemed to me that it must be part of his culture not to express that pain either verbally or non-verbally, and there do seem to be differences between South Asians and Westerns in their expression of pain. The language in which pain is expressed of course varies according to the cultural group. In South East Asian cultures, for instance in India, many words used for pain are also used to describe food and plants, with a one-to-one metaphorical relationship between the two, to such an extent that words such as sweet pain, hot pain, burning pain determine its treatment by applying herbs which can cause heat or cold etc. In Britain there have been a couple of studies suggesting that the way people express pain such as headache, depends on their knowledge of medical terminology, and may go along to their GP and say 'I have a migrainous pain in my head'. This is something unknown in non-Western cultures.

I am going to talk a little about expression in cultural groups in relation to emotion. Do some cultural groups somatise? (i.e. express psychological distress through bodily symptoms). Among anthropologists, until about 15 years ago it was assumed that people from non-Western cultures (especially from south Asia) expressed their emotional symptoms through pain or weakness or lethargy. That seemed to be almost a truism. Today I think our ideas have changed. Arthur Kleinman – perhaps the best-known medical anthropologist in the world – looked at people in Taiwan and a cohort of patients who were attending a clinic because of pain and tiredness. He found that they had very high levels of depressive- and anxiety-related disorders. It seems to be the case that it was wrongly argued some ten years ago that some racial groups don't have a lexicon of affect, meaning they are unable to express emotions verbally and have to do so through pain or tiredness. In recent studies in the UK involving interviewing people going to see their GP, if you asked them what they were going about some will say I've got pain in my arm or headache or whatever, but if you ask them how are they feeling many will say I feel so low, upset, I want to cry, I feel hopeless; but although they are actually very able to articulate the emotional symptoms when they go in to their GP they complain about their pain. It seems that somatisation is nothing to do with an inability to verbalise, it's a cultural concept:

doctors are not there to listen to emotional problems. Much of my own work in Southern India, in Kerala, suggested that people are able to articulate emotional distress very well.

Because pain is very easy to 'put on' it seems in Western cultures that there is a culture of mimicry, and syndromes such as Munchausen's Syndrome and Hypochondriasis seem to be much more common in the West.

Explanations of pain

For an anthropologist pain is part of suffering. Pain necessitates an answer – an answer to the question: why me? Something we find is that in non-Western cultures (I'm not idealising non-Western cultures but rather generalising – but perhaps I should be more specific and refer to India where I have worked) pain is seen not just as private body experience but as something interpersonal. In other words, pain results from some breach in social relationships. This has been very well described by anthropologists in the last 60 years or so. Evans Pritchard talked about the Azande, a tribe in the northern Sudan, who when they experienced pain put it down to witchcraft. Pain must indicate some disorder within the social world. The remedy for pain is not just medicine, but to repair that breach in the social fabric. Something we often find in these groups is that traditional healers don't just address the symptoms but the interpersonal causes as well. And this is an issue we will talk about in a minute in the context of religion, because if pain is inherently meaningful it begs for an answer to the question 'Why is this happening to me? And 'What is going to happen ultimately to me?' Pain is inherently biological, emotional and, I would argue, very much spiritual.

Religion and pain

We know that religion provides not just a framework for understanding misfortune but also a framework for dealing with it. In the monotheistic religions Judaism, Islam and Christianity, ultimately pain derides from *The Fall*. To put it very simplistically, if it wasn't for Adam and Eve eating the apple in the Garden of Eden we wouldn't have all of the suffering. The question for these religious groups is, however, what do we do about pain and how do we treat it? Within Judaism, (and I am Jewish) pain is not something to be valued; it may be a punishment from God, but at the end God expects us to do something about it. Similarly in Islam, although pain may be seen as a punishment there are some areas of Islam that maintain that pain can be a learning experience, and although Islam argues for the idea of fatalism, and at the end of the day it is from God, they don't just leave it there. The Prophet teaches that people are expected to seek medical help. The Prophet even said in the Qur'an that every affliction bears its cure apart from one: old age. As a Psychiatrist I do sometimes see people from the Bangladeshi/Bengali community in East London and when they are ill they are very fatalistic about it. Even if they have cancer they may say 'This is what Allah has given me – I have to endure it'. But that's not true: Islam teaches that you have to move on and seek help. And it's difficult to reconcile the idea of having the pain and curing the pain. Christianity is a very generalised term and I am going to focus on Catholicism. Pain has been a very pertinent feature of Christian writing through the centuries since the birth of Christ. The pain and death of Christ on the Cross is obviously seminal to Christianity. There are many strands of belief about pain within Christianity including the idea of pain as atonement, something that needs to be endured, something that illustrates your relationship with God; which brings you closer to Jesus as you share what he experienced on the Cross. But you would be hard pressed to find any Christian group who does not use

medication for pain. Working in a hospice I do occasionally see people, generally not from a Christian background but more likely from a Muslim background who are very reluctant to have pain control. I've actually had it said to me a couple of times: 'God sent the pain and this is something I need to endure'. It can be quite challenging to work with these people and to renegotiate their explanatory model. Self-inflicted pain is common among some Christian groups. About ten years ago I did a study in Calabria in Italy of lady called Matutsa who was a stigmatic. She bled on her hands in the shape of a cross. We went to examine her: the question was were her stigmata self-induced and was she really bleeding? It was difficult; although we never witnessed it directly it did seem from the reports of the people around her that this was indeed self induced. In the Philippines, every Easter Monday there is a ritual crucifixion. People will queue up for a year begging to be crucified. Every Easter Monday, one person is given the 'privilege' of being nailed to a cross. In Malaysia we have *The Kavadi*, a Hindu ceremony where people are suspended by hooks through the skin of their backs and carried publicly around the town. Why do they do this? Why do they go to the extreme of undergoing such pain? They argue that this is what the gods want or that it brings them closer to God: a form of religious appeasement and they gain merit in the after world for doing it. One interesting phenomenon we don't completely understand, and an important area for research is that some of these people claim to be fairly immune to pain. When we look at, for instance, Fakirs walking over hot coals or Christians who have been flagellated, they claim at the time not to have experienced pain. This is similar to Beecher's observation that soldiers wounded on the front line often don't experience pain until the battle is finished.

So it does seem that your cognitive set and your expectations play a large part in determining how you experience pain. Rights of passage are very common in the world's religions. African boys in Tanzania undergo sub-incision of the penis; circumcision in Jewish or Muslim boys can be a very painful event but you still go through that in order to form a blood relationship with God. So it seems that cultures use pain for their benefit.

Pain control

I want now to move away from anthropology to current thinking about pain control and what we can learn. The figures suggest that in America the poor, the uninsured and those from a minority background – Afro-Caribbean and Hispanic – experience much poorer pain control. This is not just for cancer; people attending the emergency rooms in state hospitals in New York with fractures have a far lower level of opiate prescribing if you are black than if you're white. The interesting question is why? There are many theories but no immediate answers. First of all, is it something to do with the expression of pain? Is it people from a particular culture who are there? There is a perception that people from some cultures don't actually need the same pain control. We know that this is partly true and that there are differences in the perception of pain. But given that, these differences are very small. For instance, if you are comparing Chinese and White Americans in the post-operative situation and the use of patient controlled anaesthesia (PCA) where patients are left to treat their own pain you find equal levels of demand. There is a lot of fear of opiates. Some cultural groups, for instance African Americans, dislike opiates intensely. Also many white British people when interviewed say that opiates are only a last resort. My own patients in a London hospice, when we talk about prescribing morphine, will ask, 'Am I that bad? Is it terminal?' We also know that genetically there are some people, notably Chinese lacking the enzyme to metabolise codeine so that it will be ineffective.

Moving away from the perceptions of patients to those of doctors and nurses there is also the idea that some groups are more likely to become addicted. If we ask why they give lower dosages of opiates to certain ethnic or cultural groups they will say they are addicts – they only want the drugs because they are addicted. There is also the perception that if people really want pain control they will ask for it. But there is also the idea of being a good patient: you don't ask your doctor. In some cultures it goes beyond that: you don't tell your doctor what's wrong with you – you let the doctor ask you; but what may happen is that the doctor may not ask if there is anything wrong with you. So people have become far more sophisticated and provide the Magill Pain Questionnaire, so now you are able to tick a box, but does it really help with cultural differences in pain control? The answer is probably not. One of the problems which all of these questionnaires share is the idea of cultural validation.

Some groups are very naïve about filling in boxes, especially a Lickert Scale. When you ask North American Indians (natives) to rate their pain on a scale of one to ten you find they often use the number six – not because it reflects their pain but because it is a sacred number! In any case you can't assume that the word 'pain' is culture free. If you've just knocked your head against this wall and I ask you what does it feel like you may answer: I've got a bad headache or a bad pain. It seems that the word ache is of lesser degree than pain. When some cultural groups use the word headache rather than head pain some doctors and nurses may regard this as a lesser degree of severity and not want to prescribe any more medication. This is all compounded by the fact that medical services for the poor and uninsured in the USA are less structured and less readily available. We know that for some diseases like cancer, treatments for African American women with breast cancer are considerably lacking. We know that black women in the USA are more likely to have radical treatment like mastectomy instead of lumpectomy, are less likely to have radical chemotherapy and receive less sophisticated and inadequate pain control. Similarly for MI's the rate of investigations for black Americans is far lower than of whites. Political and social factors really play a big part.

Conclusion: Where do we go from here?

So there are many explanations for poorer pain control among ethnic minority groups. What is the future? I would argue that we can learn a lot from the anthropology of pain. It is imperative for doctors and nurses to have an understanding of culture – not some standardised version: black people do this, Jews do that. When you are working with a cultural group you need to experience and learn from that group themselves: how they see and how they experience their pain. There is a need for more formalised cultural assessment of pain. But more so, as an anthropologist I would argue that there is a need to understand, negotiate and incorporate indigenous treatments for pain. As I said right at the beginning pain is not just a biological symptom but is emotional and spiritual. There is a need to learn from and integrate not only traditional healers but also clergy and religious professionals into pain care.

Discussion

It's fascinating to me that a lot of the work looking at pathways of pain in the central nerve system (CNS) is tending to mirror what you have been describing. For example, some pathways are inhibitory so when the priority is to survive, pain is ignored and I can see how [cultural influences could work in the same way. There seems to be this balance in the CNS which varies according to circumstances.

For instance, the work of Irene Tracy's group showed changes in responses to painful stimuli in Catholics looking at a picture of Mary. [First presented at the 2008 meeting of this Specialist Interest Group]

We are beginning to understand that culture is not something disembodied. Culture can influence physiology, which is not surprising as most of the work on religion and health suggests that if religion works in terms of anything protective – it might not be protective – but if it does, it works through modulating neurological and immunological pathways. So I think that it's imperative that more money be devoted to research in this area.

We have been talking about vertical influences of culture between generations but – I'm interested in paediatric pain. There seems to be a mini-epidemic of adolescent pain at the moment ... Is this a horizontal thing involving acceptance within that group?

I think one of the big problems in this area is talking about culture which is by no means homogenous. There's no such thing as Asian culture, Jewish culture, whatever: we're all globalised and all subject to other influences. But there is good evidence that how you're brought up and how your parents experienced pain is how you experience pain. Children brought up to be overprotected way whenever they have any pain tend to be a lot more – a lot more expressive about it – as adults. So there are close links. Whether there are cultural idioms in expressing pain, or somatisation, which are passed down generations vertically is a fascinating question. It's certainly possible that there are horizontal influences within a group as well as parental ones.

As parents nowadays we are very quick to give our children Calpol when they have any pain and I worry that they are growing up believing that this sort of thing is the only appropriate response to pain.

You're very right because we're living in an increasingly medicalised society, with the feeling that no symptoms should be tolerated with advances in technology so I think you're spot on about that.

I studied children in Jerusalem in the emergency situation. There were two groups: the children in Hasidic families and those from secular families. The former hardly made a sound, and the secular group made a big and fuss. The Hasidic children all came with their fathers (because the mothers were working while the fathers were studying).

[Mostly inaudible question regarding rituals involving suspension from hooks through the skin and the non-experience of pain]

I think they don't experience pain: when you interview them afterwards many of them had been unaware of pain or indeed what went on

The same thing happens in masochistic rituals. There is probably an endorphin rush and it's a physiological phenomenon.

As a psychiatrist I have observed that people who asphyxiate themselves sexually that probably don't feel discomfort when they are in that state of excitement. These people don't hang around for long!

In the Catholic Church there is this idea that suffering is good for you, but on the other hand you have the compassion of the nuns who treat patients – there is a duality here.

It's a fascinating observation – not specifically Catholic – that compassion plays a big part but religion doesn't always facilitate coping with pain. Many of the religious people I see in the hospice are very angry with God – it works both ways.

Pain behaviour in the Armed Forces

Philip Harper

“I wanted to see what sort of guidelines were followed, both implicit and explicit, and how people in the military culture learned to view the world and behave in it... They learn by listening to people from the culture and by observing how to behave and what sort of behaviour is acceptable. They also learn when you can express pain and how much.”

I want to talk very briefly about one particular group: the British armed forces, about how they express pain and some of the reasons and explanations they give relating to that.

I am a nurse by background and spent the majority of my career as a Nursing Officer in the Royal Air Force (RAF), leaving in 2007 after 22 years. I had many different roles within the RAF, but was mainly involved with aero-medical evacuation bringing injured service people back to the UK. When we have been in conflict zones we have also treated some of the locals – perhaps that the subject of another talk could be the difference in the way they express pain from our people.

I've been interested in culture and pain for a long time and that led me to do my Master's in Medical Anthropology which I found really fascinating, looking in general at cultures and how they react to health and illness and particularly pain. I went on to do my Doctorate on military culture and pain, and how military nurses assess pain.

Military culture and pain

It became very apparent to me in my early days in the military that culture did have an effect on how people express their pain. In my first job in the RAF I worked on the male orthopaedic ward. A lot of our patients were young recruits who had sustained ankle, knee or leg injury doing their basic training. Being a very careful considerate nurse I would walk round the wards at the start of the shift and say to people “How are you?” Invariably they would lie at attention and say “I'm absolutely fine, Sir” and that was it! I was not convinced that that was always the case, and almost invariably later on another member of staff would come up and say “Private Bloggs is complaining of pain – can he have something?” and I wondered why he hadn't said something to me. And that got me thinking about military culture and why they don't express pain.

I started by looking at the literature on military to see what's actually out there. In the military they have this ‘no pain, no gain’ philosophy. And that's really important: we need you to experience this pain because we want to push you to your limits and beyond so we know you can cope with any circumstances that you might come across. If it's not hurting it's not working and you've got to work harder until it does. I had to undergo basic military training so I was subject to that as well. (And you do get to hate the instructors!) I found that it is also deemed very important that you demonstrate your masculinity by this no pain no gain philosophy. The literature goes back to back to World War Two and Beecher. It is very masculine-oriented and reveals a culture of not expressing your pain, which would be a sign of weakness. If you have pain you're going to keep very quiet about it and not show any emotion, which would not be acceptable.

I wanted to see if the literature of the 1940s and 1950s was still pertinent to today, so I did an ethnographic study looking at people in the British armed forces and their culture (defined as attitudes and behaviours that make them stand out from everybody else.) I wanted to see what sort of guidelines were followed, both implicit and explicit, and how people in the military culture learned to view the world and behave in it. They go through their initial basic training and told how they will behave, how they will dress, when they can eat, when they can sleep, when they can go to the loo. They learn by listening to people from the culture and by observing how to behave and what sort of behaviour is acceptable. They also learn when you can express pain and how much. This is all reinforced throughout their careers.

The study

So, I decided to go and observe a group of people undergoing a training course. This was a week long. It started at about 5.00 am one morning and went on until about 1 or two o'clock the next day with only two or three hours sleep and involved 'confidence' courses, all sorts of physical activities, leadership exercises, public speaking – all sorts of things. I picked one team (or 'Flight' in the RAF) of eight people which consisted of six males and two females. My intention was to become a participant observer. I asked the instructors not to tell them I was in the military because I was the only officer on the course and if they knew that it would change their behaviour – I was identified just as an observer. I went along dressed in shorts and T-shirt and introduced myself as Phil, and the first question they asked was "Do we call you sir?" I said "Why would you want to call me sir?" They replied "You're an officer aren't you?" "How on earth did you know that?" I asked and they replied "Because you look like one and behave like one!" So I was obviously fully indoctrinated into the military culture even at that stage! I intended to be a fully participant observer on the course and part of that in ethnology is that you want to be immersed and be a real member. I was already a member of the Armed Forces and had some of the cultural background and they recognised that. But after two days with only six hours' sleep in 48 hours, I was too tired to be giving interviews and making notes as well as all these activities and needed a bit of time out. I did some interviews because it was really important to get their perspective. How did they describe the experiences they were going through?

Overall I think the way the people on the course expressed their thoughts or behaved was no different from what you might expect. They used both verbal and non-verbal behaviours to express pain. Interestingly though they did distinguish between physical and psychological (or what they termed mental) pain and described those as different aspects, and didn't seem to want to discuss them together.

In describing physical pain, they referred to aches, things a bit niggly or a bit tender or a bit sore, but they never talked about pain. They seemed to want to diminish the severity of the pain. What they did describe was tiredness: "I'm shattered" (or stronger language), generally due to lack of food or lack of sleep. (They were fed but probably not enough for the amount of work they were doing.) Tiredness seemed to be a more acceptable reason for their pain. Non-verbal expression of pain included grimacing, and lack of smiling: there was one occasion when the team were carrying big long pine poles; they were supposed to rotate but because the girls were having difficulty there was one guy who didn't have his turn to rest and was walking around with a fixed grin on his face although he must have been in agony. Quite often after these exercises they were very quiet, some would lie down, some would walk around... but not once did I hear any of them complain of pain. They just carried on because that was what was expected.

Psychological pain was always associated with the psychological tests they had to do, including public speaking exercises and tests such as 'what would you do in such and such a situation'. Most of them would come out saying it was very stressful, very hard work, no time to prepare for it; and showing no-verbal expressions of unhappiness. The course wasn't pass or fail, it was intended to be 'formative', to give them an idea that if they wanted to become an officer this was the sort of selection process they might have to go through, but nevertheless they took it very seriously.

They dealt with the pain by distraction. They were busy all the time; they might wake up in the morning saying they were rather stiff but would concentrate on what they were doing that day. They also used other explanations to help themselves deal with the pain. This course was held in June and it was really hot and the terrain was very hilly with lots of running up and down steep hills but this was OK as long as they could blame the weather and things outside their control – these were legitimate things to complain about.

My observations and conclusions

So overall what did I find? The pain behaviours that I saw were really consistent with the military culture beliefs that I'd read about. It was very obvious that the no pain, no gain philosophy was still there. They acknowledged that they had to work hard and push themselves beyond their limits because that was what was expected. They believed that any individual pain should be hidden because they were working as a team, so they put on this roughie-toughie image: I don't want to let my team down because the team is more important than the individual – another aspect of military philosophy. They underestimated both physical and psychological pain, and there is still a stigma attached to the latter as being unacceptable. (As in the First World War when people with psychological pain were shot for cowardice.) Physical and mental pain are still regarded as lack of moral fibre, but attitudes are changing: because of all the conflicts we have been involved in and the consequent number of people with physical and psychological pain, this is becoming more acceptable. However it is still thought that if you put people through these stresses and inflict this pain in training they will be able to cope when they go into a conflict zone.

Discipline is still regarded as very important in the military. It may not be as harsh as it used to be, but there was still the threat and fear of it if they didn't continue despite pain they would be disciplined which might mean going round again or carrying extra loads. There was also the fear that the whole flight would be punished for one person's failure. Discipline was used so that people would become accustomed to being in the military.

We need to have some cautions. It is very easy to stereotype cultural groups. I just looked at a small number within the RAF which is only one branch of the armed forces. There are differences between the three although they have the same overriding aim. Within my group alone there were people from different parts of the country with different life experiences and ages and upbringing, and there are lots of things that influence people's pain behaviours. It also depends on what role people are playing: if you are a front line soldier – a marine or in the SAS – you were more expected to have the roughie-toughie image than if you were a nurse, for example.

I'm not sure whether the behaviours on the training course would necessarily be replicated on the front line. Context is really important. If I was walking down the High Street on a Saturday and fell over, my immediate reaction would be to get up and

walk away feeling embarrassed. But if it happened on the football field I would probably roll around in agony, because there it is expected and accepted. But you can imagine what it would look like if I rolled around in agony in the High Street!

Cultures aren't static: they continually change. Discipline isn't as harsh as it used to be and people coming in aren't expected to be treated as they were even when I joined 20-odd years ago. Now people on training courses are given cards and if things are getting too much they can hold up the cards they can have five or ten minutes out. (How that works on the front line in Afghanistan I have no idea!) Complaining of pain is becoming more acceptable. There is a big change in medical personnel: the military don't have their own hospitals any more anywhere in the UK and the military culture is becoming diluted.

In sum, I saw pain behaviours in the military which were in line with what I expected and although we must avoid stereotyping we have to acknowledge that to a certain degree culture does have an impact on the way people express their pain.

Discussion

Beecher made his observations in the battle situation ... clearly your recruits aren't in this and are having to cope without fight and flight reactions and the pain reduction from being flooded with endorphins etc.

In a [TV] report regarding troops injured in the front line in Afghanistan the interviewer asked "What about pain with you guys? It must have been terrible sometimes and one chap answered, "We don't do pain Sah!"

I am fascinated by the difference between psychological and physical pain and work by Irene Tracy demonstrating involvement of the same brain area in both. Were your subjects really separating the two or expressing physical pain as mental pain?

I think that happens to a certain degree: I was interviewing them at various times of the day and asking "How are you feeling? How did that go?" And after the psychological tests they were separating those. They didn't always want to talk about that and I wondered if there still the perception that psychological distress isn't acceptable and a sign of weakness. But after physical activity they didn't say "I'm really stressed about that". It was "I'm really tired." I sometimes wondered if tired was the term they used to cover everything. A couple of them tried to clearly distinguish physical tiredness from frustration about the way they'd behaved – but you can't always make the distinction.

You may be familiar with the paper that was written after one of the wars in Lebanon where people who had fought in this subsequently had an Appendectomy and didn't request any analgesia.

Obviously the culture of not expressing and repressing pain in the military context is useful... But the question would be does it still serve a purpose later on or is it harmful in terms of the physical and psychological recovery after injury – is that helped or hindered by this attitude?

We find it very difficult to get them to talk about their experiences... when they come for surgical refashioning of their stumps it's very apparent...sometimes they won't

progress because of this...people with a military background are very resistant to change.

It's instilled in their training that if you've got pain you keep quiet, because that might affect the morale of the whole group.

I see lots of men with clearly severe pain from arthritis who are behaving exactly as you describe the military, so I think it extends further into our culture as men, particularly of more mature years. For some this may be a hangover from previous military experience but I think it's widespread.

You're right. I have a twin sister and when we were young we were treated quite differently if we fell over – I was expected to get on with it and she got lots of attention. There is still the stereotype of the stoical British male. But I think attitudes are changing.

I just wanted to reinforce that: I see patients in Canada who work in paramilitary organisations including police officers, both men and women. Like one with totally intractable back pain – OK maybe it's a bit organic, but he spent 15 years as an undercover drug agent about which he will not talk, or see a psychiatrist. I missed that for a long time until I realised what was going on. A lot of shopping centres now have guards. That seemed to me to be a fairly benign situation until I had one as a patient who had previously been in the army. It was clearly very stressful but he wouldn't talk about it.

In the military you sign the Official Secrets Act. You are taught not to discuss things. Even when you leave you are still subject to that and it's very difficult if after 20 years you are told it's part of your treatment.

Were your group voluntary and self-selected? Everybody is a volunteer in the armed forces!

I am part of a generation who grew up modelling themselves on 'not being able to get out of bed in the mornings' role models ... How long does it take recruits to change?

Exactly eight weeks – that's the length of the basic training – and if they don't conform they're out. It's a game: you have to learn the rules and play along with them. They have actually toned down the basic training, but there is still an expectation that at the end of it you will be changed and be a member of the armed forces.

Is pain behaviour in the basic training radically different from what you have been describing? Yes.

So does that exclude people who can't modify their pain behaviour?

I haven't seen any studies but from my experience the context is different – if you fail basic training you're out but my group couldn't fail, although they would get feedback. People who want to join the military are self-selected and are subjected to a selection process, and are motivated to change. (There were a couple of doctors in my basic training group who had been consultants who couldn't bring themselves to accept any sort of authority!)

The experience and expression of pain: Does ethnicity and culture make a difference?

Jonathan Koffman

“The challenge is to integrate biomedical and cultural approaches to pain rather than allowing the dominance that the former has historically enjoyed to continue.”

My issue with this is that many of these variables are used interchangeably and ignore things like education and wealth, and when you start examining the scientific medical literature you often find race and ethnicity used in the same sentence and poorly defined.

Race and ethnicity

This makes my job as a sociologist very problematic. I am indebted to people like Stephen J. Gould and Kenan Malik, who have really helped me to understand what some of these concepts actually mean. I also want to plug Simon [Dein]'s book *Culture and Cancer Care* which sheds much light on some of them. But race has a long and inglorious history and goes back to Darwinism and Blumenbach who discovered some exquisite skulls in Africa and pronounced that those of Caucasians (a term which litters the American literature) were associated with “a loftier mentality and a more generous spirit” compared with the African skulls which showed “a greater proximity to primates”. Keep that in mind because some of these historical concepts, poor as they might be, still litter the literature to this day.

Ethnicity is a more common concept used as a metric in epidemiological research, and we enter it every ten years in the Census. It's derived from the Greek word meaning people or tribe and I like the definition from Bhopal and Senior in the *British Medical Journal* (BMJ) that associates it with “shared origins or social backgrounds; shared culture and traditions that are distinctive, maintained between generations, and lead to a sense of identity and group: and a common language or religious tradition.”

The problem with ethnicity historically is that it tended to group people into arbitrary sections so if you are Asian the term categorises you and fails to focus on the subtle differences between different groups within the Indian subcontinent. It has been more refined, but people tend to change their identity from one census to the next which makes my life as a clinical epidemiologist difficult as I am constantly trying to work out how people stand in relation to health related experiences.

Culture

I love this definition by Donovan “Culture is a recipe for living in the world.” We don't just have one recipe but many which are constantly reformed and dynamic. My recipe for life includes my love for Marmite, tea and Indian food. My antecedents come from Russia at the end of the Nineteenth Century and gravitated to Brook Lane and moved out towards North London as they accumulated more wealth. And this defines me on an everyday level.

Pain and ethnicity

The world is getting more complicated and interesting with increasing cultural diversity and your mandate as health professionals is to care for people whose ethnic and cultural identity aren't the same as your own. This creates very interesting challenges, and during the rest of my talk I want to examine these complicated relationships. I will focus on the mismeasure of treatment between different groups in relation to analgesia; on the very interesting debates in relation to biology in the way that pain is processed and how to make sense of that material; on cultural responses and how we attribute meaning to pain depending on our recipe for living in the world; very importantly on communication which bears strongly on your day to day work; and lastly on culture and its influence on who gets and who doesn't get care in the health services in relation to the overwhelming experience of pain. I will principally draw on my experience of cancer-related pain as my roots are mainly in palliative care, although my history is in transcultural psychiatry.

Acute pain in the Accident and Emergency department (A&E)

First a quote from an Afro-Caribbean patient with sickle cell disease: "In XXX hospital, the worst part was going to the A & E. The nurses and doctors didn't understand. They did all the questioning: they wanted to know why the medication wasn't working – why are you still in pain – why are you crying – if you're not crying you can't be in pain..."

Emergency medicine by virtue of its mission is there to provide universal and timely health care to those that need it. But if you examine the literature, particularly from the USA, there are gross disparities in who gets what in the critical moments. Todd found a persistent mismeasure of delivery of opioid analgesia for long bone fractures to African Americans and Hispanics, who are less likely to receive analgesia than non-Hispanic white counterparts. This is a trend which continues over time and it is difficult to understand why it is happening. Pletcher found an upward trend over the years 1993 to 2005 in opiate prescribing in emergency departments but this was consistently lower, compared to their white peers, for African American or non-white Hispanics. Why does this happen?

Cancer

The prevalence of pain in cancer rises to 98 per cent in the more advanced stages and is a symptom which is utterly corrosive. In many instances it is well managed but in some cases it is quite refractory to treatment and devastates individuals. It is a symptom which eclipses all other experiences at the end of life and has been described (by Albert Schweitzer) as a worse enemy than death itself.

While there has been enormous progress in management of pain in advanced cancer the delivery of care is often problematic. Work by Cleeland and others in the 1990s showed that more than 60 per cent of 1300 patients in the more advanced stages of the disease were suffering distressing pain and about 40 per cent of those weren't being managed, within the therapeutic window of the World Health Organisation (WHO) analgesic ladder, sufficiently to make much impact on their pain. When Todd and Cleeland started examining the relationship of ethnicity and delivery of analgesia they found marked disparities. Hispanic and African American patients were 3 times more likely to be under-medicated than white patients, and 72 per cent of Hispanic and 59 per cent of African American patients received inadequate relief, and

Anderson's findings were similar. Race is a key factor in how you make sense of end of life experiences.

In 1998, Bernabei et al studied about 13,600 people over the age of 65 in nursing homes in the US. They reviewed all their clinical records to identify individuals who were experiencing pain and throw light on the analgesia that had been prescribed to manage that distress. They found that 30 per cent of patients over 85 were not getting any analgesia at all for pain from cancer or other morbidities, and only 10 per cent were prescribed opioids (compared with 40 per cent of 65 year-olds) This is shocking stuff – this the standard of care on a day to day basis in residential and nursing homes in the USA. There is another mismeasure of care related to the colour of your skin and 63 per cent of African Americans were being given no analgesia at all.

Pain perception and ethnicity

This enters the complex territory of the pathophysiology of pain perception, and how it affects the ways in which different racial groups *experience* pain in relation to pain thresholds. Early studies by Chapman and Jones reported lower pain thresholds in African Americans and non-white Hispanics compared with their non-white peers. In other studies the reverse was found, but recent more complex studies which incorporated some very elegant measures haven't identified marked differences in pain ratings across different groups. So I think we need more work to identify why certain ethnic or racial groups are getting no or sub-therapeutic medication. This may involve some of the issues around polymorphism, pharmacogenetics and pharmacogenomics (the study of the effect of variations in the human genome on the response to medications). The jury is still out.

Pain isn't of course a matter solely of anatomy and physiology, and as Morris argues, the biomedical view often neglects the very important insights into pain that can be gained through an appreciation of art, literature and culture. The challenge is to integrate biomedical and cultural approaches to pain rather than allowing the dominance that the former has historically enjoyed to continue. I love this quote from Morris: "Pain is a bio-psychosocial phenomenon that emerges at the 'intersection of bodies, minds and culture.'" As Illich notes, in traditional cultures "...Pain was recognised as an inevitable part of the subjective reality of one's own body" – and was made tolerable by integrating it into a meaningful setting.

Pain therefore emerges at 'the intersection of bodies, minds and cultures'. Just think about the different ways in which dictionaries have understood this very common word: the Oxford Reference Dictionary defines it as 'an unpleasant feeling caused by an injury to the body' but it also refers to mental suffering, and divine punishment.

Simon [Dein] alluded earlier to the classic study by Zborowski and Zola of the different ways ethnic groups expressed their pain: they found that in some cultures, such as Italian and Jewish, people expressed and expected more extravagant displays compared with the more stoical Irish Americans. Zborowski believed that as time went on the cultural mix in New York would mean that we would start conforming to type; the extremes would become narrower so that the more vocal and extreme views would start to morph into the mainstream. In these very early studies we begin to appreciate that culture fills the space between the embodiment of disease as a physiological process and the meaning of those experiences of pain as a human phenomenon.

Culture is very dynamic and constantly shifting in terms of way that pain is experienced and expressed by a group: we're taught about pain and ways of expressing it but this is not set in stone and the way we regard pain might be very different from the way that our children might view it in a generation or two's time.

The experience and expression of cancer-related pain

Work which my colleagues and I did in South East London tried to throw light on the ways in which different cultural groups made sense of pain experienced in cancer. These were patients on the cusp of life and death. In our first study, several years ago, we interviewed close relatives and friends of people from the Caribbean and white British community who had died six to nine months previously, to explore their accounts of the presence of cancer-related symptoms and the associated distress.

The frequency of pain was remarkably similar between these two ethnic groups, but the distress associated with this was much greater in the Afro-Caribbean community. After regression analysis in relation to whether these patients were getting medication or not, whether they were receiving primary care, and the nature of the relationship with the person providing the account – sibling, parent, daughter – we found that there was no difference in these factors, and the main variable that was associated with the discrepancies was ethnicity. But it wasn't within the scope of the survey to discover what was taking place here. There was no suggestion that the carers were dissatisfied with the primary care or hospital doctors and their treatment of the symptom, so there must be some difference between the ways in which pain is expressed between these two groups. This frustrated me because the data didn't reveal what I wanted. So I went back a couple of years later to try using qualitative accounts from patients living with and dying from advanced cancer.

The aim of our study was to explore the meanings that patients in both ethnic groups attributed to their symptom experience, to help us to understand how these are culturally patterned and shaped. The interviews were informal in style and began with a general discussion about what participants felt about cancer and its causation and then progressed to explore symptoms that bothered or troubled them as their illness progressed. I interviewed 26 Caribbean and ten white British patients on the cusp of life and death. It was a wonderful experience and I felt privileged to interview people who were within days of dying. Many of these people were experiencing pain, particularly those with cancer of the breast. Almost universally the words they used to describe pain were awful, bubbling, burning, dull, excruciating, mingling, nagging, nuisance, pulling, terrible, troubling and stabbing. 24 of these patients provided me with very interesting accounts that helped me to understand how they related or found meaning in their cancer-related pain and what they were going through. Pain was seen as a challenge, an enemy, and as a test of faith and a punishment. These last two were specific to the Caribbean community.

I want to throw some light on some of these meanings in more detail. One view of pain represented a task or a hurdle that needed to be overcome by any means possible. Once such case was Bill, a wonderful old chap who in his very chequered career, had been involved in high risk, demanding occupations including boxing and scaffolding. Bill trivialised the impact of his pain and exhibited the kind of stoical bravado that reflected his upbringing in South East London. "I'll take it as it is. There's no chips on the shoulder, no worries about it. Neither does my family. We'll just carry on...My outlook is much stronger probably than a normal person. And I mean that...The only two things ever I done was fight and hang about with one arm two hundred feet up in the air most of my life. The discipline of the whole thing I've

been through. Obviously I'm not dancing up and down, but I'm...er...I'm not frightened. I'm not I...er...I'm not frightened of it or nothing. I'll take it as it is."

Essentially this was the way that he made sense of his suffering. His attitude may reflect a personal style similar to the 'bracketing off' and 'normalising' the effect of his disease and pain in particular that Mike Bury refers to in his theory of biographical disruption.

The next meaning, viewing pain as an enemy, was illustrated by the way some white and Caribbean patients saw their cancer pain. They might describe their pain as an unfair attack by a hostile force, using metaphors that you are often very familiar with in contemporary literature. People talked about fighting off or defending themselves against their pain... So for instance Jeanie, an elderly white Englishwoman with pancreatic cancer: "I used to fight the pain as much as possible...it's hardened me I think, and that's why I can (now) fight pain off."

Others were more ready to capitulate. In contrast Martin, a white British man with prostate cancer, was unable to understand his enemy in those sorts of terms. He felt helpless and very much wanted to repress his ongoing campaign against pain: "It's like the War. It's horrible and you want to forget it. But you can't". While still viewing pain as an enemy, several white patients wanted to depart from the more common metaphor of pain in the battlefield. For example a young white woman called Betty with adenocarcinoma and a vesico-vaginal fistula, who will haunt me for ever, perceived her pain as a wicked or demonic entity. She said "I look at it as if there's a devil in me ... some days I feel as if I want to cut out my own stomach and take the pain out".

Pain often represented a test of faith, particularly in Afro-Caribbean patients, and they often made use of biblical or archaic narratives to make sense of their symptoms and how they found meaning in them, and how they were able to comprehend the inexplicable. This was associated with strengthening or confirming their religious beliefs. It often involved mobilising their belief in God in the face of the unknown. For instance Matilda, a Black Caribbean woman with breast cancer said: "In some way I think he's testing me...To see how strong I am, how strong my faith is, how much I believe in him. I don't know if you ever read in the Bible about Job ... And even his wife turn around and said, "You silly man," or whatever, "Stupid man. Curse God and all that." And he's saying to her, he's so, so determined, "No, woman, you can't be like that. You can't curse God and all that," And he kept his faith. ... I'll keep hanging on, and I'm hanging on till the last minute".

So by capitalising on her unquestioning faith she had been able to overcome pain. Job, in the Old Testament, convinced of his own innocence, maintains that his suffering can't be accounted for by anything he's done. He can't find any reason for God to be testing him. He curses the day of he was born. Ultimately, however, his faith returns and he emerges whole. Matilda is travelling through the same kind of narrative but she finds it helps her to overcome the distress associated with her pain. Matilda died several days after I interviewed her.

One meaning that only Black Caribbean folks talked about was pain as a punishment. This metaphor was either focused on mankind in general, or specifically at the level of the individual. So for example Franklyn, a Black Caribbean man with prostate cancer: "I'm making lots of mistakes and want to improve."

[JK:] "How do you think this affects your cancer and the problems you have?"

[Franklyn:] "Sin is a little word name's 'i' 'n'. I know what it comes from: disobedience". He believed that we had all sinned and taken God for granted. So he

considered his cancer pain as justified so he could accommodate it more readily. This view is in stark contrast to Charmaz's study of the chronically ill that included patients with heart disease, cancer and multiple sclerosis. She noted: 'The language of suffering which severely debilitated people spoke was a language of loss. They seldom talked of gaining a heightened consciousness of the world, revelations about self or insight into human nature from their experiences.' But Franklyn doesn't conform to this. He finds meaning and strength in pain.

As symptoms arise they are perceived and evaluated by patients against a complex repertoire of previous personal experiences, experiences of others known to patients, and the group or culture they inhabit, to make sense of the way the symptoms should be regarded. So this major insult, this cancer, is interpreted by the patient with a number of important mediators or moderators which help them to accommodate (or fail to accommodate) their symptoms so that they can live alongside them. Within the context of this study the dynamic between the cancer patients and their social interactions with society demonstrated that the meanings they attributed to cancer-related pain and their reactions to it were seen to influence one another.

Communication

At its core pain represents a subjective experience, and assessment of it therefore relies heavily on impeccable assessment and communication between health care professionals and patients. But studies have consistently shown that there is a miscommunication between physicians and nurses and the patient sitting in front of them. Often this is related to misperception of how different ethnic and cultural groups accommodate their pain, and regard opioids and other forms of analgesia within the framework of how they want to be treated. Certainly, from some of the evidence I have shown you, some symptoms may be reported, especially by African American and Hispanic patients, with such a degree of stoic acceptance and accommodation that might give professionals the false impression that pain control might not be warranted. There is also a disjunction between what physicians and nurses and patients perceive in relation to severity. When pain severity is low, patients and health care professionals report good agreement in rating this symptom. However, when patients rate higher levels of pain there is evidence that health care professionals don't concur with their assessments. It seems that in this situation there may be an element of stereotyping and prejudice towards minority groups.

Health care system factors

The mis-measure of care also influences the supply of analgesics in geographical areas where larger numbers of minority ethnic communities live. Sean Morrison's work in New York has identified that opioids were frequently not available in areas populated by BME (Black and ethnic minority) communities. This is largely due to the reality that pharmacies in such areas are frequently raided so they tend not to stock those drugs. There is also evidence of an inverse care law being present in relation to specialist palliative care for BME groups. Research in the USA and the UK has shown that those with the greatest clinical needs in ethnic minorities are sometimes the least likely to access care to manage distressing symptoms like pain when it's needed most.

Implications for clinical and psychosocial care

I have attempted in this presentation to examine the multiple factors that contribute to the difference in the manner which pain (particularly cancer related) pain is both

managed and experienced by people from different ethnic groups. What the studies do is to make a cogent case that this is an important area of future research to improve the experience of pain which we cannot afford to neglect any more, particularly as society becomes more diverse. They also identify that the scientific discourse, which has largely dominated the study of pain and ethnicity, represents only one lens among others that we can use to inspect the broader canvas upon which the nature and reality of pain can be painted, and on which the day to day interpretation and management of pain can be based. I have also emphasized that health professionals bring their own cultural attitudes to the patient professional interface, and often it's a culture which collides with the patient's interface and their own experience.

We use the adage that "Pain is whatever the patient says it is" and yet in the interaction between patients and health professionals the latter's knowledge, attitudes and biomedical culture often dominate their response to the patient's pain. This is particularly true for patients whose responses to pain may seem inappropriate and even anti-therapeutic from what is considered typical or usual.

In early 1960s, Dame Cicely Saunders proposed the concept of 'total pain' which incorporated physical, psychological, social, emotional, and spiritual elements. This view of pain required multiple interventions not just from the doctor but the nurse, physio, chaplain, and social worker. Critically, total pain was tied to a sense of narrative and biography, emphasizing the importance of listening to the patient's story with an authentic curiosity to understand not only the experience of their distress but the meaning that they bring to the clinical encounter as well.

I have tried in this presentation to suggest that the current and commonly used biomedical model of conceptualizing and assessing pain does not sufficiently encompass the patient's dimension of this symptom, particularly among different cultural groups.

Discussion

A colleague of mine was working in Uganda using a very elegant measure to assess end of life experiences of people dying with HIV/AIDS. She asked a patient to score his pain, instead of reading a scale on paper, to use his fingers - no fingers suggested no pain and all fingers suggested severe and overwhelming pain. He replied that he had pain but didn't have any pain in his hand!

Prescribing post-Shipman is a problem we all face. He did an awful disservice to palliative and to primary care. Many GPs were confidently and competently prescribing opioids. But we now live with the reality that any doctor will be held accountable for any death that occurs in this context. The other issue you have alluded to is social exclusion at the end of life: who makes it through the doors of hospices which have grown in numbers since St. Christopher's was opened in the 1980s to well over 400 now. The number of beds is in the thousands but it's only about 25 per cent of people who get into a hospice in their advanced disease and die there. Most of us will die in hospital settings. My colleague Barbara Gomez has done some predictions of where we will be dying in 20 or 30 years' time and it won't be in settings of our choice viz. home or hospice. I have no simple answer to that. Hospices are funded largely through the voluntary sector and I don't think we do death and dying particularly well in this country. Hospices have been lambasted for supplying an exclusive service to a social elite: it helps to be white British, middle class, to have malignant disease and the right kind of this (not haematological).

Regarding people who regard pain as a punishment to be endured. Is there any evidence that if they require analgesia they start developing guilt because they are no longer able to self manage their pain?

I would regard the situation as a contract between the patient and the doctor who is assessing their pain and delivers a treatment. So you're in pain, it causes you distress...it doesn't limit the opportunity to provide analgesia but it might help you to understand why someone might refuse analgesia because they are drawing on resources that help them self-manage. You might argue that those are adjuvants that run alongside medicine; but if you have a patient in front of you who says I want my pain because it takes me closer to the sufferings of Christ on the Cross...you have to take that seriously. It may be anti-therapeutic but it is his or her privilege.

I'm not sure if it's anti-therapeutic; it depends on your perception of distress. If people say the pain is terrible but it is something I can benefit from, in what may seem to us a bizarre sense, treating it requires an interesting judgement as to whether someone is making a rational decision.

I have had several patients who couldn't wait to die, so they could attain a better reality than this mortal life. I was astounded, but that's what they said.

You alluded to pain thresholds. Who was doing the measuring?

Certainly some of the earlier studies were done by white people.

Yes, it's usually WASP's asking black people the questions and that in itself introduces bias and suggests that there is no such thing as difference in pain thresholds related to race and the most important thing is perception of pain related to cultural background.

Regarding opiate prescribing post-Shipman. As a GP I have often prescribed opiates without concern... and I am now horrified by the way my colleagues don't have the balls to do so.

They should read Clive Seale's work in Palliative Medicine on the probability or possibility of bringing about the earlier death of the individual.

[Inaudible question regarding palliative care at home] GPs are afraid to leave drugs in the house. We spend a lot of time trying to resolve this

This waste of time is critical because there is no second chance to get it right.

Another problem is that most people don't live near their parents and this compromises the latter's wish to die at home. The services go in two of three times a day to wash and change them but if there is no family there to care for the ... they don't have that choice and we have to accept that responsibility. But I don't think I have ever been sent out to an Asian family because they can't care for their own people.

I think that's changing. I work in close collaboration with St Christopher's and when I started in South East London in the 1980s it would have been rare to see somebody from the local Black and Asian community, but now they are as well represented as they are in the local population, and certainly the work in St Joseph's Hospice in Hackney reflects the social milieu in which it is located.

People have definitely done tremendous things to improve social inclusivity at the end of life. But more work needs to be done.

I was reading the other day about the law in California and the same applies to parts of Australia where the practitioner is protected to some extent from litigation and the fear of litigation by a series of guidelines which a doctor should know and should practice in conformity with; he or she should undergo specific training and if they have not had this the patient is referred to a doctor who has. What is the situation here?

What's the average caseload? Four patients per year will die per GP, so whether they can possess the specialist knowledge to manage analgesia in dying patients may be questionable and clinical guidelines are really important, based on the back of good systematic reviews but also good advice from specialists in the area.

In relation to threshold testing, in one of the studies the tester was female, and it was shown that men's threshold increased. You also mentioned the phrase 'pain is what the patient says it is' which is a famous quote, but if you look at McAffrey's original it says "pain is what the patient says it is unless you have reason to believe otherwise" because of cultural features etc. So even she recognised that the situation is more complex.

Culture, beliefs and chronic pain

Michelle Briggs

“When I am talking to someone from a different background with a different cultural perspective there is a big gap between us which we don’t often talk about, and something which goes unspoken about when we talk about pain.”

A project designed to explore the overlap between ethnicity and faith and its influence on the understanding and expression of pain.

I am fortunate to be part of a research team which includes experts in health sciences, pain management, palliative medicine and nursing research, as well as chaplaincy services. There were a number of drivers, and these include a paper by Jonathan [Koffman] which recommended that:

“Health care professionals develop a greater awareness of values and beliefs that may affect responses and expectations towards cancer-related pain; and in order to achieve this when performing a pain or symptom assessment interview with patients from different cultural backgrounds to their own, health care professionals should ask questions that go beyond a detailed description of pain intensity and its location, facilitating opportunities for patients to express information about their experience of pain such as beliefs, feelings and expectations of treatment and care.”

We must acknowledge our shortcomings in this, particularly in chronic pain practice. It is very difficult and we are least prepared for it by our education, especially in my profession of nursing.

The research

The aim of our research is fourfold. Firstly to undertake a systematic review of the experience, expression and management of pain for people belonging to five common faith groups; secondly to explore through semi-structured interviews how older members of these groups communicate their pain and interact with NHS services to achieve pain relief; thirdly to develop educational materials from the findings for students and health professionals and lastly to develop new approaches to improving communication about pain taking into account cultural, linguistic and faith diversity.

What we are aware of is the difficulty of difference. When I am talking to someone from a different background with a different cultural perspective there is a big gap between us which we don’t often talk about, and something which goes unspoken about when we talk about pain.

So what do I mean by a Social Care Institute for Excellence Review (SCIE)? Systematic reviews are designed to gather together in a comprehensive, transparent, repeatable way all the available knowledge to inform a particular clinical question. For example, Cochrane Reviews of Effectiveness where we are investigating, for instance, whether A works better than B are fine when the type of study you need is a randomised controlled trial. That is not a useful tool

if you have broader implementation and education questions for practice like this, and you want to take into account user perspectives, and policy and research studies are likely to be important.

SCIE allows for five knowledge sources to be identified and to develop a process for data synthesis. These are:

- Organisational knowledge gained from management and governance of social care and in the health care environment - my nursing and midwifery professional guidance; what does it say about the things we have talking about today like Shipman, and what is the organisational matter around governance, what governance decisions I can make.
- Practitioner knowledge gained from the conduct of social care: the audits that we do
- Policy community knowledge gained from wider policy environment: what the DOH policy statements say
- Research knowledge gathered systematically with a predetermined design,
- but also very importantly for this area
- User and carer knowledge gained from experience of service use and reflection on how they work.

Our aim was to pull all these together into one review. We were interested in any study that explored the relationships between ethnicity, religious identity and the chronic pain experience and expression, or sought to identify cultural and religious barriers and/or levers to successful interactions with health care professionals for pain management, through better understanding of our own and our patients' cultures. We included any paper which explores Christian, Hindu, Sikh, Jewish, Muslim, white south Asian and/or ethnic minority or cultural perspectives and pain experience or management.

The problems

The scope was ambitious and our progress so far has included identifying relevant databases, developing search strategies and testing them against known papers which include pain, palliative care and religious and/or ethnicity Cochrane terms as well as somatisation which is not in Cochrane. It was a challenge finding "religion" and ethnicity – if you search for GOD on Medline it is used as an abbreviation for glucose oxidase and "culture" comes up with microbiology studies. The other thing you can do with a systematic review is to filter: putting a hedge round your studies so you only get the ones you want. We developed a filter which found 55 relevant papers. These would have been lost if we had restricted our search to qualitative research, but without a filter we would have had to look at 40,000 papers of which perhaps 2000 might be relevant. It has been suggested that these sorts of figures may make systematic reviews of qualitative research untenable in a few years.

Combining everything in one big review may not be the way to go. We may need to look at sampling in a theoretical sampling way and start with one particular aspect but the question is: how do we choose how to divide this review up. One view is that we don't try to divide it up and look at all 40000 references to see what's in there. We took a subsample to see what sort of studies are in there and what is relevant and what is not from our inclusion criteria and found out of 61 papers, 17 that identified racial or ethnic barriers to effective pain relief. Theological dimensions of pain and suffering came up in ten and there were eight on cultural guidelines for practice. The six on assessment of pain were on validation of pain scales in Hindi. Trials of spiritual

interventions and religious coping – both positive and negative effects – were the subject of five papers. Ethnic diversity and difference in pain experience featured in three studies. There were five paediatric papers and three publications which included narratives describing the experience of specific groups and one anthropological study. But a systematic analysis of all 40,000 papers would be a huge undertaking.

We could try and reduce that by taking out labour pain and paediatric pain which would cut it down to 30,000, and just look at adult pain; or we could choose the theoretical sampling route where we decide to only look at this through the lens of older people and reduce it to 10,000 citations; or only include and look through the lenses of faiths, or ethnicity. There's more written about ethnicity so I'm not sure that that would be a good start.

So we have some decisions to make about what we lose or what we gain, and when you're making choices about how to do systematic reviews, the question you choose to answer and indeed how you frame your inclusion and exclusion criteria will make a big difference to the answers you get at the end and the guidance you give to commissions.

We don't want to lose anything, so we're probably going to start with a pain and religious identity review and work via a pain in older people review into a pain and culture review.

But I would really value your comments because the other part is that I'm searching in electronic databases and I am aware that there is a big group of people who may have a long experience of good practice and areas of expertise who could contribute to this; here is my email address and I would really like to know if there is anything else you could contribute to this review.

Discussion

Have you looked at papers which don't necessarily fall into your trawl; in other words in papers about pain in older people there may be sections devoted to religious experiences

There are some older studies dating back to the 1960s which looked at the effect of praying.

Yes – some of our references go back to 1847 because we haven't done a date cut-off because we don't think it wouldn't be appropriate for a review involving culture.

There were some studies done at the London Hospital on the effect of praying on people who didn't know they were being prayed for.

This is a very interesting problem which arises all the time in systematic reviews. One trick you can use when faced with thousands of papers is just to go for the reviews, and review the reviews.

My other point is that it really depends on what question you are trying to answer – I think you need to have a clearer research question that you want to know the answer to: that can make a difference. What is that for you?

To identify the religious barriers and levers.

That's a great question; that could lead to some strategies to improve care.

The difficulty we're having is finding strategies that allow us to do that which are sensitive enough ... When we narrow it down and make it too specific we lose papers which might answer that question.

Where do book chapters come into this?

We haven't limited these – we have also included videos, guidelines and Doctorate theses.

How are you going to test the validity of what you find?

There is a framework to test quality, the transparency of the methodology etc etc.

Suffering and culture: Perspectives from rural New Zealand

Steve Main

“Does ignorance of others’ culture influence our clinical attitudes and our assessment and treatment of patients?”

I work in the far north of New Zealand near the west coast. Hokianga is an area of outstanding natural beauty but rather impoverished. The population is rather disparate, there’s not a lot for people to do and there’s not a lot of money about.

We operate from Rawene Hospital. We are effectively GPs. We are about two hours’ drive from the nearest major hospital, and provide primary care and casualty services. We have an inpatient unit with long stay, acute and maternity beds. We have nine peripheral clinics scattered about the area which we visit once or twice a week. Local transport is complicated by the river which crosses the middle of the area with a ferry which only operates hourly.

Culture and the experience of pain

Much of what I have to say has been touched on this morning. I think we are all agreed that culture and belief can have a profound influence on the experience of pain as well as its expression. Mason Durie, a leading Maori intellectual, put it very well:

“Culture is essentially a convenient way of describing the ways members of a large group understand each other and communicate that understanding. More often than not the nuances of meaning are generated by behaviour rather than words, and much of the interaction between members is determined by their shared values operating at an unconscious or “taken for granted” level. Many groups have their own distinctive culture – the elderly, the poor, professional groups, gangs, and the army. Although [in this paper] the focus is on culture associated with particular ethnic groups it should not be forgotten that in the consulting room or the hospital ward, ethnic culture is one cultural affiliation alongside others. The fact that a fourteen year old boy is a Maori for example may be less relevant in health terms than the fact that he is fourteen. The skill lies in being able to determine the culture that is likely to have the greatest significance in a specific context.”

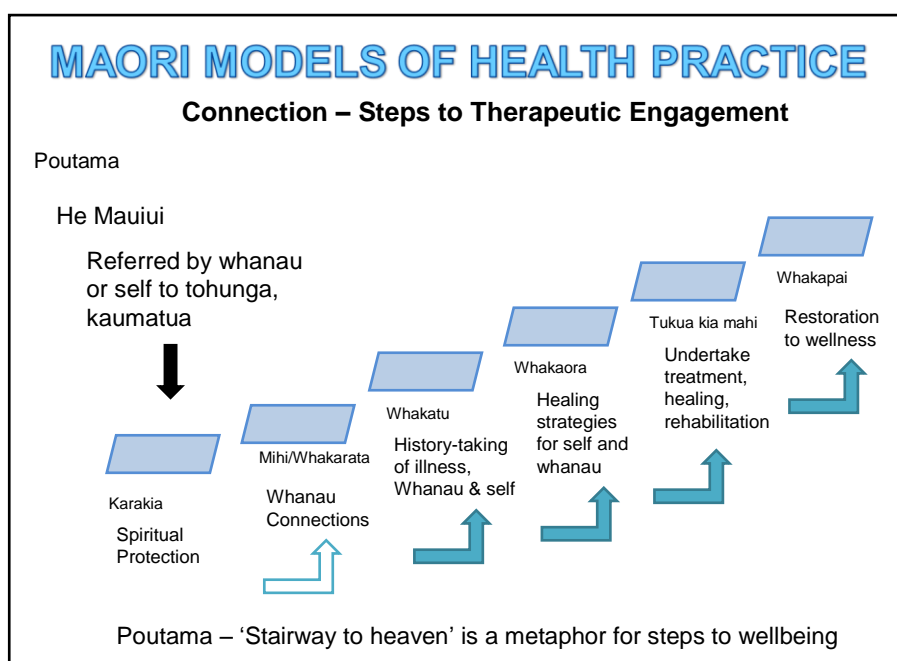
To address the questions posed in the programme: Are there limits beyond which pain is intolerable and unacceptable? The short answer is yes, of course, how can it not be? The problem lies in defining the limits. Are we sufficiently well informed about cultures other than our own? Probably not, but we must be wary of confusing culture with ethnicity. Does ignorance of others’ culture (or lack of awareness of our own cultural background) influence our clinical attitudes and our assessment and treatment of patients? Yes it does and may do so even if you reckon it doesn’t...

A Lecturer at the University of Auckland has actually looked at this problem and asked doctors about their approach to patients. In New Zealand as a whole about 15 per cent of the population are Maori and they have pretty poor health. In my area about 75 per cent are Maori. The doctors she interviewed said “Yes of course I treat

my Maori patients exactly the same as my European patients” but on careful enquiry to the patients themselves there was a definite discrepancy. The doctors and nurses really thought they were communicating well and getting on fine but actually there were big holes. That’s not just dealing with Maori – it reflects earlier studies in General Practice in the UK.

I want to bring in the horrible word *nocebo*: we are all familiar with effect of context in medical intervention for both good and harm. In *The Placebo Effect and Health: Combining science and compassionate care* (2005) Grant Thompson wrote: “Medical care is rich in irony and paradox. In the past, doctors, lacking effective treatment could console, encourage and adjust attitudes, but seldomly (sic) could they cure. Most were respected, even loved, for their time and compassion, and in many cases, these were all they had to give. Now, effective, evidence-based treatments can often improve or cure, yet if delivered without time and compassion can also alienate, dehumanize, and anger. The nocebo effects of a bad medical encounter may cancel any evidence-based benefits. Physicians, health-care managers, and enlightened public must find ways to restore healing relationships and ensure that health care is as evidence based as possible.”

It may be a reductionist bio-centric view but it could be argued that in any medical encounter, taking full account of culture in its broadest sense effectively equates to recognizing and maximizing the placebo effect. If you have a drug A, which has been demonstrated in clinical trials to be twice as effective as drug B, prescribed by two doctors; Dr X is an empathetic guy who gets on well with his patients, and the effect of his treatments has a big placebo element, so the total effect of drug A and Dr X is pretty good and he would also get good benefits from drug B. Dr Y is not in the same game. Even if he prescribes the better drug the benefit his patients are getting is considerably less and drug B may appear to be no good at all. Those proportions can change dramatically: for instance with antibiotics and anaesthetics where the context effect is irrelevant, and yet there are others, particularly psychological treatments and treatments for chronic conditions where the proportions may be completely different; not to say also that there also may be actual harm in that situation.



Maori perspectives in health and sickness

In the Maori culture four domains must be right for health: Taha Tinana, the physical side; Taha Hinengaro, the psychological side; Taha Wairua, the spiritual side and Taha Whanau, the family side; those four things have all got to be in tune. The approach of the Maori traditional health provider will start with prayer (*karakia*) to get the spiritual side right first and then attend to the Whanau connections – who you are is very important. Those two things precede any history-taking or any healing measures.

Good, Brodwin, Good and Kleinman, in *Pain as Human Experience* (1992) explain very well the difference between the Maori and Western ways of looking at health and sickness:

“In Western medicine, nature (biology to practitioners) is opposed to spirit; it is autonomous from human consciousness (subjective experience); each of its parts is atomistic, independent from the whole; and it ‘stands not only independent from culture but prior to it’. Furthermore, nature is a realm separate from morality and society. Nature, so isolated is regarded as universal. It is not dependent on the parameters of space and time. Nature-biology is the basis for truth itself.”

And further:

“The individual is a sovereign being, a distinct unit, prior to society and culture and autonomous from them... Individual orientation is as much part of biomedicine as it is of western culture. Sickness is resident in the individual, in physiology, and diagnosis and therapy focuses exclusive gaze on the individual body. Suffering is the private response of the subject, and as long as that subject is competent, the moral responsibility of the physician is limited to the individual sufferer.”

Now think what egregious influences these values exert on medical practice with patients suffering chronic pain or other chronic illness. The experience of pain is fundamentally inter-subjective. Chronic pain profoundly affects the lives of the family, intimate friends, co-workers, and even at times the caregiver, and such persons in turn shape the experiential world of the sufferer. To regard pain as the experience of an individual, as it is regarded in standard biomedical practice, is so inadequate as to virtually assure inaccurate diagnosis and unsuccessful treatment.

Words of John Milton encapsulate an awful lot of what we think about pain in the West:

“For what avails, valour or strength though matchless, quelled with pain which all subdues and makes remiss the hands of mightiest?

Sense of pleasure we may well spare out of life perhaps and not repine,
but live content which is the calmest life.

But pain is perfect misery, the worst of
evils and excessive, overturns all patience.”

From “Paradise Lost” (1667)

There followed at this point a video of a interview with four Maori people on their attitudes to suffering, which is available as a download on request from Steve Main steve.main@hokiangahhealth.org.nz . This is to be highly recommended: the wisdom and insight displayed by these people was not only enlightening but moving, and an experience long remembered by the audience.

Discussion

I used the word rediscovered which was the wrong way round: the importance of non-physical aspects of therapeutic encounters was discovered by these guys a long time ago and we have only just caught up with them.

Do you think that our society has lost its spirituality...we're treating people from a medical, physiological perspective; totally ignoring the psycho-spiritual side...we're missing a whole plethora of things wrong with people...

I think there's a lot in that; with technological advance in the last 50 years there has been this expectation that there is a 'pill for every ill' solution to everything. We have become progressively more secular and moved away from spiritual aspects of our lives. There are big differences between the way Western culture has evolved and other cultures around the world. Western Culture since the time of the Greeks has been the most successful and dominant. *Guns, Germs, and Steel: The Fates of Human Societies* is a 1997 book by the anthropologist Jared Diamond, which addresses the question as to why European culture is dominant, why we have colonised everywhere and why our ideas and technology are so much in advance of everybody else's. It's partly a matter of geography and partly because of differences in the way Western people thought.

I recently went to a conference at Chicago University and was astounded by how many professors there at the medical school are becoming more fascinated with Eastern philosophies and teaching young students about Eastern lifestyles ... and I wonder if part of that is that we have become a little bit ethnocentric

How do you define success? Do we have the wrong criteria?

Whilst white Caucasians in the UK have become more secular this is not the same as losing their spirituality and could it actually be that spirituality is hidden somewhere, and is that a field we are missing out on?

I was a GP registrar in Bungay, Suffolk where there is a Church of England convent which runs a small hospital. This started off as a refuge for 'fallen women' in the early Nineteenth Century. One of the Sisters there commented that she felt that the spiritual poverty of the West exceeded the material poverty of the rest of the world.

But she's biased because she sees spirituality as being religious but it may be that we've all lost spirituality which is not religious.

The Maori culture which although not Christian is very spiritual, but in many places they have embraced Christianity because it kind of resonated with the way they thought. There are those that say that's just an example of colonisation...

One of the Maori in the video commented that when a new doctor came on the scene it took a while to break him in, so to speak – we shall just have to change until you catch up and mould you to what we want!

In the Nineteenth Century, Western Europeans in particular went to developing countries and evangelised tremendously and influenced local cultures and sometimes even punished people if they didn't believe in what they thought was the right way forward. Do you think that people like me and others who are interested in developing countries are actually doing the same thing except that we are doing it, with the best will in the world, treating pain, when in fact there are systems there, as you have pointed out, that deal effectively with pain and suffering in a way that is not understood by us but is beneficial to the people for whom it works?

Beware of excessive missionary zeal!!

How do we overcome our inherent tendency to be missionaries?

You've got to listen ...

Yes – that also applies to our approach to individual patients. I very much believe that people with chronic pain and suffering can be helped to find their own solutions; more often than not people do know what will help them best and it's for us to facilitate them in identifying this.

General discussion on suffering and culture

About culture and physiology: we all subscribe to this cliché about pain being what the patient says it is, and of course objective measures of the subjective experience of pain are very difficult if not impossible to devise because of the nature of the beast. But we can measure physiological responses to pain, so I wonder if there is any objective evidence of this sort?

There is work on EEG responses between different ethnic groups which are very difficult to interpret... [Simon Dein]

Why do you want to know?

... If there is any objective evidence that people who don't appear to be suffering much pain are actually experiencing less does it matter if it's undertreated?

If there are measures which correlate with pain then you could argue that's more objective and amenable to treatment than what the patient says it is.

Regarding Functional NMR, there is a difference in putting you or me in a machine and an illiterate African or a Maori or anyone else that doesn't have any knowledge of what goes on. You're looking at many different kinds of brain activity; it's very difficult to unravel the basic physiology from all the other influences...

You'd have to rule out confounders... You'd need a control group to identify what's physiological and what's not...

It's an illustration of the complexity of the nervous system ... pain clearly involves an awful lot of the CNS and it's not simply a sensory phenomenon. One of the things that fascinates me is the patient who says his pain is 10/10, he's not sleeping and feeling depressed etc. You treat his depression and although his pain is still 10/10 he feels a lot better. fMRI is giving us images of pain pathways and although it's giving us better understanding of pain pathways ... You can't get away from the sheer complexity of the nervous system and pain is just part of that...

The title of the meeting is suffering and culture but the emphasis of the talks has been on pain... there have been lot of implications in the talks that there is a difference between pain and suffering, but it's all been have rather vague. I wonder if our speakers could make a more explicit distinction between them?

I see pain in the context of the response and the way it evolves into an emotional and spiritual level as suffering – pain is only part of it. [Steve Dein]

Can there be a higher level of pain and a lesser lever of suffering in the context of some of the influences of culture?

Something Jonathan said would be a really good idea – could pain be therapy in itself for religious people – could it be used to help people come to terms with their suffering and making sense of their suffering through pain?

Victor Frankl who lived through Auschwitz and wrote *Man's Search for Meaning* suggests that the worst kind of suffering is when there is no meaning in it. Even in the worst kind of adversity, if you can hang it on a framework that makes sense, which is how some of the people who you [Steve Dein] were researching were able to

comprehend the inexplicable if they could hang it on something. Suffering is a wonderful area to study. [Jonathan Koffman]

I'm not saying that people should suffer although some people may want to suffer to help them come to terms with previous failures... [Steve Dein]

It must also be true that there are various factors that influence our wellbeing, and we can have a sense of wellbeing that sort of transcends pain.

I had a very interesting experience in Malta a few years ago when during the course of some work I was doing in the Health Institute, I had the opportunity to interview some nurses and doctors who were absolutely adamant that because of the suffering of Christ which they believed in they didn't really want to relieve the pain of their patients and wanted to pass this on to them.

I also wanted to comment on Zborowski. I wish people would stop quoting him because his data are very flawed. He was a fraud and went to prison but he's still cited and cited.

[Partly inaudible]... We're still looking at suffering in terms of what pain does to us. Suffering can also be looked at in a much wider context. As an Occupational Therapist I see suffering when people aren't able to live according to their ?... and that makes sense of pain in my mind, and I don't think we've yet touched on that.

There is also something about suffering which has an element of choice and lack of it. With pain you've got no choice, whereas with suffering...choice has been taken away from you. You gain more power when you begin to realise you can choose to suffer, or become empowered when you are able to look at suffering in a different way – so suffering has an interaction with choice in a way that pain doesn't. They are conceptually very different and that's why from a theological point of view the concept of suffering has a lot within it.

They may be conceptually different but they certainly overlap a lot. Pain is at the top of the list of all the horrible things that happen to you in life, and together they amplify each other. Pain, mental or physical, is always involved in suffering. They go hand in hand and you can't really separate them. Suffering is an expression of the total of disagreeable things that affect your life: family financial etc, and an overarching umbrella.

Pain is a biological adaptive response ...Pain is a response to the human condition.

The last 25-30 years of practice have been geared up to the concept that pain is unavoidable but suffering is an optional path in life [which involves] knowing that you can't do anything about pain but you can choose.

There was a study of the use of PCA post-operatively by a violinist who was also a psychiatrist. In one ward he sat in the corner and played the violin and people in this ward used much less analgesia.

In his great book 'Pain, the Gift that nobody wants' Paul Brand talks about his hand surgery practice in India. Patients had access to morphine post-operatively if they needed it but very rarely needed more than one dose because it was the family that nursed the patient and they were camped round the bed so there was always someone there when they were needed

We tend to accept the inevitability of pain as a nociceptive phenomenon. There are two associated ways of decreasing suffering; one involving pharmacological and other means of reducing the intensity of the stimulus, but what is of more interest in this conference is a way of providing a greater integration of two approaches: one typified by the idea of identifying pain with the suffering of Christ in a way that can reduce the suffering, and the other by the Buddhist tradition where if the pain is recognised as inevitable, and you can remove the framework that you can have this wonderful life and never to have pain, your suffering will be reduced. There are two paths that we need to follow to look at and mediate the pain and I think we could do well to look at them coherently and creatively and not one or the other; I think both are essential in the way we bring the integrative path to practice and something we need to focus on and get better at...

Several speakers have remarked on the findings that Hispanic Americans get a poorer quality of medical service than whites, and no explanation has been offered. Why is that the case? Is it just another way of discrimination?

The reality is that in the US the black and Hispanic population are an oppressed minority and as a result many live in the lower social and economic strata of society and as an extension of that if you live in a poor area you're going to have a lesser quality of service in the medical system, and the problem is perpetuated by the way many people walk into the patient's room with this mindset that because they are Black or Hispanic they are more likely to be drug addicts or that they will sell their medication on the street.

It could be two way: if you are in an oppressed minority you're less likely to speak up for yourself. A lot of elderly patients, for example, don't want to disturb the nice doctor and will often go without pain relief. Nurses have been recorded that they are too scared to give more opiates to an elderly patient for fear of giving too much.

It is commonly believed that a man called Huskisson brought the analogue scale into being. This isn't true: the first to be published was in 1996 by Pilowski and myself. We have discussed how analogue scales could represent pain: we concluded that what it really does is give the patient something to tell you about what they feel; it's couched in terms of pain but does include a lot of other things as became evident in this morning's discussion. It's a focus for the patient to put on to the scale something that represents a whole series of processes going on that are ultimately enshrined in the word pain. We showed in the paper how a patient's pain scores rose and fell with the insertion and removal of intrauterine radium. That was the first published representation of the use of the scale; there had been a lot of sophisticated discussion of pain measurement at that time there was very little to go on. This slide [of pain scores and analgesic (paracetamol, weak and strong opiates administration in men and women) shows that there doesn't seem to be any relationship to the severity of pain and what people were given for it. We were rather taken aback to find that not one man in this study had received strong opiate analgesia. And that was a culturally determined phenomenon. The belief was that those men should not need it.

Why should all these pain scores be at variance with what people were given? It linked to the fact that nurses took the view that certain things gave rise to certain level of pain and therefore you gave A, B or C as a matter of routine. Even if they had no pain they would get Morphine or Pethidine but if they had a lot and it wasn't the right condition they wouldn't. There seems to be a completely random relationship between levels of pain and drugs given and reflects a dreadful level of education and ignorance about pain in nurses at that time. They worked according to preconceived ideas, and didn't actually ask the patient.

Unrelieved pain is a global phenomenon: Pain treatment should be a human right

Michael Bond

“...We don’t know the prevalence of acute and chronic pain in developing countries: we can infer what it probably is from the known prevalence of diseases... We know that resources for pain relief are low priority or don’t exist.”

During my time as President of the IASP, I was looking for a project and it occurred to me that there had been an enormous amount of research on pain management in the affluent countries but in the developing world very little seemed to have been happening.

IASP had some programmes for the developing world but very few. So we set up a developing countries working group and we have moved on quite a long way since then.

The WHO/IASP joint declaration

In 1949, the World Health Organisation (WHO) defined health as ‘State of complete physical, mental and social well-being and not merely the absence of disease or infirmity.’ There are other definitions of health but none of them make any reference to pain. That’s a problem because you have got to persuade health providers, particularly in developing countries, that providing for severe pain is very important for a variety of reasons but their minds tend to be focussed on other things. We came to the conclusion with which I am sure you will agree that unrelieved pain and suffering is a global problem and pain, especially chronic pain, destroys the quality of life; and finally in 2004 the IASP, WHO and European Federation of IASP Chapters (EFIC) held a meeting in Geneva at which it was agreed that pain treatment should be a universal human right. (The original wording was ‘pain relief’ but we decided that this could not be a right but treatment could.) Whether that statement represents a clinical desire or a moral statement, and whether it could be enshrined in law – all of those things could happen but it hasn’t been enshrined in law as far as I am aware, except in South Australia where there is a law in this State which does state that pain relief is a human right.

Developing countries

[*Slide of Indian man with a fungating facial tumour*] He illustrates something you would never or very rarely see in this country. It could be that he comes from somewhere a long way from any source of treatment and can’t afford to travel, or that he can’t afford the treatment. It might also be that having this sort of disorder is regarded as a disgrace which you don’t reveal until it becomes unavoidable. [*The second slide showed a man, also Indian, semi-kneeling in bed with his head down and his hands clasped in front of him*] This man had had radiation for a facial tumour which had left him in a terrible state. “I feel as if my head is about to burst; every now and then it feels as if someone is driving a nail through my ear... it goes on for hour after hour and I can’t bear it...the doctor tells me the pain is in my imagination” – a statement you come across quite often even in our society – “and he asked me to

stop thinking about it. No-one understands what I am going through". You will be hearing more about the great advances in cancer pain management in Kerala from Tom Middlemiss later but I just wanted to show you the same man one hour after a shot of i/v morphine costing 5 cents [*sitting up, alert and almost smiling*]. His doctor knew nothing about palliative care and by chance the patient heard about it, and he went to a unit where he can continue to receive treatment. These two men show something of the problems people face in Third World countries, of poverty, distance, attitudes of doctors (if there are any) and – what isn't shown here – is the way native medicines are used.

So what about Europe: are we a lot better? A study done in 2004 by EFIC with 30,701 respondents revealed that 18 per cent had moderate to severe pain with a median duration of 7 years. 62 per cent were less able or unable to work outside home, and 22 per cent suffered depression because of pain. 20 per cent said their doctor did not regard pain as a problem and only 22 per cent saw a pain specialist. Types of pain were musculoskeletal, especially in elderly women, back and neck pain and headache; only one per cent had cancer. We know that 67 million die of cancer in Europe annually and 80 per cent of them have severe pain. So there is a lot of work to be done.

I was reading a study recently about Western and Eastern Europe (which includes developing countries). If you add the total amount of opiates available to those two blocks, 80 per cent is used in Western Europe.

The prevalence of pain

Really we don't know the prevalence of acute and chronic pain in developing countries: we can infer what it probably is from the known prevalence of diseases such as cancer and AIDS and sickle cell disease. We know also that resources for pain relief are low priority or don't exist. Governments are much more concerned about infection, such as malaria and Tuberculosis. Of course they have to be concerned with HIV / AIDS and outsiders do much of the work in this area. The prevalence of pain in AIDS is 30 – 80 per cent and equals figures for cancer, and its severity is equal to or greater than that of cancer pain. In 40 per cent the pain is neuropathic. 85 per cent of patients are undertreated although the need for analgesics is similar to cancer and women are less likely to get good treatment than men, and this is a common pattern in developing countries.

Education

In 2006 the IASP did a survey of education in pain management all our members in developing countries. We asked if pain control was a problem in your country and over 90 per cent said it was. Remember, that these are doctors who have joined the IASP and are therefore pain doctors, although they may not be specialists, and are a selected group. Undergraduate pain education was likewise widely considered inadequate to allow newly qualified doctors to deal with the sort of pain problems they were likely to encounter as a houseman or resident. The British Pain Society (BPS) recently did a survey of medical and nursing training in the UK and found something similar so we can't claim that we are training people properly. The IASP produced the pain curriculum for medical, nursing, pharmacy and dentistry students 20 years ago but its uptake has been very limited. We are clearly not doing nearly enough in the West, let alone in developing countries.

IASP members were also asked if they had been trained as pain specialists. In only Latin America and Asia and Eastern Europe did this apply to a majority. When they were asked to rank the frequency of the types of pain they treated, neuropathic, cancer and musculoskeletal pain came out top and AIDS related pain right at the bottom, below genito-urinary pain, despite it being rife in the countries surveyed. So these patients were apparently not being referred. We don't know who was dealing with them – maybe nobody. Cancer pain came out near the top and the establishment of palliative care in India and other countries is spreading very rapidly, with oncologists and pain specialists coming together.

Among the barriers to good pain management in developing countries, lack of education is highly significant. This applies to both doctors and nurses and you have to remember that many people in developing countries never get near a doctor. They may see a nurse or a district officer who will be equally poorly educated. Government policies are often not favourable, not only because they set their priorities in different directions, but also because of reluctance to provide opiates because of the huge fear of addiction not only among administrators but also doctors and nurses.

Less than five years ago the IASP gave a grant to Nigeria whose government had only just allowed opiates to come into the country for the first time, to fund a group to go round the four provinces of Nigeria to teach doctors, nurses and pharmacists about the use and abuse of opiates. They also taught policemen as it was very important to get the police onside and counter their very hostile attitude to opiates. A grant was also given in Kenya to teach obstetric nurses how to control pain in childbirth. You might think this would have been a central plank in their education but it clearly is not.

The high cost of drugs is a major problem and drug companies are not prepared to cut their prices. In Kerala, India they got over this by importing the materials to make their own drugs at a fraction of the cost. Poor patient compliance is another factor: why don't patients take their drugs? There are a variety of reasons as we were discussing this morning and I have to say that the data we collected is very general and in a sense superficial and only gives us leads as to where we might go next and we don't know what that means for poor compliance or why people stop taking their drugs.

Discussion

I just wanted to comment on the publication of your studies. Generally they were in obscure journals – at least obscure to nurses – so if nurses don't know what they don't know, we have a problem.

I just wish we could do more about pain education generally. Why are the medical schools so apathetic? It seems to be everybody's problem and nobody's problem...

A survey of pain management in the elderly in Scotland revealed an almost unbelievable level of professional ignorance...

We jog along thinking we are doing a good job but out there is an enormous amount of suffering totally untouched. Having said that there are parts of the world where people are pouring their energies into countries like Kenya, Uganda and Kerala but there's no co-ordination: there are at least three or four groups working in Uganda. There is an organisation called *Hospice Africa* which IASP supports which started in Kenya and Uganda and now is involved in several African states, run by one very

enterprising lady. Tomorrow I'll be mentioning the Pain Summit – it's really set in the direction of advocacy because what we want to do now is not just concentrate on pain doctors in developing countries; we really need to work on people who are responsible for provision of services, medication, training etc. This is something hope will take off after the World Congress in Montreal in August. The IASP has already begun that process.

One thing that is good about developing countries is the enormous energy you find. People really want to *do* something; whereas in the West you feel people have gone into smaller groups which may be very interesting like the neuropathic pain group. But you do feel a tremendous determination to get things done across the board, and harnessing that energy is an important part of what we are trying to do.

You said the wording of the Declaration was changed from pain relief to pain management – was that because the word relief conveyed the wrong message and give the wrong impression of a magic bullet?

Yes...you cannot guarantee relief but you should be able to guarantee treatment.

They [students] know nothing about pain treatment – they know about the theory – I find that rather alarming.

I was teaching a group of final year students and asked them about pain management and they all looked rather blank. I asked them when they had last heard pain mentioned and they thought it was some time in their second year when they were doing physiology. I was to give them sessions on pain management – they wanted to know why had no-one told them before? Good question. And that's what the Pain Society found when they looked round the country for evidence about pain education and it's bad.

I think a wider problem with medical education is an obsession with causes, and we don't teach anything about consequences. It's not just about pain but the whole spectrum of suffering and illness rather than disease. It may sound heretical in this group but I wonder if we shouldn't make the campaign wider than just pain?

Indeed to re-orientate undergraduate medical education? Yes.

But people are coming round to talking about management of chronic conditions which raises a whole bundle of issues...

I have wondered about the new form of medical curriculum which has been adopted by everyone except Oxbridge which gets rid of the basic science concept and integrates basic science with clinical activity from Year one Day one. And you have facilitators and project groups and all the rest of it...and whether that will get people closer to the things we have been talking about; but actually when you ask physicians who take on new residents what they are like they say, well, it's a curate's egg: their knowledge is profound about some things but non-existent about others you might expect them to know about, so even that system appears to have its faults.

I wonder whether one of the problems is that, for instance in palliative care, we've tried to integrate teaching the theory of treating pain and bringing it together with clinical practice but how many students are spending time with patients who are in pain? We teach them the theory but we're just not getting there. [In Great Yarmouth] we are getting students to see patients with back pain and sort them out. Whereas if they are doing the CVS and the physiology and they see someone with a heart valve

lesion or an arrhythmia we can tie it in, but we are we doing this with pain and palliative care?

Courses tend to be very short so instruction over the patient is curtailed.

It doesn't matter how good the education is but once people get out in practice administrative factors tend to sabotage the whole project. In Canada we have the second highest consumption of opiates in the world (only to Denmark) and yet in the province I practice in 30 per cent of practitioners never prescribe opiates, and that's not because they don't know, because the Canadian Pain Society and the government recently published guidelines of the use of opiates in pain, but at the same time the doctors are scared to death of being investigated and subsequently de-licensed and the licensing authorities are hounding many very good doctors for what they perceive as over-prescribing.

Maybe they should look at the Californian rules which are designed to protect doctors...

...and yet in the US there are many doctors being investigated for over-prescribing but others for under-prescribing. Perhaps before we go into the developing world and start telling them what to do we need to put our own house in order?

That's one of the messages from this talk. One last thing I would like to say about doctors in developing countries and the way they work is that most I have been to see work for the state for the morning till three or four in the afternoon when they go to the private clinic which is where they make most of their income. Most of them are in major cities and people who come to them at the state level come through a process like a sausage machine and goodness knows what level of attention they receive at that level. In the private clinic they have the time and the patients have the money to pay for proper treatment, so there is a huge differential. Indeed in the USA as we have been saying there is a big difference in the way African Americans are treated – Washington for instance is a city of two parts with half living in what is effectively a third-world country and no-one cares much about that.

So my final thought is that we should be examining our own shortcomings and perhaps use this process to help others. I have never believed that we should be evangelical towards third world countries but rather let them define their needs and problems and encourage them to ask for help, instead of trying to impose our solutions on them which may well not work in their societies.

Managing Pain in Malawi: A video presentation

Roy Miller

This is available to download from www.vimeo.com/12436783

It was intended to establish a video link with Dr. Miller in Malawi to discuss his presentation but this was not successful.

A personal experience of palliative care in Kerala: The effect of culture and education of patients and staff on approaches to dying

Tom Middlemiss

“It’s almost impossible to fully understand Indian culture in relation to medicine and health care. I don’t think I could ever get to a position where I would agree with it.”

I worked in Kerala for about eight months at a palliative care NGO in Trivandrum. Kerala is a land of backwaters, coconut trees and very tasty fish curries. It is also a relatively advanced state with high literacy rates. It has the first and most developed palliative care service in India.

It has about 32 million people and like the other states in India is more like a country; and you can’t compare it with other states like Kashmir which are thousands of miles away. It’s a very traditional state and Trivandrum is a very traditional city. Unlike more cosmopolitan places like Mumbai there is a strong tradition of dominant males and women working in the home and things like that.

Dr Rajagopal and Pallium India

This quote “*Work as if you lie in the early days of a better nation*” (Denis Leigh) has always had a resonance for me and I think is appropriate for palliative care in developing countries. Professor Michael Bond mentioned the enthusiasm and energy in these countries and think this summed that up. I was working for an organisation called *Pallium India*. Its remit is different from other palliative care organisations as it also takes care of chronic pain patients in the area. (The founder, Dr Rajagopal, is an Anaesthetist by trade and was able to offer that service as there was a lack of anyone else interested) They see young people with spinal cord injuries – typically men in their twenties who have fallen out of coconut trees or scaffolding and may be bedbound for the rest of their lives, and address their physical and emotional prospects. There is a lot of education in basic nursing care for patients living at home, teaching the family how to care for them and treat bedsores etc.

Dr Rajagopal is a very charismatic character, very intelligent and thoughtful. He has travelled all over the world and is well known to many in the pain and palliative care communities. I was working in a voluntary capacity as I had some time out from the NHS. My role was general clinical work combined with teaching of their staff and people from other parts of India on palliative care courses there, and also helping

with audit and research. There was Raelee, a New Zealand nurse* who had been there on and off for several years and it was very helpful to have someone else there with a 'Western' mindset with whom to discuss things that were different and frustrating for me, and help ease me into the transition into such a different place.

* See www1.petermac.org/apli/ARTICLES/Raelee_MyExperiences.doc for her reflections on working in Kerala – strongly recommended.

Challenges

Poverty is a major problem: some of the care is free but a lot of 'supplementary' care costs money. For instance you can have a certain amount of chemotherapy free but you have to pay if you need more. One of the phrases that has stuck with me is if you are sick for instance with cancer, for the family this may mean 'generations of debt' – though there is not a lot of money around there are plenty of people keen to lend you it, and people get themselves into unbelievable amounts of debt. There are other issues of travel and support and if you take this medication then a child doesn't get education.

There are a lot of head and neck malignancies throughout India and in Kerala in particular which is directly attributable to tobacco or paan (Betel nut) chewing. It is a very difficult disease to manage and gives rise to many complex, usually neuropathic, pain problems with a relatively long prognosis, and there is also a social stigma.

One problem in education of staff is that the role of the nurse is quite different in India. It is compulsory for a family member to stay with the patient in hospital to care for, wash and feed them. There was a difference in tenderness in approaches to patients because the nurses aren't in that personal role, and looking out for things like a patient being in pain or distress was sometimes neglected. We tried to instil the ethos of palliative care into nurses that were part of the organisation.

Pallium India is only about three years old (although Dr Rajagopal has been working in the field for longer) and any new service presents challenges. It is an NGO and takes most of its funding from overseas. In the UK hospices employ professional fundraisers, but the concept of fund raising is slightly alien in India; they are managing as best as they can but resources are obviously tight. Things like patient follow-up can slip and I sometimes found this difficult.

Contributors to suffering

In India there are a number of popular misconceptions, such as that cancer is infective, always hereditary with implications regarding dowries, that morphine is addictive, and if something is free how good can it be?

Status is a significant issue and one of the biggest cultural differences I found: regardless of their status before diagnosis, patients are happy to step back from any decisions, and can often show a lack of interest in what's going on in their own body; so you are really dealing with the patient first and family second. It was interesting but I found it really difficult to get my head round to understanding this.

This led on to collusion which was very prevalent: patients being kept in the dark, either being denied information or actually lied to about diagnosis or insisting that treatment was successful that hadn't worked at all. (They were getting more jaundiced so what was going on in their minds?) The motivation behind this family

dynamic is protection but so much of palliative care is dealing with death and dying, and when you have this extra barrier of collusion it makes getting into such discussions very difficult. The family would say 'If they know their diagnosis or prognosis they will die or jump out of the window.' We had frequent discussions about how to get around this attitude of 'don't tell them they have cancer' and actually talk to the patients themselves.

Medicine is big business in India. And any time you associate profit with medicine you have potential conflicts of interests. There are so many doctors working for themselves that if you don't offer a service a patient may want such as a blood transfusion another doctor will. So it is a difficult balance between wanting to discuss the diagnosis with the patient and not upsetting the family so they will take the patient elsewhere where they wouldn't be getting any palliative care at all. Richer patients often die in intensive care because either the family or the patient hadn't come to terms with the diagnosis, and were willing to try anything; so in the last few days of life they might be intubated and ventilated. A lot of patients would have round after round of chemotherapy. And Aruvedic medicine is very popular in Kerala. People would come to allopathic doctors having had six months of Aruvedic medicine for cancer, which may not have been entirely successful.

There is also the status of the doctor: Indian society is based on hierarchy and doctors are pretty high up. They are respected and unquestioned and I could see very little accountability for them. I thought it seemed difficult for doctors to combine their social status with having to deal with the common man on the same level, and difficult for the common man to interact with doctors, to talk freely or challenge things, or to say that treatment hadn't worked. So much of what we do depends on feedback about the things that we had tried and if patients were reluctant to provide that it made things very difficult.

Finally there were problems with the mechanics of care. If the patient wasn't literate enough to read prescriptions they might not take the right drugs, or if they were on several drugs and one, perhaps an antibiotic, they were meant to stop in a week, they might stop the whole lot; or if they ran out they wouldn't be able to afford more. Flitting from doctor to doctor jeopardised continuity of care.

Reflections

So it's almost impossible to fully understand Indian culture in relation to medicine and health care. I don't think I could ever get to a position where I would agree with it. It probably needs a doctor from such a country to come to another country and see what is relevant and helpful and taking it back, rather than people like myself going there. We were talking yesterday about medical evangelism. Is what we are doing over there really appropriate? Is our way better than their way? Clearly not all the time. How much can we compare situations? Is India more like Britain 50 years ago when patients were kept in the dark, and will it go our way over the next decades?

The power of celebrity is an incredible thing – the Jade Goody effect in making people aware of cancer and palliative care – and in India celebrities like cricketers or Bollywood film stars have even more influence. If someone like that has the experience of a terminal diagnosis this might educate a country better than foreigners coming in.

Should you take an unquestioning role in another country? I came away with a lot more questions than answers, and questioning if I had made any impact or benefit.

So I leave you with the words of John Donne:

“No man is an Islande, intire of it selfe; every man is a peece of the Continent, a part of the maine; if a Clod bee washed away by the Sea, Europe is the lesse, as well as if a Promontorie were, as well as if a Mannor of thy friends or of thine owne were; any Man’s death diminishes me, because I am involved in Mankinde; And therefore never send to know for Whom the bell tolls; It tolls for thee.”

Postscript

One thing that Indians do love is a good story, so when I had finished my work in Trivandrum and had a month to travel, I set off on my bicycle to ride along the coast carrying a banner promoting palliative care for all, visiting palliative care centres on the way. It did generate quite a lot of media interest, and if it only made people aware of the subject of palliative care it hopefully was beneficial. I was welcomed and garlanded all along the amazing ride of 3000km to Mumbai where I was greeted by the palliative care organisation there, which generated some useful newspaper headlines.

Discussion

I wanted to comment on the cultural aspects of disclosing information; noting that in the US as in Britain we used to withhold information and not dispense it except under the guidance of the family. In Japan it used to be the same way but the culture there is also changing. I think it is something we have to recognise that maybe this is a rational position for the culture they are comfortable with and believe in. But with the sweep of information across the globe what’s happening today is that it’s much easier for individuals to know things than it ever was before and the government can’t even keep secrets very well any more.

So there is a tide which may sweep India later than more highly technical countries in which this sort of information is becoming more important than what doctors tell patients about decisions in their own particular syndromes. This is coming and I liked your comment that it may be better to send them for training in palliative care and they can select and be their own champions rather than us trying, even with sensitivity, to change their role.

What was there before? What has changed? (You mentioned Aruvedic medicine) Since a time before they had Western type doctors. This is exactly what we were discussing yesterday and you’ve experienced it first hand: the catching up and repairing the damage that has happened over the last years. These common people had something different before palliative care. What systems were operating?

I’m pretty sure there wasn’t anything, and nearly everyone would die in pain. Even the concept of dealing with pain from things like hip replacements – there’s no analgesia post op except perhaps some codeine and paracetamol if you’re lucky. There is very little Western doctor input there and it is the Indian doctors who were there before and are there now. There is still very little palliative care in the whole country – only tiny little pockets.

The strong family ethos in India is well known. My views on it did alter slightly – there is a fair amount of neglect, and if this couldn’t be resolved the patient would be in a side room and not really tended to; bedsores can just be left

[Partly audible] India is one of the richest countries in the world with a fast growing economy ... cardiac units ... they can do all these things ... in this situation why is there no sort of drip down in funding for looking after these people? The caste system plays a part as well ...?

There isn't much interaction between the castes or support of lower castes. It can be asked how the country can sustain a nuclear programme and send people into space while 80 per cent of the population living in the countryside – the uneducated masses - *the darkness*, as they describe it – how come they are not looking after them, how does it not bother them? I don't know. The tenderness you see in families doesn't necessarily extend to people that aren't related to them. I found it a very mean place at times and tough for many people. I don't mean to be entirely disparaging because so much is tender and amazing, but the things that strike you are the things you disagree with. There's book called *White Tiger* which is absolutely true.

Have you brought anything back that will help you practice any differently here?

The practice of palliative medicine there is very basic: oral morphine, short-acting steroids, amitriptyline is the only drug available for neuropathic pain. So you can't take too much away clinically. What you can take are the things I reflected on: dealing with frustration, with conflicts in your own mind, with communication problem...things I hadn't really thought about or that I would learn that you can perhaps take into dealing with patients in other countries.

I wondered if Aruvedic medicine has anything to offer towards pain treatment? Any natural drugs or treatments?

I didn't come across anything really effective. It seemed to help some things but I wouldn't recommend it to treat cancer.

Would you go back?

At the moment I am concentrating on finishing my training but I intend to maintain an interest and involvement in palliative care in developing countries for the rest of my career. Once you become aware of the needs for this you do feel some responsibility. The Palliative Care conference in Glasgow, that Jonathan [Koffman] was also at, was very pharmacologically oriented and there was hardly any mention of developing countries.

[Inaudible question]

There are arguments on both sides - there's a possibility of it but ... there's a lot of blunt sedation of patients towards the end of their lives ... the amount of sedatives and opioids being used these days is much less than it used to be 10 or 20 years ago but when does it become too much? Maybe palliative care is trying to validate itself in the general medical community by research involving RCT's etc. but it's important not to forget the things that make it special and different from other specialties.

You didn't mention the spiritual side of palliative care. One of the things that has always struck me about India is that their religions and their daily life are effectively one. There is no separation and everywhere you go there are temples and shrines and people praying. To what extent do patients in the palliative care unit appear to be using their religion during this period?

Kerala is quite a mix of religions but fewer Christians and Muslims than Hindus. Christians would take a lot of strength from their religion, and Muslims, but it's maybe harder to get an understanding from Hindus. A lot of palliative care services there were set up by Christians and are very strongly Christian but Dr Rajgopal himself is atheist and anti-religion – he perhaps has had experience of too much religion and attempted death-bed conversion etc. so perhaps the spiritual side is slightly downplayed in our service and we didn't perhaps attend to the spiritual side as much as we should have.

My grandfather's aunt went out in the 1880s to Madras at the request of the Church of Scotland because there were no women doctors and women were not seen by male doctors. She was essentially attached to a church. She stayed 41 years and saw the building of a new hospital and was instrumental in setting up the first medical school in [inaudible]. Three years ago my husband and I visited the hospital which still exists. We were very impressed. It was not like the hospital we saw yesterday (in Malawi) but they were doing incredible work. We met an incredible team of dedicated doctors and nurses. The school of nursing takes poor but intelligent girls from the villages and trains them up... rights and wrongs of religion... They were already a Christian community ... I was fascinated to see what they were doing with very little.

Global pain:

The size of the problem; what needs to be done?

Michael Bond

“We’re not missionaries but facilitators.”

Yesterday I showed you those pictures of drug sheets for cancer patients forty years ago. One of the doctors that worked in that ward was Frank Neil, who told me that he used to go to India with his wife for a month every year to help with cancer care. Four years ago I went to Ahmadabad in Gujarat state.

I went to their cancer unit and then to their palliative care unit where the director told me that they had a doctor who came from England every year with his wife to help look after the patients. This was the same Frank Neil who was still coming after forty years!

The scale of the problem

Although cancer pain is already a very big problem it's going to get worse. New cases of cancer have been projected to rise from 4.7million in more developed countries and 5.4million in less developed countries in 2000 to 6.0million and 9.3 million respectively in 2020, with a similar rise in deaths. The increase in deaths is going to be much higher in developing countries. (The rise in the USA is also predicted to be greater than that in Europe.) The higher levels are mainly attributable to a greater proportion of elderly people and smoking in these countries, and the lower ones to reduced smoking and a better lifestyle.

I mentioned cancer in Africa yesterday: *Hospice Africa Uganda* was set up by Ann Merriman, a remarkable lady who is now over 70. She started in Kenya and moved to Uganda. They predict that by 2020 there will be one million deaths per year in Africa which represents 10 per cent of the world total. They note that few countries in Africa have access to chemotherapy or radiotherapy, and even where therapy is available less than 5 per cent have access to it. The disease presents late. There are economic constraints. Our survey showed that even where opiates are available only a small proportion of patients ever get them. The whole problem of dealing with huge numbers of cancer patients is compounded by AIDS epidemic which gives rise to an awful lot pain at the end of life usually without any treatment. *Hospice Africa* estimates that the average patient needs 30mg/day oral morphine in solution. They have got the cost down now from \$1.5 dollars to 25 cents US per mg., so it is much more affordable and available now in 12 African countries. But is still expensive relative to people's incomes.

Barriers to good pain management

Lack of education, government policy and fear of addiction feature very highly in many parts of the world. For example in 1985, IASP sent a delegation to Argentina where the government did not allow the importation of opiates. We asked what happens to people with severe pain. The answer was that the rich ones go to the USA and the poor suffer. We asked about appendicitis – what happens to someone poor who gets it? Well, they get put in the back of a truck and taken to a hospital

where if they are lucky they get treated but if not they die. This in a highly westernised country!

The high price of drugs remains a problem, although endeavours to reduce this by getting round manufacturers have been partially successful, as does poor patient compliance.

What needs to be done?

You have to appreciate that this is IASP-speak and I am speaking as an administrator, not as someone who works in a hospice in Africa. I am talking about how we are living with this problem as an international organisation and seeing what we can do to help. Two things came out of the last talk, one I agree with and the other I disagree with. Today we have been looking at a country where the resources are not good, and yesterday at the Maori situation which seems to be very much better, and Malawi which is probably more like India than New Zealand.

It is quite evident that where resources are poor, people still depend on their own resources which they have been using for eons. It has been suggested that we should bring the doctors out of these countries and train them. There is merit in this but two things that militate against them. One is that quite a lot of them from certain parts of the developing world don't want to go back; they want to stay in the West and you can understand why. Secondly the sorts of things you do in the West and take for granted aren't going to be possible in many of the countries they come from.

So the view we in the IASP take is that all the work we do should be based on a bottom-up approach. In other words they tell us what their problems are, what they've got, and ask us to help. So we're not missionaries but facilitators. Better facilities and better pain drugs are not things we are primarily concerned with. There is a group in Wisconsin which has done an enormous amount to lower the barriers to medication in developing countries – Kerala has set the model for this system – and this has been done by co-operation with the international narcotics board. We can't do anything about lack of staff but we may be able to help with better access to physical treatment indirectly and I will come back to this.

So what about these people who are members of IASP? Our survey asked first if they had been trained as pain specialists in any way? In fact a proportion of them have. I spoke yesterday about the differences between continents in this: the overall figure is about 50 per cent. In answer to the question about outpatient facilities over 70 per cent said they did have them. 60 per cent of Asian respondents said they had acute inpatient pain teams, the rest below that level, but it did surprise me that they had gone down this track at all.

IASP education programmes in developing countries

We decided first of all that all programmes must be in keeping with IASP aims and objectives which include education and training in the field of pain, and dissemination of new information about pain research and management. We further saw our role as including advising International, National and Regional Agencies regarding standards in the use of drugs, appliance and other procedures used in pain treatment and informing the general public about pain and its management.

Our Education & Clinical Programmes for Developing Countries has a budget of \$200,000. For the last six years we have been running Education Programmes, now

15 per year. We put out a notice advertising the availability of \$10,000 – a lot of money – to run ‘a pain education course of your choosing: something that fits in with what you perceive to be the need in your country’. Sometimes we get people asking for money for a generic pain course to teach medical or nursing students, for instance for instance the one in Nigeria to teach doctors, nurses, pharmacists and policemen about opiates, one from Kenya to teach nurses and midwives about analgesia in childhood, another from Peru for distance learning courses to teach nurses who work distant from cities about pain management in the community.

More recently we have moved on to clinical training programmes. This brings us back to the question: Do you bring people back to the West or send people there? Or something else? This is in essence the third option. In Bangkok a very good set up for palliative care, pain management and also for general rehabilitation which includes people with pain problems. We started there with short three-month training programmes for people from other parts of Asia (not just from Thailand): the first time I visited there were people there from Mongolia, Malaysia and Vietnam. We then started with a one-year clinical training programme for one individual at a time and they go through the whole gamut in one year of acute and chronic pain, palliative care, pain clinics and techniques. The idea is that this person will go back where they came from to establish a centre in that country. Last year a Malaysian lady came who didn’t speak Thai so you can imagine the problems of going round with an interpreter, and she was a Muslim and had to have periods of time off. This year they have a man from Laos who does speak Thai, so it will be easier for him, but when he goes home he will be the only trained pain doctor in the country, and will set up a centre there.

You might ask how can you send people away and expect them to get on with it. The answer is mentorship. The people in Bangkok act as mentors to those they have trained. The trainees can ‘come in’ by whatever electronic means is suitable and their mentors will go out periodically to see how they are getting on and give them help and advice. This model of a centre that trains very small numbers of, but critically placed, people and then mentors them is, we feel, is a good way forward and doesn’t really involve us teaching them the sort of thing that we do; rather it involves them learning what is appropriate in their part of the world, and what resources they need and how to use them. It is very much a local arrangement with us facilitating it. We may sometimes be asked for someone to run a short course somewhere so we do pay for someone to go out there but that doesn’t happen very often.

This year we have helped set up a similar scheme in Bogota in Columbia. This is taking a one-year trainee from Uruguay. They have a good centre there run by a neurosurgeon and we would like to see it take more people.

These programmes have a psychosocial element as well which is very important, and one thing that has come to me out of this meeting is that we should be thinking about and passing to these people that we must ask what very local resources are used traditionally and how may we support those.

Then we have systems for supporting other groups of people who are doing good work and showing every evidence of expanding in a particular field, and Hospice Africa is one of them. They had \$20,000 to cover the training of two postgraduates who will work in Uganda. *Kybele* is an organisation dedicated to reducing infant and maternal mortality in developing countries; they asked us for help to which we agreed on condition that they also ran a course on adequate pain control in childbirth, which they hadn’t really thought about. We gave them a grant and they are now working in Guyana and Eastern Europe.

Like everyone else we support they are obliged to submit regular reports. What we would really like to do in the longer term is more of this. \$200,000 a year for the last five years is a million dollars, but in order to get even bigger outside funding we need to demonstrate that we have a method that works. We decided in 2004 that we should raise public as well as professional awareness of some of the major areas in pain and pain management. Following *the Declaration of Pain Relief as a Universal Human Right* we launched Global Years against Pain.

We asked all the chapters of IASP to run a programme of events over the year: publicity events, clinical events, whatever they chose to bring to the surface, in the media as well as the professions, the problems in these groups of people. You have probably seen the publications the groups prepare around the topics published by the IASP. Last year it was cancer and this year it's the very common one of pain in musculoskeletal disorders. This is part of our attempt to educate on a much broader basis but we focus for a year at a time.

Earlier this year we prepared a *Forward Strategy* which involved continuing the education programme, expanding clinical training programmes at key sites, developing mentoring programmes, collaborating with WHO and persuading governments to change public health priorities and supporting pain management as a fundamental human right. We further determined to raise public awareness of the scale of pain in the community and need for local action to improve facilities for treatment, to develop new regional centres for clinical training and facilitate translation of guidelines and other documents relating to pain and its management.

Regarding key sites, we would like to establish a site for the southern half of Africa: the middle bit is very difficult. The North African countries, all of which have chapters, are at a different stage of development from Sub-Saharan countries, at least in some instances. The southern site will probably be in South Africa and the northern probably in Cairo. India is the most obvious need at the moment; with our strong connections with Trivandrum and Dr Rajgopal that is an obvious choice, but India is so vast we need one further north as well.

Among new developments this year, the IASP Neuropathic Pain Specialist Interest Group (SIG) which is huge and growing, and threatens to become autonomous, decided without consulting anyone to move into Developing Countries. I went to one of their committee meetings where they were discussing guidelines for the management of neuropathic pain, and it was apparent that they were unaware that in the countries they were talking about very few people know anything about pain at all, and their plans were far too sophisticated and ambitious for the resources available. So they are going to do a survey through their membership in developing countries so they can develop more realistic ideas.

In various parts of the world including EFIC but also in South East Asia and South America the local chapters have decided to hold 'summer schools' of a more basic kind to bring people up to date.

International Pain Summit

The proposed *International Pain Summit* will be discussed at the IASP Congress in Montreal in August. This project was started in 1990 by Michael Cousins, (the Australians already have an internal pain summit) and the plan is to bring all the agencies together to agree on a framework for the management of pain. They want to sign a declaration with the aim of focussing world attention on the under-treatment

of all forms of pain. I always think these things sound fine but how do you do something with them? They also want to send out a call for equity of access to treatment as a moral imperative and to support pain management as a fundamental human right. This is all very laudable but I think it is all apple pie unless you do something. The Australians and the New Zealanders have jointly issued a statement on patients' rights to pain management which lists the right to have pain acknowledged, the right to appropriate assessment and management, recognition of key role of family, the right to monitoring of treatment, the right to be treated by competent health professionals, the right to appropriate pain management strategies and the right to education for patients and families regarding pain management options and planning. That's the sort of thing they are likely to want to push as part of the International Pain Summit campaign. It's going out to governments, health providers of all kinds, and to the general public.

Finally, we have been talking about the concept of the right to pain relief which has perhaps never been expressed better than by the words of Albert Schweitzer:

"We must all die. But that I can save him from days of torture, that is what I feel as my great and ever new privilege. Pain is a more terrible lord of mankind than even death itself".

Discussion

Thank you for a wonderful exposition of the global picture. But it strikes me: where are we in this country? I see the government reducing funding for the NHS and the risk is that one of the things that is likely to go first is the management of pain. So we need to put more of our own house in order – in addition to the globe.

I wouldn't have been able to say very much about this a year ago but having been through the experience of the situation in the Pain Society [while I was Acting President] I know a lot more about what was going on, and it struck me that the Pain Society was becoming a QUANGO of the Government. Almost every week there are new initiatives came to the Pain Society or the Faculty of Pain Medicine seeking opinions or bids for new projects, so there was a tremendous amount going on between the Government and the Society.

The Chronic Pain Coalition has regular meetings with parliamentarians, so a lot of information is being passed to and fro. After the Chief Medical Officer's (CMO) statement last year about pain being a priority for the NHS, which was a real first, a mechanism was set up for regular meetings with his office. That stuttered throughout last year, and what will happen with a new CMO and a new government I don't know, but the Pain Society has had quite a lot of contact with Government in different situations. It has been endeavouring through their initiatives to influence Government and there has been a suggestion (from Beverly Collet and others) to have a summit of all the providers. Kathy Price went to the Australian summit and Michael Cousins came over here at the same time. So there is a lot going on.

But what this summit will achieve I don't know. It strikes me as highly political. Anyway you really have to follow up this sort of thing with an action plan. One of the things that I have discovered is that it is very useful, if you go to a developing country, to try to get them to invite the local health authority chief to come to a meeting. For instance in Gujarat, the minister who came to a meeting at which I spoke promised to do something about education and actually did something within a few months. They are often doctors so they understand the situation, although in

many cases they appear never to have thought about the problem of pain relief – pain is only seen as a symptom of something and will go away if the disease is treated.

Chronic pain management and palliative care are in many ways related and parallel ...can you explore the possibilities at a national or international level of bringing the associations and specialties more closely together?

Yes, it's an ongoing process for the reasons you are inferring. *Pallium India* as has been mentioned caters for both under Rajgopal. At the moment we don't have any formal arrangements in the UK with palliative care organisations but some of you will have found themselves at palliative care meetings and talked about pain. There is a cross-communication of pain management with palliative care, with traffic in that direction. Both the BPS and the IASP are anxious to increase that.

Tolerance, pain and suffering: The responsibility of sufferers

Bobbie Farsides

“We have a problem sometimes when we go to a more complex idea of pain, suffering and distress in understanding what it means to individuals and groups from the outside unless we engage directly by speaking to them about it.”

I have a long-standing interest in ethical issues around cancer and palliative care. Many years ago when I was at Keele University I worked with the *Marie Curie Foundation* to establish a Masters in the Ethics of Palliative Care and had the privilege over many years of talking about the sorts of ethical issues that are raised by people working with patients towards the end of their lives, some suffering considerable pain.

But today because of the amount of expertise in the room I have retreated into my philosophical home and set up a few ideas for us to discuss, looking at the relationship of these ideas of pain and suffering, seeing how useful it is to keep them together or in some circumstances to uncouple them, and also to introduce the concept of tolerance, which I present as a philosopher's perspective later on. I should warn you at the outset that we are going to step into some areas that might be somewhat unexpected.

Theories of ethics and suffering

There is a very strong link between many theories of ethics and concepts of pain and suffering. The theory of *utilitarianism* has become very popular at least at a managerial level in health care. According to it we judge the morality of an action by looking at its consequences and essentially want to know that by doing something or refraining from doing something we are going to create more good than harm, and in fact avoid harm as much as possible. We can see how the avoidance of any form of pain and suffering might be seen to be a moral good, and something which increases or does not take the opportunity to remove existing suffering is harmful. Jeremy Bentham, the founder of utilitarianism, was attracted to this way of thinking about ethics because he felt that it linked inextricably to fundamental truths about human nature. For Bentham, being human was about attempting as far as possible to avoid and pursue pleasure. So you need a moral theory which will fit into those intuitions rather than fight against them. But also for Bentham this idea of avoiding pain and suffering and pursuing pleasure was at the root of a very profound egalitarianism. He was famous in his age for trumpeting various forms of equality but perhaps most unusually equality between humans and animals, and in his *Introduction to the Principles of Morals and Legislation*, he said:

“... The question is not, can they reason? Nor, can they talk? But, can they suffer? Why should the law refuse its protection to any sensitive being? The time will come when humanity will extend its mantle over everything which breathes...”

We may not have got as far as that but we have certainly understood that the suffering of any sentient being is something with which we should be morally concerned and engaged.

If we look at the *consequentialist* model of ethical thinking we certainly see how pain and suffering plays its part. But not everyone is drawn to this – some would say we can't simply negotiate our moral lives by always looking forward to consequences particularly given the uncertainty of our future. Perhaps instead we want to ground our moral thinking in some certainties: some ideas of the moral laws, obligations or duties that should govern our behaviour; some account of the obligations we feel that we should have towards others. And that leads us into a completely different way of thinking about basic ethics. *Deontology* involves the idea that morality is in some sense backward rather than forward looking because we judge what we ought to do by understanding the principles we wish to be governed by; the laws that we think are important; the obligations and duties we have. But having said that, it doesn't mean that any narrative around suffering disappears. If you open any basic moral philosophy textbook and look for deontological approaches, it's very interesting that you often get presented – maybe in different words – a very similar hierarchy of moral duties: the idea being that if you haven't got a whole life to dedicate to being good, here is the way you should prioritise things.

First of all *do no harm*. Doctors among you will be aware of the way that has been built into your professional codes. If you've got a bit of moral energy left over after you've done no harm to people perhaps you could spend some time *removing existing harms*: look out to see where there is some wrong or suffering in the world and expend some energy getting rid of that. If you are still inclined to do more then you could start looking at how you can *prevent harms in the future*. Finally if you're really committed you can *do some good*.

As you see the priority in the first instance is keeping your own hands clean, not adding to harms already in the world, and finally moving through to positively doing some good.

Suffering

So built into the very fabric of moral thinking are the ideas of pain, harm and suffering. If you look at how moral philosophy and theology engage – for a profoundly deontological account – you can turn to this declaration by Pope John Paul

“.....even though man knows and is close to the sufferings of the animal world, nevertheless what we express by the word "suffering" seems to be particularly essential to the nature of man. It is as deep as man himself, precisely because it manifests in its own way that depth which is proper to man, and in its own way surpasses it. Suffering seems to belong to man's transcendence: it is one of those points in which man is in a certain sense "destined" to go beyond himself, and he is called to this in a mysterious way.”

Salvifici Doloris (1984)

So you might also present suffering as an essential feature of humanity that can to a certain extent be understood, but also might transcend what we understand in the ordinary world. Such suffering is represented familiarly in art. [*Illustrated by a classical painting of the Pieta*] We also have literature to help us understand the idea of suffering, for example:

“Deep unspeakable suffering may well be called a baptism, a regeneration, the initiation into a new state.” (George Elliot, Adam Bede)

Pain has an element of blank;
 It cannot recollect
 When it began, or if there were
 A day when it was not.
 It has no future but itself,
 Its infinite realms contain
 Its past, enlightened to perceive
 New periods of pain

Emily Dickinson

That's an incredibly powerful evocation of the sense of being trapped in the experience of pain.

So there are many ways in which we can seek to understand and represent the idea of suffering. But of course we are speaking in the context of medicine and health care and how the idea of suffering transports into this world. We have to be very well aware of the medicalisation of this concept and the concurrent risk of reductionism. I have picked up that this is a concern of this audience. Someone made a wonderful comment yesterday afternoon about having a great interest in understanding and then teaching where things come from and how they are caused, but perhaps falling short in understanding how they are experienced or what they mean. That has implications both in terms of identifying suffering but also responding appropriately.

So what we need to do is to use the various tools that we can employ to give us this broader understanding, and to see why Emily Dickinson presents this to us in such a powerful way. Because it's actually very easy to represent, with the help of an X-ray, somebody suffering lung cancer to medical students. We can see what it means in terms of that X-ray; to see even more we can remove that diseased lung from the human body. But neither of those images tells us anything at all about the person who experienced the illness or what the illness meant to them. So we do have to constantly find ways of building back in that understanding of the situation. When we stop to talk about, or talk to, or converse with people suffering disease it is sometimes quite surprising how they explain to us the major problems associated with it.

I have found the paper *Stigma, shame, and blame experienced by patients with lung cancer: Qualitative study* by Chapple, Ziebland and McPherson, very powerful. One of the things that distressed participants most was, as they described it, the stigma and shame and blame they experienced with lung cancer because of the association with lifestyle choices, especially smoking. In particular people who had never smoked found this very unjust and distressing. That is the sort of thing we can only learn by talking to people who are suffering.

So there is an enormous role for good qualitative research into the area of pain and suffering. Another study which has had a long-term influence is that of Bach, Campangolo and Hoeman on *Life satisfaction of individuals with Duchene muscular dystrophy using long-term mechanical ventilatory support* (1991). If we think just in abstract, suffering in this way sets off all sorts of alarm bells in our minds about quality of life and what that experience must be like. But this study actually showed that when compared to the normal population there was not too great a difference in terms of the dissatisfactions with normal living amongst this group of patients. And perhaps rather worryingly, health care professionals caring for these people greatly over estimated what they would consider the impoverishment of their own quality of life.

Slevin and colleagues' 1990 *Study of attitudes to chemotherapy: Comparing views of patients with cancer with those of doctors, nurses, and the general public* asked what sort of risks these patients would be prepared to take as regards toxicity and side-effects in order to gain quite small benefits and again the differences between the perceptions of the various groups were very pronounced with the health care professions being much more cautious than the patients themselves.

So we have a problem sometimes when we go to a more complex idea of pain, suffering and distress in understanding what it means to individuals and groups from the outside unless we engage directly by speaking to them about it. We now have in various parts of the world countries or states that have chosen to legislate to allow a certain amount of medical assistance in dying, a well-known example being the *Oregon Death with Dignity Act*. One thing to have come out of this is the series of very interesting annual reports which give us a very clear picture of what is actually happening in terms of who requests assistance in dying: not only the diseases they are suffering from but also people's education levels etc., and also what are the reasons that people give for requesting assistance and what was actually gone through with. In 2009 the report states: "As in previous years, the most frequently mentioned end-of-life concerns were: loss of autonomy (96.6 per cent), loss of dignity (91.5 per cent), and decreasing ability to participate in activities that made life enjoyable (86.4 per cent)."

You will notice that pain does not feature in that list and if you look at research that has been conducted in the Netherlands over many years you will see that pain usually comes in around fifth in the list of issues (although I have heard anecdotally that pain seems to be rising up the list.) Here again we have the idea that the form of suffering that leads these people in these situations to want their life to come to an end is existential suffering: the person they think they have become, the autonomy and dignity they have lost, and the way their life has lost the associations that give it value. Hopefully these statements are being made in the context of good palliative care where all that is necessary is being done to relieve pain and other distressing symptoms.

Where do we go from here?

We have this idea that the removal or avoidance of pain and suffering is an ethically important issue built into most of our moral theories; and that the way in which somebody with ethical concerns might engage with pain and suffering has to go far beyond the physical to think about the spiritual and the existential. But we also have to think back to your discussions yesterday about culture, and where in society pain and suffering exists and who might get involved in the management of that at a more societal level. What I want to explore now is if we think it is important to remove pain, are there any points at which we might have some sense of a conflict of interest; or are there other values or things of moral importance that we might wish to preserve, promote or not interfere with that would mean that when we looked at the opportunity to remove pain and suffering we would have a conflict to deal with.

The first example I have chosen is a very difficult one to discuss in many ways: it is that of Female Genital Mutilation (FGM). This quote is taken from a WHO factsheet:

"FGM is recognized internationally as a violation of the human rights of girls and women. It reflects deep-rooted inequality between the sexes, and constitutes an extreme form of discrimination against women. It is nearly always carried out on minors and is a violation of the rights of children. The practice also violates a

person's rights to health, security and physical integrity, the right to be free from torture and cruel, inhuman or degrading treatment, and the right to life when the procedure results in death."

That's a very full-on moral condemnation of a practice that is still culturally embraced in many areas of the world, so without making a judgement we already realise we have a problem. If this is seen as culturally significant and if the refusal of the choice not to engage with this practice also has costs associated with it where are we going to stand nationally and internationally on this issue? In the UK it is not permitted for medical professionals to be involved in this practice, and one of the things that the WHO has worried about in recent years is the medicalisation of FGM as a bid to counter the arguments around safety and the risk of death. So we are saying here we are not going to allow the medical profession to be involved in this, but we have in certain boroughs in London large populations that still wish to practice FGM on their daughters and there has been a high level of social service intervention trying to prevent children being removed from the country for this purpose.

So here is a situation in which the harms involved are of such a sort, both moral and in terms of not respecting equality of the sexes, not protecting children from harm, violating physical integrity, and harms easily understood as regards what is done to the human body, that we will not tolerate them; and we are going to stop this being done here and even try to prevent people going elsewhere to have it done. Our tolerance stops at this level. And it stops even though this is something which is being done even within a cultural setting where this is understood very differently, and if we go back to John Stuart Mill's way of thinking, some would say that it is a private matter.

Let's look at another example. I don't know if any of you remember the legal case that followed on from the police operation 'Spanner'? Some years ago in the quiet town of Whitchurch in Shropshire the police happened upon some film that had been taken at a regular gathering of the local sadomasochistic (S&M) circle. Unspeakable things were being done to people and the police started to investigate it as an issue of Gross Bodily Harm (GBH). As soon as their enquiries began what they actually discovered was that this was a group of fully competent consenting adults having what they thought was great fun. The film had never been meant to be let out. When the matter eventually came to court it became a case about something quite different, i.e. what is the state's right to intervene in the lives of people who are unquestionably doing things that were physically harmful to one another, but was their choice even though there was an element in it which most of us would fail to understand. The English court said: "A person does not have the legal ability to consent to receive an act which will cause serious bodily harm, such as extreme activities of a sadomasochistic nature." But this had become such an issue that the groups took it to the European Court of Human Rights who came up with the same judgement that the law did not have to tolerate this sort of activity but expressed it rather differently: "Whilst a person has a general right of free will, a state may, as a matter of public policy, restrict that in certain cases, for example for the general public good and for the protection of morals"

The present case was judged by the European Court to have fallen within the sovereign scope of the UK Government's right to determine its legality, and current (as of 1997) human rights legislation would not overrule this.

So here we have the idea that a society has the right to intervene in private decisions of individuals in order to protect its own moral standards and the general public good.

Tolerance

I suspect there are people in this room wondering where on earth this is going to go next! So where have we got to? I have used the term tolerate, and the concept of tolerance is central to what I am going to say next. If you talk to a moral philosopher about what it means to be tolerant of something I think that you would use the language much more carefully than we sometimes do and therefore there would be things about it that may slip out of use in common parlance.

Firstly there is no point in talking about tolerance in an atmosphere where everybody is terribly *laissez faire* about what people do in terms of the moral standards they support through their own actions. Where we take the view that it's all relative and you do what you want and so will I so we can muddle along together, then that's not an area in which we have to think very much about tolerance, because tolerance is something that usually comes alongside commitment to particular moral views. So to be tolerant is something that often should accompany your actually being committed to certain views yourself, such that you do look out on the world and think that other people are doing things that are wrong. You're not completely *laissez faire*: you have some idea of right and wrong. Tolerance becomes an issue when you look out there and see people doing things that you consider to be wrong. But when you do this you demonstrate a willingness to allow that act to happen, because you want to show respect to those individuals with regard to their rights and their autonomy to do that which they think is even morally right, or at least morally indifferent, in ways that you do not. So it is a profound form of respect to individual to individual autonomy. But it can't be and it shouldn't be and it isn't completely untrammelled because we have limits to our tolerance. There is a sense in which we call a stop to things.

To use a very trivial example: we have neighbours who are blessed with a huge beautiful garden, but the end of it is very close to our house. One of their favourite summertime pursuits is have a garden party and they always go to our end for it! I think that's wrong but I am prepared to tolerate it – but at 2.30am recently my point of tolerance to noisy music and teenagers came to an end! So we are prepared to allow others to do things that we consider to be wrong and prepared to some extent to allow harms to be created; despite our inclination to do no harm we might allow other people to do things we think are harmful as we need to respect their autonomy. But in saying that you tolerate something, always remember that you are carrying with you the idea that you are putting up with something that is wrong, which is why for some people tolerance is not enough. I remember many years ago Peter Tatchell talking in the context of equal rights for homosexuals and saying *“Don't tell me you tolerate me because in saying that you are also saying that what I do and what I am is wrong.”*

So where are we going to take this idea of tolerance? Back in 2001, I was very fortunate to be asked to be one of the specialist advisers to Lord Joffe's House of Lords bill that was looking at the possibility of introducing assisted dying. It was an incredibly polarised debate: not only in society but also within the House of Lords committee. In some ways it wasn't a pleasant experience being caught in the middle. But actually one of the discussions that kept coming back to the committee, and perhaps one in which people were prepared to put their differences aside and really think about what they could agree on was to do with the very first paragraph from the bill which defined it as: *“A Bill to enable a competent adult who is suffering unbearably as a result of a terminal illness to receive medical assistance to die at his own considered and persistent request, and to make provision for a person suffering from a terminal illness to receive pain relief medication”*.

It was generally accepted very early on that the latter part of the bill was misguided. It was an attempt to soften the pill but it could be argued that that right already existed. There might be certain societal issues we have to deal with in order to ensure that doctors remained confident to provide adequate pain relief at the end of life and that things like the Shipman effect don't have too disastrous an impact on prescribing practices; but generally it could be said that we have accommodated to this. Where the discussions kept coming back to was how do we decide that suffering is unbearable when we are not just commenting on an individual case but moving that concept into legislation, and therefore as a society looking to make profound changes in the law based on the evaluation of a particular individual's suffering. And frankly it was one of the major stumbling blocks for this piece of legislation that people could not give content to this idea of unbearable suffering: they didn't agree on who should judge if and when suffering became unbearable, and proposals were made that if this ever came back again in a slightly different form perhaps that concept should disappear completely and be replaced by *unrelievable* suffering. We are not looking to an individual to define and explain their suffering in a way that convinces us of its unbearable nature, but puts the onus on health care professionals to ask themselves the question; have we done everything we can to relieve this suffering, be it physical, psychosocial or spiritual and if we have and it is still there, what does that mean?

So the problem of definition was resolved in the legislation thus: "Unbearable suffering' means unbearable suffering whether by reason of pain or otherwise as a result of an irremediable condition, the ending of which suffering would be a humane act for that particular patient; and 'suffering unbearably' shall be construed accordingly". What Lord Joffe tried to do in drafting this bill was to say that the very definition of unbearable suffering entails the fact that the ending of that suffering by whatever means - in this context we are talking about medical assistance with dying - would be a humane act; thus challenging the widely held but opposing view that to introduce the notion of patient killing into the medical arena is to produce a profoundly unethical concept.

The interests of society versus prevention of unbearable individual suffering

So how does this all tie together in terms of the title of my talk? Lord Joffe told the House of Lords in the final reading of the Bill, at which it was defeated, that patients should not have to endure unbearable pain for the good of society as a whole. The cross-bench peers said we must find a solution to the unbearable suffering of patients whose needs cannot be met by palliative care. Now this of course is political rhetoric, but I think the idea contained in that final statement is very interesting in terms of what we will or will not tolerate as a society round issues of pain and suffering. Because what we saw in the two cases I discussed earlier was a great willingness of society to intervene and to have laws and mechanisms whereby we protect people from particular forms of pain and suffering.

Even when in the first case (FGM) a robust cultural defence is offered for that, because we see that the degree of suffering to be such and also that the suffering is exerted on children between the ages of nought and fifteen who might not, indeed should not be seen as competent to choose in that context, we intervene, we do not tolerate. In the second case, (S&M), we again see pain and suffering but in this instance it has been chosen, sought and people have gone a long way to find it. But again we're going to say we are not going to allow that. In this case we have people telling us that they have unbearable suffering and asking for the law to be changed in order to allow them to be relieved of it. And going back to Joffe's claim, unbearable

suffering is suffering the ending of which it would be a humane act. But we chose through our legislatures to reject that argument. So what have we in effect done? I would say we have asked the people who claim to be suffering unbearably to tolerate that pain in the interests of a society which feels that there are important reasons to take very seriously any proposed change in the law that moves towards medically assisted dying. So we have actually turned the issue on its head and said in the first few instances we will not tolerate pain and suffering, but in this case we have to tolerate a certain level. Can a society faced with this example choose to tolerate what a small minority of people tell us is their unbearable suffering in the interest of protecting those people and others from harms they do not recognise or acknowledge? Should those who claim to be suffering unbearably be expected to tolerate their suffering in the interests of defending moral principles they see as inappropriately applied in their case, protecting society or in order to avoid the harms others believe would follow on from giving them the right to seek assistance in ending their lives?

Now I'm not making a judgement on these issues. All I hope I have done is shown you how by using some of the conceptual frameworks we use quite happily in other areas we end up with what we might think is slightly uncomfortable reversal of asking people to tolerate their own pain and suffering in the interests of society.

Discussion

I think as professionals we would say to you we can reduce unbearable suffering by whatever means and I think that's the fundamental argument. We heard yesterday that only 5 per cent of patients seek assistance with ending their lives so there are other things society needs to do before we start getting into the realms of killing patients because we can end intolerable suffering without actually killing someone.

I'm going to preface my response to that by saying that on the one hand I'm not an advocate of assisted dying. I remain firmly perching on the fence; and I am also a great friend to the palliative care profession and spend a lot of my time working with them, but I don't think you can care away some forms of suffering. You can relieve symptoms and control side-effects very effectively; and for the vast majority you can give excellent psychosocial and spiritual support. But for a minority of people – and these are the people that become recognisable in the Oregon death with dignity act – who are possibly a sort of phenotype of psychological mindset rather than a set of physical symptoms - for some people you cannot make their suffering bearable and those are the hard cases. I know hard cases make bad laws but I would challenge anyone in this room to say I have succeeded 100 per cent over the years. It might be a very small minority but for some people the suffering that is associated with their particular condition - it's not anyone's fault, it's their illness experience, their sense of being, nothing to do with any deficit of care - but the question is what is that small minority of people entitled to expect of the rest of us.

I wonder whether the core difficulty is the conflict between on the one hand the acceptance of the autonomy of the individual, and yet on the other the protection of that concept. The examples you gave illustrate that conflict. You've got the young girls who are not going to be able to participate in exercising autonomy or even if they are a bit older they still can't because of other pressures. You've got sadomasochism – and I suspect that society's concern is that people aren't entering that with total freedom. And they've got neighbours: the autonomy of the partygoers versus the autonomy of the neighbours who are trying to get to sleep.

I think one of the big factors in terms of assisted dying is the concern that those that enter into or request it are actually being pressured in some way.

You've put it beautifully. There is always going to be that concern. If you have an autonomy argument you'd first of all want to know that it's a valid, authentic autonomy. Certainly in the mutilation case we have to have very serious concerns. We must analyse the facts of the case and see that it genuinely fits into how we want the argument to run. When we get to the assisted dying case, if you look at the Oregon data there is very little to suggest that we should worry about coercion or lack of autonomy or people being socially disadvantaged or having financial concerns. It seems not to be the case, but it is not so clear that we can extrapolate from that that it will never be the case that people will feel pressured to make choices of reasons that we may not feel were inextricably bound up with unbearable suffering.

But interestingly, even thinking about that, some philosophers have come up with the idea that when we express our autonomy it's naïve to think that all we do is to say what we want to do in an individualised, actualised, sovereign way. Actually when we exercise our autonomy we often have the interests of others in mind but they are close others, and we might make a decision that we would like to end our life sooner rather than later in part for other regarding reasons. The interesting question then becomes is that OK? If nobody has imposed that upon me might I think that I would like my life to end now rather than later not only for my own reasons but out of concern for others.

It is possible to over-legislate, and to get into situations mindful of mediaeval philosophers arguing about angels on the head of a pin. You can always relieve suffering without killing somebody. And the point at issue there is you can give someone an anaesthetic and put them out of their misery but you may not deliberately kill them but their death may not be a looked for but an acceptable side effect. A lot of the debate goes around the difference between assisted dying and relieving pain knowing that a possible side-effect is dying earlier than they probably would otherwise.

What you are describing is appropriate pain relief – it's nothing to do with causing death. I might say that's great because I trust you to use this so-called doctrine of double effect to relieve my suffering because this is the only means you have available, and I accept this side-effect of earlier death – I'm trusting you to stick to the primary motivation to relieve suffering, because if you don't think that way then you get the possibility of people being driven to say this person would be better off dead, and if I give them that treatment it will hasten death. Some people worry as much about that possible switch in thinking which would be very difficult to legislate for, because it happens in the heads and consciences of individual practitioners. I find the doctrine of double effect very useful and reassuring in discussing these matters with people involved in pain relief issues at the end of life. What people worry about is the people who in some way pervert that knowledge to say the only way I can relieve this suffering is through death and here is a form of pain relief that looks like a respectable way of doing that. But we will never effectively legislate against that because it involves the consciences of individual practitioners.

The majority of us here are not primarily involved in palliative care but in the treatment of chronic pain situations where there isn't the option of assisted dying, but the pain certainly appears to be truly intolerable, and we might in some desperation be tempted to resort to measures that are possibly harmful to the patient.

There was the famous case of Dr Potts who was a Rheumatologist whose long-term patient had a devastating form of arthritis and had got to the stage where she couldn't bear to be touched and howled like an animal in pain if someone even brushed against her. She and her family were begging Dr Potts to do something for her, and eventually he injected her with potassium chloride. He recorded that in her notes and a nurse who profoundly disagreed with what he had done reported him and it went to court where I think he was found guilty of attempted murder. The General Medical Council (GMC) ruled that he could only continue to practice if he underwent further training so he was sent on a pain management course. Their response was perceived to be lenient because here was a doctor who had known the patient for years and had her best interests at heart and came to the point of thinking – mistakenly, the judge thought, because if he had had more knowledge he might have known where to send her for better pain relief – that he really had to do what this woman asked.

So there are cases, that being the most famous one, of people who are driven to agreeing with a patient that their pain is unbearable and unrelievable. There is an extra tragedy in those circumstances because of the long term caring relationship between these individuals and the family group. So I have no advice to offer but huge amounts of sympathy with the predicament. Maybe that says as much about the support services that should be as available in chronic pain as they are in oncology where we have got much better at delivering a more holistic model of care: something that acknowledges that pain and suffering from chronic diseases is as complex and challenging and might result in just as much of a crisis as may arise in other areas.

What happens if you have the 'fix' for pain and it does not fix you?

Paul Dieppe

“We need more research, including comparative studies on other types of chronic post-operative pain.”

I'm going to talk mainly about knee replacements (TKR). There are over 60,000 done per annum in the UK alone, far outstretching hip replacement, and continues to rise fast.

There are a number of reasons for this including obesity. It is claimed that over 90 per cent of operations are very successful, and indeed if you look at the average pain scores they do get better, but of course not everyone is average - one of the many *Achilles Heels of Evidence Based Medicine*. The problem is that there are actually quite a lot of people who have the same problem after the TKR as before. I'm going to talk about three aspects of this: a bit about epidemiology and biomedical mechanisms but more about experiences and consequences: what is it like to be left worse off, and how do patients and doctors deal with it .

It is extremely difficult to ascertain how common this is as grateful patients feel they must be better off without the arthritic joint and they need to rationalise the decision to have it done, and are reluctant to say that it still hurts. Based on registry data of outcomes using pain and satisfaction scores six months after TKR there appears to be a 'satisfactory' outcome in about 65 per cent, an 'unsatisfactory' outcome in about 15 per cent and an 'uncertain' outcome in about 20 per cent. We have also looked at one of our own cohorts in Bristol where out of 632 patients 272 (44 per cent) reported chronic pain in the operated knee which was 'severe' in 71 (11 per cent). 190 of those with chronic knee pain said it was less severe than pre-operative pain and 82 (13 per cent) said it was as bad or worse than before TKR. So it seems that more than 10 per cent of people had worse pain but this is likely to be a big underestimate.

The risk factors seem to be what you might expect for any chronic pain: they include demographic ones such as female gender, advanced age and low economic status, disease-related factors such as worse pre-operative status and number of co-morbidities, and psychological factors including low self-efficacy and poor coping strategies, as well as low preoperative pain threshold.

We know very little about the mechanisms as this is a problem which has been largely ignored until recently. There are many possibilities, including mechanical pain from the joint or peri-articular tissues, neuropathic pain, either prior to or as a result of surgery, or something else. I have seen a patient with a grossly bent leg (the X-ray showed both tibia and fibula broken and healed at a bizarre angle) who said her severe pain had been cured – she couldn't walk but then she couldn't before the operation. This illustrates the dichotomy between technical outcome and patient outcome, and there is almost no relation between these. So it is patient outcome that we have to think about. The operation is occasionally done wrong but this is rare. In a small case series of my own of 21 patients with chronic pain after TKR, seven had activity related pain similar to that prior to surgery, 7 had a neuropathic type of pain (I

don't know whether they had this before surgery) and 7 had something else which I think may be a bone response related to raised intra-osseous pressure. In addition there were a lot of psychosocial issues and other factors.

Qualitative research by Gillian Woolhead and more by Anna Sansom revealed that the patients' common themes were confusion about what had happened, denial of the problem and self-blame. And from the surgeons? Confusion, denial and self-blame! The blame culture that we live in is a factor here; a typical patient reaction is that surgery went well so it must be my fault – I must have done something wrong after the operation. Surgeons have denied this problem for a long time but now think if they see somebody who tells them they have pain they think they must have done something wrong and blame themselves, and some suffer from a quite distressing level of guilt. Some people have to shift blame on to other people: either patients on to surgeons and think they must have messed up the operation, and surgeons on to patients – 'The X-rays are fine so it can't be painful.'

How do people make sense of this? I'm going to show you a few quotes from people who have had the fix and it hasn't fixed it:

"I had a very good outcome...I do get a lot of pain still ..."

(By far the commonest reaction; it illustrates the difference between the public view – the former – and the private view, the latter. And we are all capable of holding conflicting views at the same time).

"It's nothing to do with the joint now; it's more down to me ... I think I might have done too much too soon."

"You only receive what you deserve from God"

"Everything's wearing out, and I can't, you know, blame the operation"

"It's hard because I feel there is something wrong, but the x-rays are telling me there isn't"

Most of these responses militate against seeking further help with the problem. We think, although there is no way of being sure, that most people don't actually come back because they have found some way of making sense of the situation. And that allows us to think this problem doesn't exist.

What do we need to do about it?

First we must acknowledge the extent of the problem. Next we must try to work out the risk for any individual pre-operatively. I am working with the NHS decision-making project (NHS III IDM) to try and allow people to get an idea of the likely risk and gains of joint replacement surgery, but we don't have enough data at the moment. It may be that we have to approach consent differently, and one of the things Anna Samson has been working on is the wildly different approaches surgeons take to this from everything is going to be fine to it might kill you. Then if a patient does have a problem we need to validate it. And we need more research, including comparative studies on other types of chronic post-operative pain.

Unbearable pain

Finally I want to get back to the subject of unbearable pain. A lot of people describe the pain of severe joint disease as unbearable. I have had several consultations that have gone something like this:

“What was it like before surgery?”

“Absolutely unbearable, I had to do something”

‘What is it like now?’

“Much worse”

‘What are you doing about it?’

“Well you know, it becomes part of you...you just learn how to deal with it...”

This worries me. I want to leave you with two disturbing thoughts that have come out of this work. The first is that maybe people only get better from joint replacements because our culture says they should. Maybe it's about response shift: (I must have been much worse than I am now) or context effects, belief, rationalisation or gratitude. It's a recent phenomenon in which all the rhetoric is fantastic so people get better – maybe it's all just a trick.

My second disturbing thought is that maybe joint pain has only become 'unbearable' since we have had the technology that is supposed to fix it. I worry about this in the context of the conversation about the previous talk: what does unbearable mean? Does it mean you think there is a way out of this? Is that what people are saying when they say “unbearable”?

So none of this is as simple as I thought it was a few years ago.

Discussion

Some patients who have had a successful TKR have pain after a technically satisfactory procedure on the second side, which is a mystery.

If you've had years of chronic pain beforehand you must have central sensitisation so it is difficult to see how the procedure ever works. In a study of people with bilateral knee pain we injected one knee with either placebo or local anaesthetic, and if people got a response to LA they got it in both knees. That is fairly strong evidence that there is spinal cross-representation and there is other evidence of that.

Most people with hip replacements get almost immediate and almost total relief for their preoperative pain. They must have had sensitisation, but for some reason just taking away the nociceptive drive cures the hip - and often cures knees. So perhaps we need to assess sensitisation preoperatively and treat it more aggressively. Pain threshold in other parts of the body is also quite a strong predictor.

If we are honest about this a lot of patients will say “I wish someone had told me that I've been wasting my time having all these bloody awful treatments”.

This applies to virtually everything we do in chronic pain. Nothing we do does any good and yet we continue in this kind of delusion of hope. In reality we should be saying there's nothing we can do, so you should be looking at some other parts of your life and see if you could make them better.

But I don't think it's right to say everything is finished. I think hope is important and sending people away with no hope is a very serious mistake.

Alleviating suffering at the end of life*: Symbolic mortality and other coping strategies

Robert Zalenski and Luisa Kcompt

“Immortality, the concept of living in a physical or spiritual form for an infinite or inconceivably vast length of time, can be interpreted in various ways which may prove helpful to dying patients and their families.”

** The recording of this session was lost and this version is a reconstruction from the speakers' PowerPoint presentation and notes. Inevitably there is no record of the discussion.*

The Final Stage of Life

This is an extension of Erikson's Stage Theory which suggests that each stage has a dystonic and a syntonic element. The key challenge in this context is to counter despair with integrity so that the patient achieves integration in place of hopelessness.

This approach involves specific goals and challenges. A terminal diagnosis produces a crisis which evokes the call to *turn* to face the crisis of death; to be willing to undergo *transformation* and engage on the tasks of the final stage; and to experience *transcendence*, rising above the illness.

This involves specific tasks for both patient and carer:

1. To accept one's mortality
2. To control pain and other distressing symptoms
3. To alleviate emotional distress
4. To express love and affirmation
5. To connect with family and loved ones
6. To find meaning through review of one's life
7. To complete important tasks or actions

These are tasks that the palliative care or hospice clinician needs to facilitate at end of life. Notice that most of them are psychosocial and spiritual in nature. Fulfilling these tasks leads to a reduction in suffering.

What is suffering?

“Who is there in all the world who listens to us? Here I am – this is me in my nakedness, with my wounds, my secret grief, my despair, my betrayal, my pain which I can't express, my terror, my abandonment. Oh, listen to me for a day, an hour, a moment, lest I expire in my terrible wilderness, my lonely silence. O God, is there no one to listen.”

Seneca (65A.D)

Cecily Saunders transformed this inchoate concept of suffering into a composite structure consisting of four elements: physical, psychological, social, and spiritual. This can be translated into four types of brokenness: broken bodies, broken minds, broken roles and broken beliefs. Suffering refers to the psychological, social and spiritual pain that a patient may experience in addition to, or in the absence of,

physical pain. If left untreated, psychosocial and spiritual pain can manifest itself as physical pain or exacerbate current physical pain symptoms.

The crisis facing patient and family

Grief begins when the diagnosis and prognosis are given. These challenge our sense of immortality. When newly confronted with the awareness of their impending death, many patients experience a psychological and spiritual crisis. The abyss experienced is the direct knowledge and intuition that 'I'm going to die' and their sense of future is altered, which triggers a search for meaning in their lives. Patients struggle with spiritual questions, such as what happens to me after death? Is there really a God? What is the meaning of my suffering? Why me? What is my sense of purpose? They may be overcome by the fear of death and the process of dying. The emotional equilibrium of the patient's and their family's world is threatened. To soften or attenuate this suffering, the spirit reaches for an antidote, a potion or belief that restores our sense of immortality - or what we are referring to in this presentation as *symbolic immortality*.

Patient losses

The dying patient must face a catalogue of losses. These include loss of *health* from debilitating disease which may result in chronic or acute pain, loss of *independence* through loss of mobility or control of bodily functions and loss of *self-image* resulting from changes in physical appearance. They may lose their *role* as illness changes the family dynamic and they can no longer fulfill their previous role as breadwinner or nurturer, and they are no longer involved in decision making. This may be accompanied by loss of income and financial security. They may lose *friends* and illness may result in social isolation. They may experience loss of their *own space* in hospital, hospice or nursing home: loss of their own kitchen, a favourite view out of a window or a pet, as well as their daily routine. Comfort within one's own home environment may be compromised if they require homecare services or private caregivers in the home. They may lose participation in a spiritual community if they are unable to attend their church. Patients in hospices and nursing homes may suffer the loss of a roommate. Overshadowing all these losses may be the perception that there is no future to look forward to.

Family losses

Family members may also experience multiple losses; as well as facing loss of a companion, an escort to social events and a handyman/woman about the house, they may be losing someone with the role of family leader, be it patriarch or matriarch. Not only may they have to assume the burden of caregiver, but the loss of real and potential income involved in staying at home to care for the patient may add to anxieties about financial security.

Longstanding family conflicts may give rise to both resentment and guilt, but remain unresolved due to reluctance talk about them in the circumstances. Painful but hidden scars from the deep wounds of childhood abuse, neglect or abandonment may emerge.

Anxiety

Anxiety is another source of psychological pain. As well as the losses described above, and obvious anxieties about pain and suffering, there is fear of the unknown, of personal extinction, of mutilation and decomposition; loneliness and a sense of abandonment, together with perceived loss of identity add further distress.

Pharmacological treatment of anxiety may be necessary to manage pain and symptoms, but it does not treat the fear that eats away at the psyche. Helping people to identify the fear behind the anxiety can lead toward the resolution of that feeling. Often it is simply someone's presence, compassion, and gentle reassurance that can help to alleviate the fear of loss and assist in accepting what will be.

Death anxiety may overlap with spiritual issues because much of this involves questions about the afterlife. Spirituality and social support can reduce death anxiety. It is important to allow people to openly discuss spiritual issues and clarify their own beliefs.

Commonly expressed apprehensions include:

What will happen to my body and mind as this illness progresses?

How much pain will I be in?

What kind of help will I need to function or survive?

Who will be there for me?

Will my family and friends still love me if I look ugly and smell bad?

What will happen to my family after I die?

These topics may be difficult for patients (or family members) to verbalize and discuss openly. It takes trust within the helping relationship before they can feel safe enough to express these concerns, especially if the source of the pain stems from the past.

Spirituality and Spiritual Pain

Spirituality may be defined for our present purposes as: the search for meaning and purpose of life; connection to the moment, the self, others, nature or a higher power; and the capacity to preserve hope in the face of challenges to the quality of life. It is the dimension of human life that encompasses one's relationship with others, self, "God," or ultimate source of meaning. It involves seeking answers to one's ultimate questions about the meaning of life, illness and death. For many of us, the spiritual aspect of our lives remains undeveloped until a traumatic event, such as a serious illness or the death of a loved one, confronts us with our own human fragility and mortality.

Spirituality is a much broader and more inclusive concept than religion, which is a system of beliefs and practices, often institutionalized, that express one's spirituality. The Latin word *religio* means to re-link or to bind up again. Religion is usually a subset of spirituality. Spirituality is more about whether or not we can sleep at night than about whether or not we go to church. It is about either being integrated or

falling apart, about being within community or being lonely, about being in harmony with Mother Earth or being alienated from her.

“Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connections to the moment, the self, to others, to nature, and to the significant or sacred”.

Ronald Rolheiser, *The Holy Longing*

Spiritual pain involves feelings of alienation from God, self and others, perhaps including one's religious community. It may be aggravated by loss of access to religious rituals. People suffering spiritual pain find themselves unable to find meaning or hope in the experience of illness. Sometimes any comfort they can find in their spiritual belief is undermined by opposition to this from family members and even health care providers.

The relief of spiritual pain demands helping someone to discover a higher purpose in life and a sense of connection or oneness. They must be encouraged to resolve spiritual issues connected with the meaning of life and suffering, to finish their unfinished business and achieve life closure. This may require them to clarify their belief system and develop or reinforce their relationship with a Higher Power, whatever they perceive this to be. Necessary steps may include reconciling with a loved one, praying for forgiveness, forgiving oneself, or asking for forgiveness from another.

The prospect of dying prompts many questions which people may seek help with resolving. These include:

Who am I?

Why am I here?

What is the purpose of my life?

What good am I when I can no longer do the things that I used to do?

What happens after death?

Symbolic Mortality

Immortality, the concept of living in a physical or spiritual form for an infinite or inconceivably vast length of time, can be interpreted in various ways which may prove helpful to dying patients and their families.

The term *Symbolic Immortality* was coined by Harvard psychiatrist Robert J. Lifton. Lifton discussed our propensity to identify with things greater and more enduring than ourselves. He recognized our connection to an enduring human reality. Symbolic Immortality refers to what remains from our lives after death. These things may be material (what we have built, created, or given birth to) or ephemeral (thoughts, values, network of friendships). There are five main types of symbolic immortality: biological, theological, creative, nature and experiential.

Biological (or genetic) immortality is based on the continuity of one's family across time. Our lives are reflected in the continuation of our thoughts and values in our family, children, and grandchildren. Cultural traditions and the meaning of one's life will continue to live on in future generations. The emphasis is placed on history, memories, stories, and one's philosophy of life. The traditional grand vision of being

surrounded by multiple generations at one's death bed may be powered by the sense of genetic and cultural transmission and extension in time through the family lineage.

Theological (or Religious) immortality involving belief in life after death is seen in most religions and spiritual practices. Religious conceptions held by patients can help to reconcile the conflict between their strong survival instincts and the new knowledge of their mortality.

Such beliefs can take many forms, ranging from ideas such as that the personalized view of the soul persists after death: one's energy of being reunites with the cosmos and the merged individual continues to exist, to more traditional religious concepts of an afterlife including heaven and reincarnation. With religion, death no longer means the end of life, but becomes the dividing line between this life and the after life or the next life. Religion consoles us. It reconciles the conflict between our strong survival instinct and the knowledge of our own mortality.

It is important for carers to assess spiritual beliefs, and respect, support, and validate the patient's need for immortality and hope.

The idea behind *Creative Immortality* is that one escapes death by living afterwards through acts and accomplishments that will be remembered for generations and possibly centuries. Human essence resides not in the physical body but rather, in the minds of others. Therefore, a person can live on through his works and through memories of his deeds. For example, Leonardo Da Vinci's creation of the Mona Lisa will have everlasting creative symbolic immortality. Providing benevolent kind acts for someone in need also falls in this category because these actions make a difference in other people's lives. Through their acts, physicians, nurses, teachers and others in the helping professions provide another form of creative symbolic immortality.

Nature can be seen to exemplify symbolic immortality. Nature is everywhere and will survive forever. We experience eternity when we learn to understand and appreciate the life and death cycles of nature. For example, following the atomic bomb explosions in Japan in 1945, the trees appeared dead, but the cherry blossoms bloomed in the springtime, reflecting the ability of nature to regenerate. The symbolic immortality of nature is also evidenced in people's attempts to preserve some natural habitat or species of life. Nature is increasingly preserved in parks and zoos.

We are part of the natural world. The substance that made us will appear in the soil, trees, plants...we will reenter the ecosystem as carbon, nitrogen, and other elements which will be re-infused into the natural world.

Experiential transcendence is different from the other four modes of attaining symbolic immortality in that it is grounded on "A psychic state – one so intense and all-encompassing that time and death disappear" (Lifton). Experiential transcendence involves moving beyond or transcending the mundane and profane, and can be experienced in all of the other modes. Thus, one might experience a sense of transcendence through a deep spiritual experience such as a baptism and being born again in the Christian sense, or being in a mystical trance - a feature of many worldly religions. Transcendence can also be found in epiphanic experience such as giving birth, or a rapturous encounter such as the use of psychedelic substances, and the ecstatic transcendence that is derived from orgasm. Here, according to Lifton "The self feels uniquely alive – connected, in movement, integrated –which is why we can say that this state provides at least a temporary sense of eliminating time and death."

What is unique about experiential transcendence is that when in the experience one feels as if one has overcome death because of the immediacy and intensity of the event.

Achieving Symbolic Immortality

There are several ways in which the carer can guide a patient in their search for symbolic immortality. The first is to validate their contribution to their family. Their lives are continued through their descendents after death. Such contributions may include a sense of family cohesion, the role the patient played in the family structure, the lessons they have taught to the children or grandchildren, stories that will be passed on to the next generation, etc. One could use the picture of an immigrant who travels to a new country in search of a better future for the next generation. Being able to do so changes the family's history forever and may have a positive impact on standard of living or quality of life for generations to come.

It is important to remind people of their life accomplishments such as their contributions to science - their theories and publications – art and society. One could use the example of Sigmund Freud, who after 16 years of struggling with mouth cancer was more concerned about the loss of his theories than the loss of his life. Contributions to society might include foundation of a charity or institution which will change peoples' lives for generations after one's death.

Some people might be encouraged to consider body donation, for example to a medical school to educate future physicians or for scientific research, or organ donation in which a part of them will continue to live on in another human being.

Legacy Activities

Helping patients to define their legacy and achieve a peaceful life closure may help to decrease their fear of death or the dying process. It may give their lives a sense of meaning. Legacy activities are projects that may assist individuals and families in initiating the process of life review and result in a product that can be enjoyed by family and friends prior to and after the individual's death. These legacy activities are examples of biological and creative symbolic immortality. They include reminiscence and life review which can be given permanence through the medium of audio tape and film. Scrapbooks and even cookbooks are also useful adjuncts to encourage and record reminiscence, as is the recollection of favourite music.

Dignity Therapy was created by Dr. Harvey Chochinov to address psychosocial and existential distress among the terminally ill. Patients are invited to talk about their lives or what matters most to them during a 30 to 60 minute session with a therapist. The conversation is recorded, transcribed, and edited. Then it is returned within a few days to the patient, who is given the opportunity to read the transcript and make changes before a final version is produced. Many patients choose to share the document with family and friends.

Ira Bycock, who has written extensively about the ways people find to strengthen bonds with people they love and to create profound meaning in their final passage, has identified the four things that people want to say that matter most in this context:

I forgive you. Please forgive me. Thank you. Goodbye.

Other ways to decrease suffering

So what attitudes and approaches can we as carers adopt in our endeavours to comfort (both in the sense of to console and in the older one of to strengthen) the dying? It is suggested that these include providing an authentic presence, being respectful and reverent and acknowledging suffering. It is important to maintain a non-judgmental attitude, seeking and respecting the wishes, preferences and decisions of the person for whom you are caring. Eliciting stories and encouraging reminiscence will allow a person to reflect on life experiences and make meaning of them. If poems, songs, prayers, readings or rituals are meaningful, make them available.

Above all we must approach with an attitude of humility and an openness to learn, and to *listen* to and try to understand the dying person's experiences, successes, struggles, and search for meaning. And we must never forget that silence is as important as words. Allow silence between you and find ways to make yourself less anxious with that silence. When your question goes unanswered, let it be. It is good to be there without saying anything as well. Silence often allows disclosure of deeper issues.

"[Patients do not] want to know whether or not interpretations are scientifically true; they are satisfied if they feel true and give meaning to life"

Erikson

Further reading

Symbolic Immortality and Social Theory: The Relevance of an Underutilized Concept
Lee Garth Vigilant, John B. Williamson, forthcoming in *Handbook of Thanatology: Essays on the Social Study of Death*, ed. Clifton D. Bryant

The Broken Connection: On Death and the Continuity of Life (1979) Lifton, Robert J.

The Four Things That Matter Most: (2004) Ira Bycock

Pain, suffering and ‘loss of dignity’: Valid reasons for killing?*

Michael Platt

“Why aren’t the hospices, charged with relieving the suffering of dying, trusted to do so?”

**The recording of this session was also lost and this version is a reconstruction from Dr Platt’s PowerPoint presentation and notes. Inevitably there is no record of the discussion.*

What has happened?

Over the last few years there have been a number of cases of death by ‘euthanasia’, ‘assisted suicide’ and the like. Dignitas takes ill and not so ill people to Switzerland, where they can die at a time of their choosing with assisted suicide. Why is this now becoming such an issue?

Why are people apparently so scared of dying in pain that they demand the ‘right’ of a so-called ‘good death’, pain free, without suffering and without ‘loss of dignity’? Why do people not trust the health service to be able to sufficiently care for them so that death is not a terrible suffering, with uncontrollable pain, without killing them? Why aren’t the hospices, charged with relieving the suffering of dying, trusted to do so?

Historically, those dying tended to be looked after by families, possibly with some input from the family doctor, who would pop in and administer pain relieving remedies. Most were surrounded by the love of family, and tended as such. Some would have severe pain, untreated, or unmanageable, with the family desperately trying to ameliorate it. Life was shorter; death was due to pestilence, war and infection. Death was part of society and living, less of a taboo than it would appear to be today. Death rates by different causes have changed over the years, influenced mainly by the invention of antibiotics, and prior to this, the advent of public hygiene and the invention of the water closet. The public health act of 1858 sought to reduce the deaths due to cholera in London and other cities. Death slowly began to become more of a controllable medical issue, people began to live longer and survive into old age.

By the middle of the twentieth century, more people were dying in hospitals, mainly from cancer, which was starting to become one of the main causes of death, along with cardio-vascular disease. Medicine demanded cure. Death meant failure and medics were not interested in the dying. More people started to survive cardiac disease with the development of cardiology and cardiac surgery. However, hospitals were not ideal places to die. Often dying patients were not well cared for, the main focus of care being the well. Pain was not well managed. Even in the few hospices that existed, patients who were dying were often told ‘there is nothing to be done’. Dame Cicely Saunders made it her life’s work to revolutionise dying and brought in the concept of ‘total pain’: the idea that the dying not only have pain, but also issues about existence, spirituality, family and financial issues, as well as other symptoms of disease such as nausea and breathlessness. This constellation of negative attributes contributes to a sense of suffering. As an almoner at St Thomas’ Hospital, Cicely Saunders was shocked at the lack of care and completed a medical degree in order to change attitudes. She began the use of morphine by the clock in appropriate

doses to alleviate pain before it became a problem. She opened St Christopher's Hospice for the holistic treatment of the dying, also encouraging research and teaching – the birth of modern palliative care.

The paradox of modern end of life care is that as universal free medical care is so much improved, there is so much distrust and fear of painful, terror-filled death. Is the ethos of care in post-modern society dead? Are we so self-sufficient and autonomous that care is no longer important – least of all care of one's fellow man? Modern death is taboo; it only occurs behind closed doors. Modern medicine is no longer a mysterious art practised by those special medical practitioners with secret potions, but approachable via the internet, television and reading. Doctor no longer knows best, but gives the patient a choice of possibilities who then can choose using his or her inalienable right to autonomy. What has happened to the trust between doctor and patient? Why is paternalism so bad that doctors can no longer be trusted? *Principlism*, the use of reasoned principles of ethics, as espoused by Beauchamp and Childress, rules medical ethics. Care is not mentioned. Virtue is not fashionable. Autonomy of the patient rules, regardless.

The Journey to Today: a short history of care and vocation

Medicine in the western world began with the monasteries – repositories of knowledge held by monks throughout Europe. The parable of the Good Samaritan was the model used as the drive to care for those disadvantaged or ill. Some monks were experts in herbalism and grew gardens of herbs used to treat the ill. Each monastery would have a hospice for the care of the ill. The vocation of these monks was medicine, for others it might be law or teaching. Thus what became the professions originated in *professing* a vocation.

In Britain, with the destruction of the monasteries by Henry VIII, universities became the repositories of knowledge, attracting those with a calling to treat the sick, or for the other professions. Medicine and surgical colleges became licensed, and the medical profession looked after itself, under licence from the Government. Care was important and patients trusted the medical and nursing professions to look after their illnesses and alleviate pain and physical suffering.

In the 1980s, Harvard was exporting Managerialism and commerce massively, converting communism to western style democracy and finance, and demoting as inferior any other systems of organisation, including professionalism, seen as old-fashioned and wasteful. The Thatcher Government welcomed this and sought to put more management into the NHS which was seen as a big black hole of wasteful spending.

Post-modern society insisted on autonomy: patients wanted more control and 'choice' became the buzzword. Fear of pain and death created a market for the seeking of more control over death – I want to die without suffering. And yet, although palliative care has grown and hospices have developed apace, only 25 per cent of the population die in a hospice, or cared for by them.

Instead of doctors doing their best for patients at all times, with a caring bias and professional dedication, their working times were contracted, no longer working overtime to ensure patients were properly and adequately treated. GP's now had to be incentivised to treat patients. Shipman terrified all of them – no longer would patients have good pain control, for fear of inadvertently causing death with morphine.

What can we do?

First of course pain must be controlled by all possible means, and all physical pain can be controlled or at least made tolerable either by sophisticated drug therapy tailored to individual patient needs by experts in palliative care, or if needs be by invasive interventions administered by pain specialists and neurosurgeons. But of course suffering associated with dying is never simple and many things other than pain contribute to it. As well as physical symptoms such as constipation, nausea and vomiting, drowsiness and poor co-ordination, and difficulty sleeping, anxiety is an almost inevitable problem for both patients and their families. As Bob (Zalenski) and Luisa (Compt) have just been telling us, sources of anxiety and distress may include not only spiritual and existential issues and fear of dying, but difficulties in communication with friends and family as well. Poor communication with the medical profession may lead to a vicious circle whereby the fear of pain, together with all these other factors, intensifies the perception and appraisal of pain. All these things need to be addressed to save people from the experience of total pain.

But there is one other subject which constantly arises in the context of assisted dying, viz:

Loss of dignity

What indeed is dignity? There seems to be no appropriate definition in the current context, although it is used in legal documents and the proclamations of the WHO and the UN. It seems to include such slightly nebulous concepts such as 'our value as human beings'. Perhaps the important thing is to establish what individual patients think it means when the subject comes up: what they may fear is loss of *autonomy* and it is necessary to clarify the relationship of this to dignity as they see it. Above all they may need reassurance that their carers will never forget that *you are important because you are you*.

Means of maintaining dignity include enabling people to make choices about the way they live and the care they receive, speaking to people respectfully and listening to what they have to say, and practical things such as providing a choice of nutritious, appetising meals that meet their needs and choices, and enabling them to maintain their usual standards of personal hygiene. Practical assistance will enable people to maintain their independence. It is also important to respect people's personal space, to afford privacy in personal care and ensure confidentiality of personal information, and to maintain social inclusion by helping people to keep in contact with family and friends, and to participate in social activities. And of course it goes without saying that excellent pain management: ensuring that people living with pain have the right help and medication to reduce suffering and improve their quality of life, underlies all these other measures.

Can there be valid reasons for killing?

So have lost our spiritual reality? Are we simply afraid of being incontinent, demented and at the mercy of dedicated carers? Is this what we really mean by *Loss of Dignity*?

Society seems to be demanding ever more perceived control over what appear to be highly unpleasant occurrences and issues that occur in life. Of all these, in our modern post-modern society, perhaps death is the scariest. Post-modern society has a fear of death in agonising pain and with 'loss of dignity'. The medical

professions have not been good at death and its amelioration. Many patients die in unacceptable pain, treated by doctors who fear prosecution. Despite an evolving palliative care service and expanding hospice movement, only some 25 per cent die with hospice care. But if we are in a loving environment, cared for and valued, and our spirituality cared for, *there is no valid reason for killing*. To reduce demand for Dignitas and euthanasia, we must improve the care of the dying, with earlier referral from hospital to palliative care and more and better collaboration between pain physicians and palliative care professionals. The training of GPs and medical students in pain relief has been woefully inadequate and requires urgent attention.

Care

But perhaps the over-riding need is to encourage an ethos of *care* in society and medicine. Caring science does not deny the presence of suffering, even though it aims at soundness and health; suffering is the point from which it begins. Not until the patient has come to terms with his suffering can he hope to recover. Suffering is the most important basic category of all caring. It gives caring a unique quality and soundness and is something which all forms of caring aim to alleviate. Real caring is not just an abstract idea, philosophy or ideology, it is concrete work confronting suffering in real situations.

“When a Christian believer is going through any distressing or disquieting experience, it can be a source of comfort and encouragement to him to remember that the Lord Jesus ‘knows all about it’ – that He Himself went through the very same experience. So it may be that the thought of the handing over of Jesus – of His transition from action to passion can be of practical help to people who must face, or have already faced, a similar transition in their own lives. We have already stressed that the word ‘passion’ does not mean, exclusively or even primarily, ‘pain’ : it means dependence, exposure, waiting, being no longer in control of one’s own situation, being the object of what is done. So the passion of Jesus ‘connects’ not simply or even primarily with the human experience of pain. It connects with every experience of passing, suddenly or gradually into a more dependent phase or area of life-with going into hospital, with retiring or losing one’s job or having to wait upon the actions of other people and other factors beyond one’s control. If the thought of the passion of Jesus is helpful at all, then it may be helpful not only to the person who is bearing the ‘cross’ of pain but also to the person who feels that he is ‘on the sidelines’, that he has become useless or ineffective, that he is no longer making his mark in the world or his contribution to it. ‘To be handed over’ in ways such as these is particularly disquieting to a person who, by habit or temperament, has been exceptionally active and energetic or a notable achiever; and such a person may well find comfort in the thought that a similar pattern appears in the life of Jesus — that He also passed from activity and work and achievement into a final phase of waiting and dependence and passion.

From *The Stature of Waiting* (1982)
William Hubert Vanestone (1923-1999)

The pain(s) of chronic pain: Frustration, inconvenience and despair.

Beatrice Sofaer-Bennett

“We found that if independence and control are effective, older people adapt better to chronic pain.”

I am a qualitative researcher at the University of Brighton and work one day a week as a counsellor in the pain service. Talking of culture, a word about my background:

I was born in Dublin and my parents were first generation Irish Jews. They were Orthodox observant Jews whose parents were refugees from pogroms in Eastern Europe. I was brought up on a diet of W.B.Yates, James Joyce and gefilte fish. On the one hand I had my father saying “Don’t eat bacon” and the other the nuns at the convent where I went to school saying “keep yourself for your husband” – and I didn’t eat the bacon! So in terms of pain I was hearing “Oy vay” at home, and at school, where I was taught by very talented and gifted nuns, my favourite nun was Sister Trea, the art teacher. She went around with her hand between her face and her wimple because she suffered terrible trigeminal neuralgia. Last week I had a fifty year reunion with my classmates. I learnt that I was the only one in the class who liked Sister Trea because she was terribly grumpy. I would like you to imagine a child of ten going into a convent and seeing all these dreadful pictures of a man nailed to a cross. I later became a nurse, and I went on to do a Doctorate in acute pain and the effects of educating nurses about this on their management of it in post-operative patients.

Qualitative research and pain

I want to share with you some qualitative research I have done at Brighton University. Qualitative research is incredibly difficult to get past ethics committees, to do, and to get published. It’s also difficult to get funding. I had a recent proposal turned down as the charity I applied to sent it to five quantitative reviewers.

I would like you to consider the statement “Pain is what I say it is”. You can put the emphasis on each or every word:

Pain is what I say it is
Pain *is* what I say it is
Pain is *what* I say it is
Pain is what *I* say it is
Pain is what I *say* it is
Pain is what I say *it* is
Pain is what I say it *is*

Depending on who says it: the patient, the doctor, the nurse or the physio, there could be some dissonance. There is an Arab proverb “*Consult a man of experience; he gives you what cost him much, and for which you pay nothing*”. I am interested in the experience of pain and that is what qualitative research is about. Its aim is not to find significance in numbers but to emphasise themes that emerge from commonalities of human experiences - typically from small numbers of participants.

The first paper that we had published in collaboration with Professor Immy Holloway was called *In the system: the lived experience of chronic back pain from the perspective of those seeking help from pain clinics*. We reported in that study that participants told how they became entrapped within the medical, security and legal systems. These were designed to help people if they were ill or disabled but effectively rendered them powerless and angry. There is a splendid piece of work by Gwenda Lansbury entitled *Chronic pain management: a qualitative study of elderly people's preferred coping strategies and barriers to management*. It demonstrates how older people prefer their own coping strategies. We did a qualitative study on how pain is perceived by older people, and I interviewed 63 elderly people in their own homes. None of them were sitting in front of their TV's – they all wanted to get on with their lives. They had a desire for independence and control and had adapted to a life of chronic pain. With only three exceptions none of them were seeking help with practical issues and so they lived in fear of loss of independence. They had ideas about pacing, helping other people and use of prayer, looking good and feeling good. One lady of 76 said to me: *"People stop me in the street and say when I've got my makeup on 'oh, you do look well Mrs A'...if I don't wear make-up they say 'you don't look at all well Mrs A', and I don't like that, so I'd rather put a bit of makeup on"*. That was very typical of the people in the study. We found that if independence and control are effective older people adapt better to chronic pain.

Another study we published was *The experience of chronic back pain: Accounts of loss in those seeking help from pain clinics*. These patients' narratives revealed a catalogue of socio-economic and other material losses including loss of physical and mental abilities, loss of occupational and social abilities. These led to financial hardships and changes in interpersonal relationships, culminating in loss of self-worth, future and hope. Financial hardship runs throughout the studies. One patient said "It [the pain] destroyed my life; it's destroyed my husband's and my daughter's. We planned so much the things we wanted to do... but I can't do (anything) now because I can't sit in the car for even half an hour". So as you all know the consequences of chronic pain include fractured relationships, plummeting self-esteem, loss of hope and stigma. Stigmatisation emerged as a theme from another study: we found subtle and overt stigmatising from family and friends, health professionals and the general public and we need to address the realities and practicalities of dealing with stigma. A major theme to emerge was that people wanted to keep occupied and to focus on social activities. Mary, aged 63 enjoyed going out for a meal *"I'll hardly be able to walk after, but I won't not go. I'm not giving up my life, you know. I shall be in dire agony and I shall just have to put up with it because I have enjoyed myself."*

A further study of older people with neuropathic pain identified a combination of pain-related limitations and uncertainties, related to social withdrawal of patients and social isolation for patients and their spouses and raised questions of the relationship between neuropathic pain, its physical and emotional consequences and social outcomes. One of the participants in that said to me "You need to find out what is happening in families" so I decided to investigate this, interviewing families including children. This hasn't been published but we made a film and invited the participants whose narratives the script was based on to see it. They loved it and said "You've got it right". Two quotes to conclude: *"To be wise by rule and by experience are utterly opposite principles; so that he who is used to one is unfit for the other"* (Francis Bacon) and *"Pain is"* (Pat Wall, *Why we do we not understand pain?* The Encyclopaedia of Ignorance.)

The film can be found at <http://student.brighton.ac.uk/videos/videos.php?ID=618>

Public health and private angst: Ethical dilemmas, unwanted information, and vCJD

Peter Bennett

“So the ethical principles governing decisions tend to favour Utilitarianism rather than rights: we ask what are the consequential harms of informing or not informing?”

I stand before you with three crippling handicaps. One is that I’m not a pain researcher, two is I’m not a medic of any description and three is that I work for the Department of Health!

Most of what I am concerned with is risks to public health so you can think of me as a sort of poor man’s epidemiologist. Nevertheless it struck me that there are some things that I am engaged in which if not directly to do with pain certainly are to do with suffering and with ethics. I am very keen to get some responses from you about the ethical dilemmas I shall be talking about, in particular some of the tensions between the imperative to protect public health and the danger of doing so in such a way that may arguably cause harm, and certainly angst and suffering, to individuals.

Variant CJD

I want to illustrate this from one area I have been involved in for the last 12 years, variant CJD, in particular issues around blood transfusion and how to deal with people who are at increased risk of carrying the infection. In order to take public health precautions to prevent passing on of the disease you have to tell people they are at risk. That is not something you would want to do to anybody lightly.

Mad cow disease loomed large in the news from about 15 years ago. Variant CJD is the human form of this. It is a fatal neurological disease; it is incurable and still indeed effectively untreatable, and a very nasty way to die. Beyond all reasonable doubt it came from cattle infected with BSE (bovine spongiform encephalopathy) It was recognised as a disease in 1996 after fervent denials from Government and scientists from the Chief Medical Officer downwards that BSE posed any risk to human health. That remains part of the context of the whole story. It was seen as a failure of the scientific and political process and even now, if you get into an argument with someone about politics science and ethics the chances are that they will say “They were wrong about mad cow, weren’t they?” And yes, they were. Some ministers were even foolish enough to say there was no *conceivable* risk.

By 2000 the food chain was claimed to be under control but it had been estimated – this is a frightening figure – that something like one million BSE-infected cattle had entered the human food chain. New vCJD cases were rising year-on year but although they were mercifully small projections of human vCJD cases were going up to many thousands. It did look fairly apocalyptic. The apocalypse hasn’t happened and it now looks as if it won’t happen on the sort of scale we were talking about then. The current situation is that there are just over 170 definite or probable cases in the UK. These are typically young adults with a median age onset of 28, struck down in the prime of life with a particularly unpleasant condition, in contrast to ‘sporadic’ CJD with a median onset age of 68.

The rate of new cases has fallen to about one a year. It has however spread beyond the UK and there are probably about 200 plus worldwide. There are hugely expensive precautionary measures still in place all over the world. If you live in Britain hardly anyone else will accept your blood: Americans certainly won't.

So why the continued worry? It's partly because it is a prion disease which have long 'incubation periods' and symptoms may only appear decades after infection. We don't know how many people have been infected but have yet to develop the disease but there may be quite a lot. All the known cases have been of one particular genotype which comprises about 40 per cent of the population. Do we expect further waves of cases? We probably do and the most worrying thing of all is that it might be transmittable person-to-person. It is certainly transmittable by blood transfusion and almost certainly by surgical instruments, particularly those used for brain and spinal cord surgery, and standard decontamination does not remove the infective agent effectively. This remains hypothetical as we don't know of any cases of vCJD that have been caused in this way, although there have been some of sporadic VJD.

Risk assessment

So what I have been engaged in is risk assessment and modelling, and trying to be a bridge between science and policy choices. I have been addressing such questions as how great could the risk be? How bad could things get? What can we do about it and what interventions would make a difference? Which should be prioritised and would be most cost-effective? What are the most important research topics? How do we deal with individual incidents of possible infection?

The important thing here is the amount of stuff we just don't know. vCJD is an exemplar of scientific uncertainty but of course it's not unique. There are lots of diseases around about which we know less than doctors are prone to tell people. This is an extreme case of uncertainty because we are still reliant on evidence either from animal models which are slow and uncertain, (and what we do to Syrian hamsters doesn't necessarily transfer to human beings, although if we do unpleasant things to sheep that is probably a bit more applicable,) or other human prion diseases such as Sporadic CJD and Kuru, which is associated with cannibalism (there is some doubt among anthropologists about this) in a tribe in New Guinea who have almost killed themselves off by eating each other or smearing bits of flesh on each other.

For blood-borne risks, we simply don't know how many infective donors there are. We know it can be spread by human blood but we don't know how infective it is or when it becomes infective. These are all sorts of things we might be expected to know but don't. You find you don't know mundane things like if you have a bag of red cells what's actually in it? Or who gets how much blood and what is their survival rate? What else did they die of? We know more about these than when we started but there are still surprising amounts of uncertainty. Survival matters hugely: if you've got something with an incubation period of 10 or 20 years, how many blood recipients survive long enough to show symptoms.

We know very little about prevalence: it has been quoted as 1:4000; this is to take a figure out of the air but if you assume infective donors could range from 1 in 1,000 to 1 in 100,000 and there are over two million blood donations per year that could possibly mean a lot of infected donations.

Individuals at risk

This is where the ethical issues arise. A lot of this stuff is about risks at a population level but there are people who are at heightened risk of being infected, either from surgical instruments or from tissue grafts and implants (there are quite a lot of recorded cases of spread of sporadic CJD by grafts); or, as I want to talk about now, who have been in receipt of blood or blood products. What do we do when we find that someone who has developed vCJD has acted as a blood donor? And what do we do at an individual rather than a population level? Whenever there is something difficult governments like to set up a panel. The CJD Incidents Panel is an independent advisory committee (with a former senior policeman as an independent, non-medical and very effective chair) which deals with all forms of CJD. As well CJD experts, it includes people from the blood services, surgeons, nurses, public health docs, social scientists, an ethicist, a patient support group, and a lawyer. They get analytical advice from our team.

We have to bear in mind that when talking about blood that there are two categories of risk. People who have received blood components, i.e. red cells, platelets and fresh frozen plasma and have been given a large volume of material from one (or a few) donors per unit have an apparent high risk of transmission if the donor is infective. People like haemophiliacs getting plasma products like factor VIII, factor IX, albumin are getting something pooled – great vats of stuff and every time you get a dose you are exposed to something like 20,000 donors, in tiny amounts from each one: a quite different from of exposure.

The notification dilemma

So this is where we come to the ethical issues. When and how should people be told that they are at increased risk? The aim is to reduce risks of onward transmission. If someone is at increased risk we want to make sure that they don't donate blood or tissues. If they have had surgery, or certain forms of surgery, you would want to stop re-use of the instruments. This raises a particular problem in haemophiliacs, who typically need quite a lot of invasive endoscopy, and endoscopes are damned expensive things, so we are in the position of telling the NHS to quarantine thousands of pounds worth of equipment every time they are used on someone at risk. That requires the person to be told; you can't just do this behind their back. So here is the dilemma: of what use can it possibly be to you to tell you that you might be at risk of vCJD? There is no test for it, no effective treatment, and no cure. We can't give people answers to what they might regard as obvious questions about the level of risk. "If I am carrying the infection, what are my chances of developing the disease?" "Sorry, we don't know." This has the potential to cause massive individual suffering and to ruin lives. It has already achieved this in this country, up to and including suicide: one individual became so convinced that he would develop the disease, despite the chances being tiny, he took his life.

It also has practical and perhaps financial consequences affecting for instance getting a mortgage. The Government is trying to mitigate these sorts of consequences: it has spoken to the Association of British Insurers who has said as a matter of their policy they will not discriminate against people in this position. This is sort of generous but one suspects that this is something they are able to do because the numbers are very small.

Access to 'normal' health care may be affected: there are instances of people being notified that a dentist wouldn't treat them.

But against all that is the question: what if someone really has drawn the short straw and they really have been infected with vCJD, and they are going to go down with it. In the earlier days of this story the view was that the harms of telling were so great that perhaps it was ethical not to inform people. Some of the recipients of blood from infected donors were not informed. One in particular was not informed and went on to develop the disease and died of it. Ever since, his mother has been on a sort of one-person crusade to put about how terrible it was that they were not informed, and how the Government let them down - quite understandably. Even ten years ago there was more of a paternalistic attitude of not telling people things that were no use to them. But her argument was that if they had known sooner they would not have wasted months going through blind alleys and misdiagnoses.

Nevertheless it is still a dilemma. What the panel has done is to adopt a 'threshold' approach. Anyone at increased risk of having been infected should be treated as 'at risk for public health purposes', all the necessary precautions applied to them, and they should be notified, unless the increased risk can be shown to be below one per cent (above what everybody has), even if pessimistic assumptions are used. My task is to work out if even in the worst case their risk is above one per cent. Why one per cent? It's a sort of attempt to be consistent and treat people according to some consistent criteria. It's a round number: round numbers do have their attractions, particularly if you are trying to explain to somebody that their risk could be more than 1 in 100. It's also clearly above background prevalence; we are all at risk so if you put it at 1 in 1000 you'd be getting near the risk we all have.

Furthermore it's a value judgement: it suggests it is something like one hundred times worse to fail to inform somebody who has actually been infected than to inform someone who has not been infected. That's something the panel hasn't really discussed, at least not in those terms, but they are implicit. It is highly precautionary because when you think of all the uncertainties actually to say "We're going to inform unless even on pessimistic assumptions your risk is less than one per cent" implies a strong onus on informing.

Regarding blood, blood products and plasma derivative recipients: haemophiliacs and other bleeding disorder patients had been by far the largest group prior to 1999 when we stopped using plasma for fractionation from UK sources and to import it from the US. Nevertheless there are something like 5000 haemophiliacs who were in receipt of UK products. They were identified as an 'umbrella' group, after consultation with the haemophilia society, rather than trying to do an individual assessment for each of them. We need to consider people who have donated blood to someone who has gone on and developed the disease. Clearly the donated blood couldn't have infected them but the fact that they have donated to a case means that they could be the source of infection. Should the donor(s) be notified? Should other recipients of their blood be notified?

There is also question of multiple routes of exposure. The first haemophiliac who may have been infected with vCJD died of something else and at post mortem signs of vCJD infection were found but where had he got it from? It transpires that he had undergone four invasive endoscopies, had received blood components and plasma derivatives from "implicated" batches (i.e. batches that a vCJD case had donated to) and many more from other UK-sourced batches. In addition he had been exposed to food-borne infection like anybody else. This raises quite sophisticated questions like what is the relative likelihood of each infection route? That has practical consequences because that then influences who else in the pattern of contacts needs to be treated as 'at risk' and be told.

Introduction of a blood screening test sounds a jolly good thing to do but unless you have a test of amazingly good specificity you find that out of two million blood donations you end up with the danger of identifying a whole lot of people (with a 99 per cent specificity 20,000 out of 2,000,000 donors) who you can't accept blood from any more, whom you would almost certainly have to tell why, and some of them would interpret that as "you have vCJD" even though their actual chance of infection will be less than two per cent.

Ethical and communication questions

What do you tell donors in advance of testing them? It's not a good idea to introduce a test before you start thinking about what you are going to say if it is positive! What should we tell the public? What do we tell donors testing 'positive'? We cannot legally carry on taking blood and pouring it away! But you have to tell them something. Should they be treated as "at risk" when you really don't know the prevalence and are unsure about the test performance. Then the really tricky one is what in Heaven's name do you do about previous recipients of their blood; should they be traced and told?

Broad ethical themes

Are you informing people because they have the right to know? There is some sympathy with that view but it is seldom the dominant argument, which is prevention of onward infection. But early information is important for clinical cases and if someone really has the disease and you don't tell them it really messes things up. What about the right not to know? What about my right not to have my life ruined by extraneous information that I don't want and can't do anything with. This is really can't be accepted as you have a duty to know and act to prevent risk to others, and can't hide behind the right not to know. (But haemophiliacs who were informed as an entire group were given the choice of whether to know if they received 'implicated' batches or not.)

So the ethical principles governing decisions tend to favour Utilitarianism rather than rights: we ask what are the consequential harms of informing or not informing? The dominant public health ethos is prevention of avoidable harm unless the risks are tiny. It is the duty of the Department of Health, the panel and by implication the person informed to minimise the danger of someone else suffering this horrible thing. But there is some recognition that doing no harm at all may actually be impossible; by informing people you are inevitably doing them some harm. And 99 out of 100 of them might not be infected.

It has been recognised, perhaps rather late in the day, that this balance of harm needs to be informed by research. There is a qualitative study about to be published on the effects of being notified. If it is done reasonably well it appears that the effects are not as devastating as we have been led to believe, although it is notable that most of the people in this small study were actually blood donors, who may not be entirely typical of the general population. They seemed to fully appreciate the precautionary principle and fully understand that their blood should not be used even if the risk was very small. Haemophiliacs as a group have had a very hard time and are perhaps understandably inclined to blame the blood service and the Government and say: "Loads of us have been infected with HIV, loads of us with hepatitis, that was all your fault, and now you are telling us that there is this other thing!"

So the ethical Imperatives for the Panel and the department probably boil down to prevention of avoidable harm, but also full consideration of the competing harms. They must ensure transparency of process by making sure that anybody who wants to find out how those decisions were made can actually look at the minutes of the meeting and find the risk assessments on the DHS website. Finally there must be honesty about uncertainties: I think we have long gone since past the stage of thinking it would be acceptable, or even have any hope of success, to kind of bluff our way around the uncertainties and pretend that we know more than we do.

Discussion

It's rather a pity you didn't give this talk last year when our theme was consent and deceit in pain medicine. There are so many parallels about imparting information with what we were talking about then that if you have any doubts as to whether your talk would be relevant to us and the sort of problems we face you can forget them!

Regarding the haemophiliacs: can you tell us the proportion of those asked who chose not to know?

I can't give you a percentage off the top of my head but I think it was a relatively even split.

Regarding relative risks: it strikes me that in the years since we've had vCJD and similar blood-borne diseases the price of a unit of blood has gone up from about £30 to about £130 because of the safety measures the blood bank put into it like taking out white cells, and while blood is a lot safer it is much more expensive. And when CJD was a big issue we were using disposable instruments for things like tonsillectomies – I gather that's gone back presumably reflecting a reduced risk.

The price of blood is an interesting one: the increase is partly because of these safety measures but there has been a change in the business model by which it is supplied. The other interesting question is the extent to which the usage of blood does or does not correlate to its price. The transfusion services hotly denied that there were any economic effects and even if the price were doubled people would be using the same amount – I don't think it's the case - but there is a whole issue around better blood transfusion as well: quite a lot was unnecessary in the first place. So if driving up the costs leads to more careful use it may not be entirely a bad thing. The single use tonsillectomy kit is not a happy story. Because the kit appeared to be relatively simple and because the tonsils were thought to be a site of infectivity that would be a sensible place to start. The plan was that hospitals would use the same kit but only use it once and money was in theory allocated for that – but it didn't necessarily get used for that at all, and some started using inferior equipment and there was at least one death attributable to duff single use instruments.

If a donor gives blood which is found to be 'at risk' of infection why can't that be thrown away and the donor not told if he had opted not to be?

You could probably do it once, particularly given the uncertainties round the test but you cannot carry on taking blood from a donor and not using it without telling him. It is a legal requirement under European law and you would be committing a battery.

So what is their justification even though the donor donates knowing in advance that there is this possibility?

The technical possibility of a test seemed very promising about six months ago but now the chances of it being available any time soon are actually quite small. You could also argue that blood is not the only route of transmission. It's not just that you want to stop someone donating if you will have to throw the blood away. You're also talking about quarantining instruments, for example. There has to be some mechanism by which the hospital can know if somebody going in for surgery is at risk; either the patient and the family must know or it must sit on their notes.

But in the donation situation why is it a battery when I know what the possibilities are?

If you are asking me would it be sensible to try and get around this by saying in advance to all donors: if you are found to have disease X, Y or Z we will give you the choice as to whether we tell you, or if we don't tell you we will keep on taking your blood and throwing it away – getting it all set up in advance – I must admit I find that quite attractive as well. We ran that past the legal eagles but it didn't fly. They said you can't do that.

People can consent to something the rest of us think is stupid but they are entitled to that choice.

In the early days of HIV a lot of blood was thrown away without the donors being told. This is no longer the case. But in HIV there is a screening test. So at least you are giving the patient information which is relatively definite. And yes they are told. There is anecdotal evidence of people who may fear they may be at risk of HIV volunteering to become blood donors in order to get the test.

[Partly inaudible] Is it possible to tell people that their blood may be discarded due to a theoretical risk to others and that they may no longer be eligible to be a donor... and saying if you would like more information, providing a procedure for finding out ... that would prevent inadvertently informing a lot of people who don't know what to do with the information.

That middle option does actually operate with some tests where there is a non-repeat reaction; you're worried enough about it not to use the blood but the significance is so doubtful you really don't want to worry the donor. You can do that once: throw the blood away and tell the donor there was some technical problem with it but not specify what; you can fudge it temporarily

But this is giving them the opportunity to find out everything that they want – it's not fudging it...

It would be nice to set up some alternative mechanism for this which would allow people not to be informed if they didn't want to be but which set the whole thing out right at the beginning to get around the legal arguments; but the legal opinion is that will still not get through the legal hoops.

Treating pain in body, mind *and* soul

Jeremy Swayne

“We know a great deal about the body and the mind, but the soul, if we take it seriously at all, is a mystery. It probably will be beyond our ability to comprehend it fully in this life, but we must try to do so as best we can.”

In 2001 the BMJ produced a themed edition to coincide with a conference at the Royal College of Physicians (RCP) on integrated medicine.

The ‘Editor’s choice’ which introduces each edition of the BMJ had the title. In it he wrote, ‘It mightn’t be too pretentious to say that the full richness of what might be achieved through the growth of integrated medicine might restore the soul to medicine. The soul being that part of us that is the most important but least easy to delineate.’ Later he acknowledged what a counter-cultural suggestion this was, adding ‘Hogwash’. “The BMJ has finally flipped”, I hear some readers shout.’

The Journal and the conference to which it relates interpret ‘integration’ largely in terms of bringing complementary medicine into the mainstream. But this is too limited an interpretation. The best understanding of the concept of integration in medicine is that it should be ‘integrative’; that is, whole-making. It must make health care whole – bringing its diverse professions, disciplines and techniques together into a true community of care. And it must be whole-making for patients – firstly by acknowledging and respecting all that makes them a unique and complex person and gives meaning to their lives; and then by responding appropriately to whatever of these mixed dynamics is contributing to their illness or their pain.

The soul of medicine

I have used complementary medicine in the form of homeopathy for many years, and I have been aware of the role of the spiritual dimension of health care for even more. But from my early years in general practice, before either of these influences became part of my repertoire, I was concerned at the narrow biomedical perspective in medicine. In 1976 I published three papers on this theme which are best summarised in the title of one of them *Medicine and healing: A broken marriage?* I was concerned then, and am still concerned that medicine has lost its healing vocation; has indeed lost its soul.

And the reason I am here again this year, following your invitation to speak at last year’s conference, is that I found in this group and in the presentations a truly holistic and integrative spirit. I found a group of mainstream health care professionals in whom the soul of medicine is very much alive. I felt very much at home. Which has encouraged me to tackle the matter of the soul directly with you this year – not just in the broader sense of the spirit of medicine, its healing vocation, but as an aspect of human nature that has to be understood as part of the reality of human experience in health and illness, just as much as the body and the mind. And that has to be understood a great deal better than it is at present in medicine or in the Church, if either is to do its job properly. But our culture is not conducive to conversation about the soul. There is plenty of conversation about religion and about doctrine, but that is a different matter.

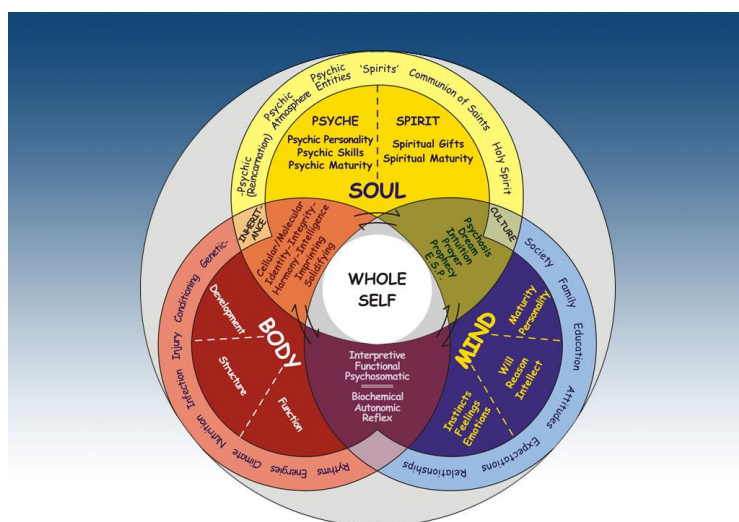
The nature and plausibility of the soul

One aspect of the culture of a particular society or a period in history is its *plausibility structure* – its framework of beliefs about human nature, life, and the universe we inhabit. This is a broader concept than *paradigm*, which is more a set of rules or precepts about the way we should think or go about our affairs. A *model* is the practical application of that set of rules or precepts. Religions have a plausibility construct based on beliefs about the nature of God and man's relationship with God, a set of doctrines which constitute their paradigm, and a model of religious observance based upon these. The Western medical model is based upon the reductionist biomedical paradigm committed to the control of disease; a manifestation of a materialist plausibility structure. The biomedical paradigm is not conducive to a holistic perspective and certainly does not accommodate the soul; and the modern medical model does not recognise its importance.

Two things led me to seek a better understanding of the nature of the soul as, so to speak, a clinical reality. One was an emerging sensitivity to certain psychic phenomena and awareness of the psychic dimension of human nature. The other was the realisation that there are wounds to the psyche that are not accessible to psychological help alone. This is a judgement based not just on my own psychological insights, which I might possibly over-rate, but on the fact that over the years I have seen patients who have clearly benefited from the mature psychological skills of others, but without their wounds being healed or their suffering relieved. I interpret these as wounds to the soul, and have found that a greater degree of healing is achieved when this is recognised, acknowledged and responded to appropriately.

After seven years in general practice I set up a new practice on my own in order to provide routine 15 minute appointments to a smaller number of patients. This was to allow me to attend more closely, understand more thoroughly, and respond more effectively to all the varied and mixed dynamics of illness in individual patients.

As part of that process I created this diagram, which I showed you last year:



It represents my understanding of what it is to be human, of all that goes to make us what we are. The three familiar dimensions of human nature – body, mind and soul

– have the core attributes shown in the respective circles. And each is subject to the influences shown around the perimeter. The overlapping areas show the processes by which each aspect of our being interacts with another, emphasising the intimacy with which each relates to the whole. Its essential character is the complete integration of every aspect of human nature that it represents.

There are no separate compartments. Whatever the focus of illness, pain or disability, whatever the circumstances from which it arises, it affects the person as a whole and must be treated as a whole. You all know better than I do how true this is of pain.

We know a great deal about the body and the mind, but the soul, if we take it seriously at all, is a mystery. It probably will be beyond our ability to comprehend it fully in this life, but I'm sure we must try to do so as best we can. For health care professionals I believe this is, as I have suggested, a clinical duty – and seeking to understand the soul, for all that it is immaterial, is a task for science, as far as science will take us, as well as for philosophy and theology. The soul is an aspect of human reality, and the exploration of reality is humanity's unending quest, as Karl Popper put it in the title of his autobiography. I will talk about the soul as I have come to understand it; well aware of the limits of my personal competence and insight.

The soul has been described as 'the information bearing essence' that expresses our unique identity as a person. In the diagram I have represented this essence as comprising psyche and spirit. And deciding what we mean by psyche is the first problem. Part of the difficulty arises from the various uses of the words psyche and psychic. The Greek word *psyche* has entered the English language and acquired a life of its own. Not only does it have to accommodate the concepts of psyche in modern psychology, but also the phenomena that are commonly described as psychic.

The psychic dimension

The psychic dimension of our nature has been called 'the intermediate dimension' - intermediate between mind and spirit. It embraces the unconscious elements of our personality, and the collective unconscious described by Carl Jung. It includes those attributes that are described as extrasensory or paranormal. There is a tendency to melodramatise the psychic dimension, but it is worth remembering that electricity was regarded as occult before its true nature was understood. We live in an environment of electromagnetism, radiation and gravity – natural phenomena, energies, that infuse our everyday lives. Psychic energy is another. We inhabit a complex network of relationships – electromagnetic, gravitational, ecological, emotional and psychic. We all possess some psychic sensitivity and some psychic attributes, to a greater or lesser degree. The psychic dimension is a normal aspect of human nature and of the world we inhabit. Its moral and spiritual value, as with all human attributes, such as intellect and sexuality, depend upon the use we make of them. It is on this level of psychic rapport, in addition to our emotional empathy and our psychological insight, that any of us may develop a healing relationship with another person; whether within a professional health care relationship or in everyday life.

Our psychic nature helps to form and is formed by our personality. We are all susceptible, to a greater or lesser degree, to psychic influences, which can affect our body functions and our personality. It is by the exercise of their psychic attributes, working initially through the psychic nature of the patient that some therapists, variously but often inappropriately called faith healers or spiritual healers, operate.

Our psychic nature can be seen as the matrix of the soul; the element in which our spiritual identity is formed and develops, through the imprint and working out of our life experience, and by the presence in the core of our being of the Spirit, the divine essence - by its action within us, and our response to that action.

That imprint is, so to speak, the recorded music of our life; a unique improvisation, but with a part to play in a greater composition that a theist like myself sees as God's creative purpose; a part whose fulfilment will depend upon its faithfulness to the spirit of the composer's intentions; a sort of two part invention, whose counterpoint is between the essence of the person and the immanent, affirming and life giving essence of a personal God. It is through the intermediate dimension of the psyche that prayer is effective in promoting healing, by the agency of the Spirit, usually in the absence of any overt psychic gifts in those who pray.

In short, I see the structure of our personal wholeness is the interactive, interpenetrating and interdependent relationship of body, mind and soul, infused by the spirit of God, in whom we live and move and have our being, and in whom we have unique value in relation to one another and to the 'bigger picture' of creation as a whole.

Homeopathy and psychic wounds

Homeopathy has been one source of insight into these matters for me through its use to treat mental and physical pain with a prescription based on aetiological factors in the past, often the remote past. There are, for example, numerous homeopathic medicines related to deep psychological wounds that, whatever their function within the therapeutic 'black box' may be, I have found helpful in treating the long term consequences of those wounds – ailments from grief, anger, humiliation, fear, failure, guilt, shame, parental domination, various kinds of abuse, and so on. Michael Bond's story of the bald girl whose handsome red wig was snatched off on the dance floor, who immediately developed abdominal pain and who progressed to a history of recurrent and chronic pain, is a perfect example of this. Her chronic pain will never be relieved until the pain of that devastating psychic wound is healed.

Wounds as deep as this may well prove resistant to psychological healing skills. Wounds like these that have damaged a person's sense of identity, of self-worth, of meaning, even of the right to life, so severely, and left such an indelible imprint in the psyche, constitute a wound to the soul. These otherwise intractable problems need to be understood spiritually and treated accordingly. That is, in terms of that 'information bearing essence' that comprises the patient's unique identity and is the point of intimate relationship with the divine. The reality of such a profound degree of damage has to be acknowledged and addressed. And the resources that exist in that relationship with the divine, whose nature is unconditional love, will need to be evoked.

The chronic pain requiring a spiritual response that I am best acquainted with is mental pain, though it may well have some form of physical expression as well. I am going to talk about spirituality and depression, because it illustrates some of the issues particularly well, and I am going to take a traditional clinical approach, describing aetiology, symptoms, differential diagnosis and treatment.

But first, I must say what I mean by spirituality. As an example, consider sexuality. Sexuality is one aspect of our common humanity. It is rooted in our physiology, and expressed through our personality. But it involves our aesthetic and moral sensibilities, our social and cultural milieu, and most importantly, our relationships.

Spirituality is another aspect of our common humanity. It is rooted in the soul. It, too, is expressed through our personality, and reflected in our aesthetic and ethical sensibilities, our social and cultural milieu, and the quality of our relationships - with others, and our world. Above all, it has to do with our sense of value and meaning as a unique individual, not just in terms of our material existence, psychological attributes and personal relationships, but in terms of our significance and value within a bigger picture that has to do with some sense of a transcendent reality, or God-consciousness.

Spiritual experience is represented by observable patterns in the brain, but as with other aspects of mind is not convincingly explained by them. Spirituality and spiritual experience are *embodied* aspects of our psychosomatic unity; and *embedded*, sometimes to our detriment, in the religious and cultural context of our lives. But they are not epiphenomena of neurological states. And unless we recognise and accept the reality of our spiritual nature, as well as our psychological and biological nature, we will not be able to do full justice to one another in our personal relationships, and particularly in our therapeutic relationships.

Depression

Aetiology

Any of the recognised causes of depression may affect a person's spiritual equilibrium, just as they may affect physiological and intellectual function, personality, or behaviour. But in addition, factors that directly affect the psychic and spiritual dimensions may include:

Doctrine Abuse: Exposure to religious teaching or attitudes that distort or deny a person's innate spirituality.

Psychic 'infection': Exposure to influences in the psychic environment.

Psychic wounds: Deeply destructive experiences of the kind I have already described. Psychic sensitivity of a heightened degree, causing increased susceptibility to these other influences is exhibited by some people, just as others may exhibit a high degree of sensory or immune sensitivity.

Spiritual burdens such as guilt, shame, hatred, fear or doubt, may be too deeply rooted to be accessible to psychological help alone.

Symptoms

Symptoms include the whole spectrum of physical and psychological symptoms that may be found in any depressive illness. But language or behaviour that has explicit spiritual reference, and that could be interpreted as metaphorical, delusional or hallucinatory, should be considered as possibly representing actual experience and spiritual disorder.

Differential diagnosis

This will need to be as subtle and wide ranging as in the diagnosis of any psychological illness, but open to the possibility of a spiritual component. Close attention to the narrative of the illness and the patient's life is a *sine qua non*, and can reveal the presence of, or exposure to the aetiological factors I have described.

Empathy and intuition may induce a resonance in the carer that he or she may recognise as, or feel to be spiritual.

Discernment is actual spiritual insight in the carer; a prayerful awareness of the condition of the other person, under the guidance, in Christian understanding, of the Spirit of God.

Treatment

Any of the repertoire of psychiatric treatments and psychological skills may be appropriate for patients whose depression has a spiritual component or cause. Sensitive and perceptive use of psychological skills may themselves assist healing at the spiritual level. Insight and reconciliation achieved within an accepting, loving and non-doctrinaire therapeutic relationship may be enough. And the carer may not need to share the patient's spiritual perspective.

However, more may be needed. The person giving help may need to be able to speak with *authority* about the spiritual predicament. This might include an authoritative acquaintance with the relevant religious tradition. But above all it needs to be rooted in the evident integrity, insight, intelligence and compassion of the carer.

Intercessory prayer may be needed to deal with psychic interference causing depression. This is not the uttering of magical words; it may be couched in some form of words, but essentially it is to be present, to be *en rapport*, in such a way as to make room, in Christian terms, for God's spirit to initiate the healing process.

Deliverance, previously called exorcism, is too often evoked in popular and some religious thought, but rarely needed. It is a seriously abusive and damaging activity when misused. It requires the wisest, most competent and most discerning diagnosis. In the Church of England it is meant to be used only with the authority of people appointed by their Bishop.

In the Christian Church these healing acts may be reinforced by sacramental means – in the Eucharist or Communion, with laying on of hands, or perhaps anointing.

Conclusion

These are examples of illness in the soul manifesting in depression. But it could be in other forms of mental illness; or in physical pain, which may be psychogenic, or may have an actual physical component. Or the disorder in the soul may be a complication of a pre-existing physical disorder. So this brief 'clinical' analysis of spiritual aspects of depression may apply equally to pain of any kind that has some resonance in the soul. And it is certain that any chronic pain will have some resonance in the soul; which is inevitable if, as I maintain, every human experience has that resonance. If my 'structure of wholeness diagram is valid at all, that must be so, because the wholeness of every one of us is indivisible.

And now you are welcome to question and challenge me. I subscribe to the philosophy of Michael Polanyi which he expresses as a disclaimer in his book *Personal Knowledge*; which is to set out one's conclusions as cogently as one can, always accepting the possibility that one may be wrong. Because medicine is so deeply embedded in the culture of its society and its time, my challenge to the health care community is to recognise that to restore the soul to medicine will help to restore the soul to the wider community that it serves as well; to recognise that this is actually a responsibility that is inseparable from medicine's healing vocation.

Discussion

Would I be correct in saying that at the core of your construct is a belief in God? – that seems to me to be problem because for someone who doesn't, much of what you are talking about could be accepted but at each step there is a flaw to it. For instance what is the role of prayer to an atheist?

Austin Farrer, a theologian, said that there was no such thing as an agnostic because at almost every point of the day one is having to decide whether or not to pray. So prayer would have no point to an atheist and I accept that a core of my therapeutic approach to this question is a Christian one, and does involve an awareness of God.

Do you think that someone who doesn't believe in God might still have a spirit or a soul?

I certainly do, and that is why I have tried not to make what I have been saying exclusively relevant to people of particular faiths. The Royal College of Psychiatrists has an SIG for spirituality and produces a leaflet, which I think you can get from their website, which is a non-doctrinaire approach to the subject.

I have seen two patients in whom the intervention of a theologian became necessary. The first was a Jewish lady who when young had married outside the faith and been cast out by her family. Her husband abused her and she was divorced, but remarried. All was well until she turned up in the neurological unit paraplegic with no apparent cause. She was referred to me and told me that it had started when her mother died and she didn't get to her in time to be reconciled to her or receive the absolution she sought from her. The psychiatric explanation for this involves punishment, and when I suggested that the punishment had gone on long enough and she was able to walk. I advised her to talk to a Rabbi about the spiritual side.

The other one had phoned me in the neurosurgical unit and said she wanted to kill herself, because she had MS and paraplegia, was in terrible pain and wanted the neurosurgeons to cut through her spinal cord as had been suggested. I got her in straight away, and when she came in the evening I missed the fact that she was slightly drowsy. I was rung at 6.00am to be told that she was in status epilepticus, and it took us two days to get her out of it. After recovering she denied any memory of her admission and that there was anything wrong with her legs, which she moved vigorously. When I showed her to the surgeon who was going to do the cordectomy he turned very pale!! It transpired that some time earlier she had decided to become a Catholic (she came from a Presbyterian family) and the day of her admission she had had a terrible row with her husband. She rang me again in great distress a year later; she told me that this was the day of his acceptance into the Church and this was causing a terrible conflict with her husband. I advised her to see a priest, as although we had dealt with the physical component of her problems the spiritual component clearly required appropriate intervention.

When I worked in the pain clinic in Jerusalem the very Orthodox families would always consult the Rabbi before seeing the doctor.

Which comes back to what Steve was saying about the Maoris...

Is the experience of feeling somebody in a room when there is nobody there a psychic phenomenon?

I would say it is but it needs diagnosis ... interpreting ... its nature needs to be clarified. To an extent a psychic experience and a religious experience is what I say it is. Understanding this may require certain diagnostic gifts. It would be a great mistake to dismiss such an observation out of hand as imagination or delusion.

I have had such an experience. In a room at the Athenaeum I woke in the night with an intense feeling that there was someone in the room, but when I put the light on there was nobody there. When I asked the maid the next day if the building was haunted she told me that the Archbishop had had a similar experience in the library.

We are all to a greater or lesser extent sensitive to these things: I am very sensitive and in my role I can sometimes help if there is a problem.

... I don't have a faith of my own and I don't know anything about the faith of my [physiotherapy] patients, but picking up on your point about intercessory prayer, I think what we do is form a space into which what is going to come comes ... sometimes I just sit and the patient just sits – I don't know what they are doing ... and I have been astonished how often with just this sitting something resolves for the patient.

Do you remember one of Stephen's Maori quotations about *being with* ... If I am right and we all have this aspect of our being which I call the soul, then your 'being with' that person is creating the kind of rapport I was referring to on this deeper psychic level and because of your compassionate and attentive attitude this will have a healing quality for that person. You're not calling it prayer but the word is quite often misused and it is something perhaps a little simpler than people make out.

In another fifty years, like electricity, this may all be easily explained without having recourse to God or other entities ...

I'm not saying that because human nature has a psychic dimension is a proof of God: I'm just suggesting that this is a faculty we all possess, and it is my understanding that it is that aspect of ourselves within which people of faith would conceive the relationship between the human and the divine. Yes – it may be that the psychic dimension becomes as familiar as electricity ...

Psychic healing is a very natural phenomenon – it's not mysterious

...I'm trying to make it less mysterious ... that this faculty of human nature is a dimension in which this can happen. That's not dependent upon the religious attitude of the persons concerned.

Hope and hopelessness

Peter Wemyss-Gorman

“Are honest realism and optimism often compatible? Or do we have to look elsewhere for hope?”

These thoughts started as reflections on Chris' Chisholm's wonderful and inspiring talk last year on maintaining hope to the end of life in the dying.

But my background, as is most of yours, is mainly in chronic pain, in which hopelessness may perhaps sometimes be even more of a problem than in the dying. People with advanced cancer whose symptoms are unrelieved (a situation which as we have been discussing, has been by no means eradicated world-wide) may hope or even long for death as an escape from their suffering, and this may not be a distant prospect. But although the severity of chronic pain may sometimes be comparable to that from cancer, for many there seems only the prospect of many years, indeed a lifetime of an existence dominated by, and a lifestyle dictated by constant pain. Hopelessness is a dominant feature of depression, and in chronic pain it may sometimes seem the only realistic reaction to the situation. So it is clearly incumbent on us to do all we can to restore and maintain hope. But can we always achieve this without a measure of deceit? – The other theme of last year's meeting which prompted these reflections. When before I started my pain clinic back in the 1970s, I spent a few days in Abingdon learning from John Lloyd, whom the older among you will remember as one of the pioneers of pain management in this country. When things weren't going very well and early measures had failed he always used to terminate consultations with the words “Don't worry – we'll get this sorted out” – expressed in the most sincere and confident tone. The patients seemed to cheer up considerably and I thought it was wonderful. But when I started on my own and became more and more confronted by my own therapeutic failures I began to wonder if this was very honest, and whether by raising false hopes I might be doing my patients a disservice. I have been out of clinical medicine for many years now and I'm sure things have improved in many ways but I don't get the impression that the number of patients you can't cure has diminished a great deal. So I'm sure that this is a problem you all confront; I won't presume to give you any advice but my intention is to give you the opportunity to share your own thoughts and ways of dealing with it.

Is it axiomatic that hope is always a good thing? The ancient Greeks apparently considered hope to be one of the most dangerous of all the world's evils: when Pandora opened her box she let out all the evils except one: hope. Friedrich Nietzsche argued that “Zeus did not want man to throw his life away, no matter how much the other evils might torment him, but rather to go on letting himself be tormented anew. To that end, he gives man hope. *In truth, it is the most evil of evils because it prolongs man's torment.*” I suppose we might agree with him to the extent that single-minded hope for cure is a block to acceptance and the pursuance of realistic goals. I would welcome help with making the distinctions between acceptance, resignation and hopelessness. I realise that acceptance is generally regarded as positive, resignation perhaps as too passive, and hopelessness as thoroughly undesirable, but I would imagine that for some patients the distinctions may be blurred – “She is asking me to accept my pain and stop fighting it – does that mean I have to give up all hope?” Is hope the same as optimism? Is it necessary to be optimistic to be hopeful? We can at least address unwarranted pessimism and reasonably honestly reassure people that they are not going to grow inexorably

worse, as many seem to assume. But are honest realism and optimism often compatible? Or do we have to look elsewhere for hope?

False hope

So if there might be some ambivalence about hope which we may not always be aware of, there cannot of course be any ambivalence about false hope, and raising false hopes – of course it is always a bad thing. Or is it? It is only in my medical lifetime that attitudes to truth-telling, especially about dying, have changed diametrically, and last year we debated the extent to which the pendulum might have swung too far. We also considered the value of an optimistic tone in selling treatments in enhancing the placebo content of their effect. But we cannot but be aware of the damage some of our surgical and other colleagues have done in raising false hope, and the consequent cynicism and hostility to the medical profession some of our patients come to us with. We are probably all agreed that one of the first steps in pain management is to wean people away from a single-minded but futile search for cure and guide them towards acceptance and a positive attitude to living with their pain. The difficult part is replacing false hope with a more realistic one and I wonder how you all approach this. Outcomes of pain management programmes are by no means 100 per cent successful, and where they are not the situation may seem even more hopeless than before, especially when despite our best efforts patients may have had false expectations about them and unrealistic hopes of what could be achieved. And as we were discussing yesterday, some pain, especially neuropathic and central pain may be not only truly intolerable, but nothing to do with fear-avoidance behaviour and the other things we try to correct. Where is hope to be found for these sufferers?

I used to mumble rather unconvincingly about advances in pain science and therapeutics, but as time went on I found it more and more difficult to do this with any conviction and I was never very convinced of the honesty of my suggestion that advances in medical science would one day 'conquer' pain, or at least give biomedical therapeutics a much sharper cutting edge that it has now. Is this still the case? Is the big breakthrough as elusive as ever – or even more so? Is there any brighter light on the horizon? Or is the nature of the beast such that biomedicine will never hold many of the answers? Or are the biomedical guns simply trained on the wrong targets?

Another obvious problem is that not only doctors but the majority of patients are stuck in a biomedical mindset – or in the biomedical culture if you like. You might think that my asking the last question suggests that I am not entirely free of it myself. It is a much easier concept to grasp than biopsychosocial medicine and I sometimes wonder whether the time spent getting patients, with perhaps limited education and ability to think conceptually, to understand the latter can be all that helpful in achieving the goal of restoring hope.

Hopelessness

So if there is some ambivalence about hope, can we conclude that hopelessness may be sometimes and in some ways acceptable? Surely not! Hopelessness must be among the worst features of depression, and where depression is associated with chronic pain the darkness must be blacker than ever. I am open to correction but I would imagine that is less difficult to treat hopelessness when it is the result of disordered thinking than when it appears to be an entirely realistic reaction to a life

situation which cannot apparently be changed. And I would very much doubt if any pill could make much difference to it.

Religion and hope

I suspect very few of us would feel comfortable with bringing up the subject of religion in the pain clinic, but it is undoubtedly relevant. For a lot of people it may seem the only source of hope, and I would imagine that this particularly applies to the situations which were the subject of our second main topic on Tuesday. My concordance revealed 166 mentions of hope in the Bible. In the Old Testament a lot of these seemed to be either in the Psalms, and, perhaps surprisingly, in the book of Job. His situation might have seemed hopeless indeed: at one point he says "My days are swifter than a weaver's shuttle and come to their end without hope". But later he was able to say "Still I will hope in God". Surprisingly there were no references in the Gospels but there are countless uses of the word in the Epistles. Saint Paul famously listed hope among the three cardinal virtues; I was reflecting however that although I have heard countless sermons on faith and love I can hardly recall any on hope. Is this perhaps – even unconsciously – because hope implies uncertainty? (Where there is certainty of a good outcome hope becomes redundant, and where there is certainty of a bad one it is futile) Does the expression of hope then imply uncertainty of faith in a loving omnipotent God? Speaking personally, I have always found faith difficult but have found much consolation in the thought that I can always hope for things I cannot be certain of, and may even seem improbable, without compromising intellectual honesty too much. The word hopeless, incidentally, doesn't seem to appear in the whole bible. Apart from Andy Graydon, whom many of you will remember as a participant in some of our earlier meetings, I don't know if there are any clergy directly involved in pain clinics although all hospitals acknowledge the need for chaplains – perhaps there should be more?

Incidentally Michael Kell, who is not himself religious, is quite happy to use his patients' religions and their religious language if he thinks it will help them. I suppose a Buddhist might be inclined to agree with Nietzsche that hope may have to be abandoned to escape from suffering. But we still have to find a secular equivalent that will not cause difficulties for either patients or therapists who find belief in God impossible and religion meaningless. May I recommend the article *Spiritual Care in a Secular Society*, by Eileen Palmer which you can find in the transcript of our 2007 meeting: *Suffering and the World's Religions*.^{*} I won't try to summarise it but her underlying message is the need to help people find meaning and purpose in their otherwise apparently hopeless lives.

I should imagine that most of you would say that there are no "One size fits all" answers to these questions and probably as many answers as there are patients, and part of the art of pain medicine is finding a language which may be different for each patient which we can use to keep hope alive.

So far we have been talking about patients. Although I don't think I ever succumbed to hopelessness when I was working I certainly went through periods of pretty profound despondency, and I imagine that I am not alone in this. I put this talk last on the programme as I hope that the discussion, at least, may send you on your way with renewed hope in your work.

^{*}available as a download at www.britishpainsociety.org/meet_sigs_p&e_transcript_2007.pdf

Discussion

John Lloyd's remarks crystallise the concept of hope we use in palliative care. We think of it as an attribute of relationship between you and your patient – not just you: your team, your clinic; there is this commitment. When he was saying “we'll get this sorted out” what he is saying is no matter what condition you came in you and your team are going to stick with this person and their family to get them to a better place. It's hard for me to imagine that with your expertise, whatever mill they have been through that we can't get them to a better place. Often that means you're not going to get a cure but things will get better. I'm not going to abandon you and if I have no solutions I won't stop seeking them from my colleagues until we improve things somehow. And I think that if you have that attitude hope will authentically arise and be maintained. Getting it sorted out means we're not going to leave you to fend for yourself and struggle...

This involves what Caroline was saying earlier about 'sitting with'. No matter how many people they see the answer may not change but... we may not have the answer but we are still here for you – we might be pretty impotent but we won't abandon you.

As a GP, if a consultant in any of the clinics had said to the patient “There's nothing more to be done – goodbye” it's extremely difficult to turn that around and re-install some hope.

[Partially inaudible contribution] In coping with helplessness as a health professional I was drawn to the ancient stoics, and more recently to the concept of the stoical patient – the wise patient. This involves not looking at your situation with fatalism but rather accepting it and moving forward in a hope that is not hope of a cure but an engagement of living, of being and owning your own life with the guidance of 'mit zein' as Heidegger speaks of it: being with your health professional. The stoics have been a source of hope for me, and this conference, too, is a source of hope.

Coming back to this idea of being with the patient: in North America there is an increasing tendency for pain clinics to offer what they call pain programmes. There is a regionally funded programme [in Calgary]. This lasts for six weeks and at the end of that time you're out. There is no follow-up. In contrast I still see patients I saw in my first three months in Canada 25 years ago, and someone told me recently about a patient I had seen in Salford in 1980, whom I had inherited from Mark Swerdlow, who is still being seen there every six weeks. Nobody does anything but it keeps them going. This is real keeping with the patient, no matter what, is all about. We can at least offer ourselves for a short time.

.... false hope is really unhelpful. A lot of people say “I wish I had known this: I wish I had been told years ago that there wasn't going to be cure for the pain”. But the way that is delivered is really important because equally if people have been told that there's nothing to do – go away, that really leaves people in a state of helplessness and hopelessness. It's also to do with locus of control: if you're looking for hope outside, a cure that someone else is going to give you, that can lead to hopelessness. But if you can keep your locus of control inside: that is something you can do to improve your lot in life, then that empowers people and gives them hope. It has to do with that therapeutic relationship. We don't say to people, “Goodbye, you're on your own”, we say “Any problem at all, whether it's two years or then years down the line, come back to us – we're here for you.”

As a GP, what I find very difficult in the sense of that continuity, that healing, is quantifying that in order to justify the ongoing relationship with the patient and to maintain that because it's not cost-effective. I've got ten minutes and if I seem to make someone dependent on me that is seen as perpetuating my role and I'm doing a disservice to the patient. But actually what I can do for someone is being with them and have that ongoing relationship. But justifying that as a therapy – quantifying the value of that, to make an argument for it within the health service, is a very hard thing to do.

Part of that is not what you do; it is what you don't do. Patients I see and do nothing for aren't going to have a seventeenth MRI – they're not seeing someone who is going to do some useless invasive procedure. In North America these programmes have to be demonstrated as financially viable. If you're an insurance company you won't pay for someone to see the same doctor for 40 years. What you will pay for is an incredibly expensive six-week programme which costs \$60,000 and chucks half the patients out at the end, worse or not changed at all.

It's a shame then that half the profession in the UK, and probably world-wide, seems to be getting dragged down the wrong road. I get the impression since I left [the UK] nine years ago of GP's abandoning their patients. That's not what the old doctors who were around when I was training would do: a lot of them would say "I just jolly her along..." The value of that is immense.

From a personal point of view, this week has been fascinating. It has strengthened the multi-modal management of pain. We have heard from overseas - about spirituality: I am still fascinated by the Maori film. I thought the connection they had with family, the environment and their ancestors is something we have lost in our society. I just wonder: in our modern society people are very alone; they don't have family support any more. I see patients who never leave their house or flat except to come and see people like me, and they are very lonely. I wonder if we need to evolve centres, perhaps in the community where patients could come and socialise; see people about their pain, about sorting out their finances – we need places like this because people don't have family support. Those things we offer to dying patients we need to offer to chronic pain patients; maybe that is one of the lessons from this meeting.

Talking about personal hopes and prayer reminded me of our study of older people. One of the things I thought – I hoped – I might encounter was the role of prayer. But in the interviews nobody talked about prayer.

I do believe in not giving falsehoods but when you first start seeing someone do you introduce the possibility that there may not be a cure or do you initially give the hope that some of the first interventions you may try will be beneficial?

I think if you believe that you may help it's not a falsehood ...

... and bring in the idea of living with it later? ...

You need to prepare them to ensure they don't feel betrayed [We can say] if you haven't got any improvement we can help you deal with that ... it's quite personal, some colleagues do and others don't

We were talking about the right to know about CJD: there is a much lower probability of developing this than there is of chronic pain becoming intractable. Do people have the right to know that there is this possibility?

I would say that there is almost always something you can do. Most people coming to pain clinics have been through the hands of many doctors, and are in a confused state: they are not sure what is wrong – Dr X said this and Dr Y said that, several doctors haven't even told me what is wrong. So the first thing we can do is to say "We (I think the we is important) are going to look at this problem together and find out what it's all about and then decide what we can do to make things better. It may not get rid of all your symptoms but we can certainly look at what can be and can't be done." It's that kind of conversation which gives people hope but doesn't lead them down the path of believing they are going to be relieved of all their problems.

I think we are guilty of medicalising pain to the point where we focus on the pain when actually we should be focusing on the dysfunction. We and the physiotherapists should be teaching people how to regain that function. And that will also help the pain.

I think we're falling into another trap here of being guilty of thinking we are the only recourse that people use when they are suffering. I took part in some qualitative research in people with upper limb pain. They were using all sorts of resources among which the pain clinic or the GP only played only one small part. Through the process of coming to terms with the problem they will at times be using complementary practitioners as their mainstay of advice, and in another part it might be the next door neighbour. We are falling into a trap of arrogance here: we are only one of many resources people use.

Would anyone care to address my question as to whether it is honest to say that medical science will one day hold the answer to a lot of these problems so that people won't need to cope with their pain?

It seems to me that most things we have been talking about have lots of different aspects. Hope is many-faceted and the best that we can do is to direct people's thinking towards some sort of aspect which is realisable. If it's a question of medical science 'dealing with' that particular problem it may be most unlikely, so you want to get that low down in their food pyramid. I try to convey the idea that there is a cupboard there and lots of things in the cupboard but you have to look hard sometimes.

But is that antithetic to acceptance?

No, because you are accepting that there is a problem, but acceptance of a solution is a different matter altogether.

What I try to do with people for whom it seems appropriate is to suggest that they can stop the journey which led them to the pain clinic at the door, and start another journey from here, through life – not just the pain clinic. So for me, where I find a comfortable place to start is: can we accept, not the pain, but life as it is today. And can we look at any number of strategies, building on some they may have started, some they may have thought of, and even some they may find quite hard. Can we agree a set of strategies that start with how we are today, and when I see you again we'll have another look at how you are that day. So you're not either relying on hope or dismissing hope, you are thinking each day that's how I am, and what are my strategies for this day. My philosophical background for this is in Buddhism.