Airing Pain Programme 13: Culture, epidemiology and back pain

How do culture and religion affect the way we experience and manage our pain? Dr Shilpa Patel, Dr Sue Peacock and Sir Michael Bond talk about the relationship between cultural background and pain.

Also in the programme: Dr Steve Gilbert answers questions from people experiencing back pain; Phil Sizer of Pain Association Scotland provides advice on pain management programmes; and we learn about the epidemiology of pain and hear from Generation Scotland about how their study of pain in the Scottish population can help with the identification of risk factors.

Lionel Callaway: Hello, I'm Lionel Callaway and welcome to ***Airing Pain,*** a programme brought to you by Pain Concern, the UK charity that provides information and support for those who live with pain. Pain Concern was awarded the first prize in the 2009 NAPP Awards in chronic pain and with additional funding from the Big Lottery Fund's award programme, and the Voluntary Action Fund Community Chest, this has enabled us to make these programmes.

Dr Steve Gilbert: At its loosest definition, up to half the population actually have chronic pain. At the most severe end, about one in twenty people have chronic pain.

Sir Michael Bond: It's very interesting to ask people from different religions what pain means to them. All of them linked pain to punishment.

Phil Sizer: Pain management isn't really ultimately about managing pain, it's about more about somebody managing their life – so what we are looking at in our programmes is reducing suffering as a way of reducing the impact that pain has on somebody's life.

Callaway: More on those stories later; but first, remember one of our aims here at ***Airing Pain*** is to put questions you've raised with us to our panel of experts. Today Dr Steve Gilbert of Queen Margaret Hospital in Fife is dealing with some of your questions about back pain. One ***Airing Pain*** listener writes: I've had bouts of back pain for several years, which usually clear up. But this time it hasn't cleared up for four months. My doctor says I don't need a scan, I just take painkillers. Is the doctor right about the scan? I don't want to take painkillers forever – what other ways of managing the pain are there?

Gilbert: The main reason for having an MRI scan is to identify something that might be helped with an operation by an orthopaedic or a neurosurgeon. Discs often bulge and don't necessarily cause any symptoms. They can be pressing on nerves or there can be a narrowing of the whole spinal canal without it causing any symptoms in the patient, so if there is disc bulging which is pressing on a nerve, and that ties in with symptoms you are having which is most often a shooting electric shock pain going all the way down to your foot or a burning or nerve type pain which is there most of the time, not just coming and going, then that can sometimes be helped with neurosurgery.

The answer is, if you have nerve pain all the way into the foot, or if you have other nerve symptoms like weakness or persistent loss of feeling, in that case it might be worthwhile having a scan.

If you have been unwell in yourself, if you have lost weight or you have an infection or you have any past history of cancer, or what we call ‘red flags’ – these are things that the doctor should look out for as there is a chance there is something really serious going on in your back, in that case you would be worthwhile getting a scan.

I must emphasise that the red flags are very, very rare. The majority of people, the problem with back and leg pain is to do with the way the back is working. It is to do with tightening and sensitivity, nothing serious, it’s a normal part of life. Often I see people in the pain clinic and they have been started off on paracetamol and some anti-inflammatories and then they’ve gone on to get some codeine as well perhaps, then they get drugs like tramadol and then moving on to really strong pain killers like morphine and oxycodone, very strong, powerful pain killers.

When I have a look at their back, usually I find that there is quite a lot of tightening and sensitivity from a very light touch and this is because the muscles are tightened up. The nerves are very sensitive. It has to do with the way the muscles and the nervous system interact with the back. It has a lot to do with the way the brain works and it has lots of different connections in this pathway which aren't easily dealt with by strong painkillers. The best way to get better from this is to try and relax the muscles and to try and gradually increase your fitness and desensitise things.

Callaway: Doctor Steve Gilbert of Queen Margaret Hospital in Fife and he will be answering more of your questions about back pain later on in the programme. I'm Lionel Calloway and you’re listening to ***Airing Pain***. Epidemiology is the study of the distribution or patterns of disease amongst the population in order to identify risk factors, best treatments and preventative measures, so in terms of chronic pain it’s finding out how many of us have it, the types of people we are and any other factors that link us together. One such study is Generation Scotland. Blair Smith, who's a GP and Professor of Primary Care Medicine at the University of Aberdeen, is a senior member of the Generation Scotland team.

Blair Smith: Generation Scotland is a study taking place across the whole of Scotland, where we're asking volunteers to come with their families, to come and help us with information about their health, their lifestyle and to give blood from which their DNA and genetics can be extracted. We can look at a number of different important illnesses and chronic pain is one of the ones we are looking at. In common with a lot of chronic conditions, it tends to affect poorer people or people that are less well educated, people from deprived areas, it follows the patterns of most chronic conditions. What we are really trying to struggle with is whether it is cause or effect, is it people who have less money that tend to get chronic pain, or is it having chronic pain, and the disability associated with it, that makes work and income generation more difficult – we don't know that, and we're still trying to work it out.

But more recent research following up people who have had chronic pain has found over a course of a ten year period, that people reporting chronic pain at the start of the ten years

were more likely to have died during that ten years. In particular, people were more likely to have died of heart disease or respiratory disease. Where there are several very good reasons that you might postulate for the reason for that link, it could be that if you have chronic pain you are disabled and less likely to be able to exercise, or there might be an actual link between chronic pain and stress. We are beginning to look at this in other research, which is actually finding that people with chronic pain have higher cholesterol. There is emerging evidence that it certainly runs in families, whether that is because of genetic effect or because of the lifestyle in the family, or the culture in the family, we don't know, but there is certainly emerging evidence of some specific genes that might well be associated with chronic pain.

Callaway: That was Professor Blair Smith and you can find out more about Generation Scotland from their website at generationscotland.co.uk. Staying in Scotland, Pain Association Scotland is a charitable organisation working in collaboration with the NHS. It's pioneered the development and delivery of the self-management training approach to chronic pain in 32 locations throughout Scotland, using intensive pain management programmes. So who are the programmes aimed at? Phil Sizer is the Lead Trainer for Pain Association Scotland.

Sizer: It's people who are struggling to come to terms with the change in their health, and that's really key in our work, trying to get people to adapt positively to a change in their lives with the classic things of pacing and stress management. In the intensive programmes, perhaps a little bit more than the group programmes, we tend to get people who come from hospital-based clinics; so it's kind of interesting that people find it an exit strategy from a chronic pain management service or a back pain service. The intensive programme is basically what we are doing in one of our regular groups but compressed into eight weeks.

So, we start off looking at the impact of pain in somebody's life and how self-management sits alongside the medical model – it doesn't replace it – then start to get people to look at the things that have changed in their lives, then get them to look at what they can do about that. It's kind of interesting because pain management isn't really about managing pain – it's more about somebody managing their life. So what we're trying to do is looking at ways of taking the total load someone is living under, so the focus isn't about pain per se, it's more about pain and suffering. So what we are looking at in our programmes is reducing suffering as a way of reducing the impact pain has on somebody's life.

Callaway: Phil Sizer of Pain Association Scotland. And you can get more details from their website chronicpaininfo.org. I'm Lionel Callaway and this is ***Airing Pain*** brought to you by Pain Concern, the UK charity providing information and support for people who live with pain.

Now we are delighted to announce that two of the most highly respected people in the pain community – Dame Anne Begg MP and Professor Sir Michael Bond – have agreed to be patrons of Pain Concern. Dame Anne Begg has been Labour MP for Aberdeen South since 1997. She's also a campaigner for social justice, welfare reform and pensions, as well as civil rights for disabled people. Professor Sir Michael Bond was knighted in 1995 for his services to medicine. He is an authority on the psychological aspects of pain and on the

social and psychological consequences of severe brain injury. He has served as president of the British Pain Society and the International Association for the Study of Pain, and now lends his expertise to the development of clinical programmes of pain management in developing countries – a journey which started in his early career, when he realised that pain treatment was given according to the cultural influences of the practitioner rather than the needs of the patient.

Bond: I worked as a new doctor in two cancer wards, as they called them in those days, and I conducted a study to find out how efficiently pain was being treated in the men and the women on the two wards. None of the men, in a week, received any of the most powerful narcotic-related drugs, even though they had advanced cancer in many cases; whereas the women did. What we discovered was a lot of the prescriptions were given according to beliefs of the staff about the painfulness of the conditions. There were women being given injections of powerful drugs for certain gynaecological conditions which were believed to be painful but which weren't necessarily painful. So that was Britain 40 years ago, there were strong cultural influences on how people were treated, and that of course has changed a lot; but you still find similar beliefs in other parts of the world.

It's very interesting to ask people from different religions what pain means to them. If you think of the Christian religion, most people would say that pain is perhaps a sort of punishment, and in fact the word pain comes from the Greek word for punishment. I spoke to a Hindu and asked him what serious pain would mean to him and he said, well really… it's a test of your fortitude – if you pass the test you will have a better afterlife. The Buddhist was different; he said, if I have severe pain then something was wrong in my previous life and I now have to atone for that, so all of them linked pain to punishment.

One of the natural consequences of not having specific services for pain relief, other than native medicines and native practices, is that you have to bear it and you're expected to, and you expect to, because there isn't an alternative, particularly in the poorer part of the developing countries. In very poor parts of India or south-east Asia, you find people bearing pain that would never be seen in the west. If you think in the deepest parts of many developing countries, the only medical person the community might see is a nurse, and probably one nurse for many, many people and they do everything.

So rather than being evangelical, if you forgive the word, we felt that we should address the problems as they see them, so in other words bottom up. They say 'What we need is…' and we say, 'Well, we can help you get there if we can.' So our educational programmes are based on submissions from individuals in developing countries, they might be doctors or nurses, seldom any other professional group, and they are as varied as wanting to run a simple course for teaching people about pain. I couldn't believe this, but in Kenya we were asked to support a course for the training of midwives in pain relief, now it is beyond one's imagination that training of midwives would not include pain relief, but apparently it didn't.

We have had quite a lot of requests for programmes for the management of people with severe advanced pain due to cancer but, of course, the other major cause of severe pain,

particularly in sub-Saharan Africa is HIV/AIDS. If you think about it, 70 per cent of people who reach the advanced stages, and we're talking about millions, will not be given any relief for pain, yet the pain they suffer will be as bad as people imagine the worst pain is from cancer.

Calloway: That was patron of Pain Concern, Professor Sir Michael Bond. Whilst his works focuses on pain management in developing countries, the UK's own multicultural society can also present challenges for health professionals. Dr Shilpa Patel is a researcher and chartered health psychologist working with directly with patients with chronic pain. She conducted research into how general practitioners in the Leicester area manage chronic pain in the south Asian community.

Dr Shilpa Patel: The challenges they face are often around the consultation process, so when patients from the south Asian community, and when I say south-Asian I'm talking about patients from the southern sub-continents, of people who have originated from India, Pakistan, Sri Lanka those kind of countries. And often what GPs said, in the consultation, they found some of the presentation was quite bizarre, it didn't quite anatomically fit with things they knew, so often people would often present with widespread pain, it was difficult to pinpoint where that pain was coming from, so if you asked them to point out the pain, the pointing would more kind of all over, so you can imagine from a GP's perspective, it's like where do you start the treatment.

Also language barriers - if English was your only language and you had patients that were coming in that spoke Gujarati, Urdu, Punjabi, Bengali and often you don't have a translator available then and there and you've got family members coming to translate, they are not always telling you what the patient said, sometimes things are lost in transmission, so that can be quite a barrier.

They also talked about acculturation, now that is kind of looking at when somebody comes to this country how they take on the beliefs and values and perceptions of this country and the beliefs they hold. Now, they said that the older generation that had come over, the way they presented and perceive pain and beliefs about pain are very different from British-born south Asians, because they just said that there is a big generation gap and the British-born south Asians are very much like white British patients. So there wasn't much difference there, but it was the older generation – they wanted a cure, they wanted treatments, they wanted things to be investigated, they wanted to know what their problem is. So GPs said they could benefit from having better translation services or things like CBT specialists or counsellors, because some of the pain may stem beyond just the pain – there's other things going on that need investigating – but often they felt they couldn't do it. So they needed more help in those areas.

Dr Sue Peacock: I think acculturation plays a huge part in how people present with chronic pain and everybody, and every culture, has different health beliefs, different ways that they perceive health and illness and pain. Those things are brought to the consultation whether we like it or not, so I think we need to be aware of how these cultural factors influence, not only people's pain, but how they present with pain, how their wider communities see pain, their pain behaviour and whether their pain brings them to the pain clinics.

Calloway: Dr Sue Peacock there, she's a health psychologist at the pain clinic in Milton Keynes Hospital. Her doctorate research was into the effect of culture and ethnicity on the management of chronic pain. Her study was also based in Leicester, where around 26 per cent of the residents say they are Asian. Indian or British Asian Indian.

Peacock: The sample in my study were very acculturated, in that they all spoke English, so most of them could read and write English, 11 out of 13 of them wore westernised clothing outside their family and English was the most common language used at home. What I found in my study, which was quite surprising, was it was so different to my work in Milton Keynes, where they were new immigrant populations, not well-established ones like in Leicester. The Leicester population actually had very similar beliefs to white British people and it was actually gender that created more differences, particularly in terms of things like learned behaviour and learned expectations and where we've learned what responses to make to pain and also in terms of our roles in society. Interestingly, all of the people in the study said that women coped better. They showed less pain and coped better than men and everybody said that, and the reasons tend to be summed up by, I think the quote was, 'Women have babies and women's troubles, so they can cope with everything'.

What was interesting was the white British participants, as time went on, they had to adapt and they actually coped in very similar ways. The people that I talked to very much felt that men took to their beds to start with, and the women got on because they felt obliged because of their social roles as wives, mothers, carers and all their responsibilities. Quite often it was that fact, that they couldn't fulfil those roles, which caused them a lot of distress whereas men eventually realised that they couldn't stay in bed forever and they had to get on because this pain wasn't going, so eventually they came up with similar coping strategies and new similar coping strategies to the women.

Some of the things GPs said that, maybe the patient was using the pain as a way into the consultation, in the door but behind that it's actually other things that are going on. They might be feeling a bit low or depressed, but it's something they can't say, and the stigma involved in having depression and so forth within the south-Asian community, it can be problematic, so they may not want to go into the GP's consulting room and say, 'I feel quite low' or 'I feel quite depressed'. They might use pain as 'a ticket for an admission', one of my GPs said, it can be like a ticket for admission into the consulting room because pain, you can't really see it, it can be anywhere, so some of the GPs did talk about whether it was expressing emotional symptoms in physical ways.

Calloway: That was Shilpa Patel you are listening to ***Airing Pain*** with me Lionel Calloway. Before we continue I would just like to remind you that whilst we believe the information and opinions are accurate and sound and based on the best judgements available, you should always consult your health professional on any matter relating to your health and wellbeing. He or she is the only person who knows you and your circumstances and therefore is the only one who knows the appropriate action to take on your behalf.

Now we have another question, once again about back pain, for Dr Steve Gilbert from Queen Margaret Hospital in Fife, from a listener who is struggling to because of his or her pain. 'I've started to feel a pulling pain in the lumbar region of my spine. My doctor has

prescribed me painkillers and if I feel numbness or difficulty holding urine I should go to the hospital. The pain has now moved to the buttock and thigh, what should I do, should I get an x-ray?'

Gilbert: Well I wouldn't worry about this; this sounds like a typical muscular pain. Often the problem starts off in the back muscles where they are joined into the back of the pelvis and as you tighten up and try and stop things moving, which is what your brain does for you, not something you are consciously aware of, then the bottom muscles which are attached onto the other side of the pelvis become tightened up as well and this can spread into your thighs. There's a muscle that goes from the front of your spine down into your groin and often this makes the pain go into the front of your thigh, especially when you're trying to stand up from sitting, or if you are trying to go upstairs. So this sounds like a normal muscular back pain which is what most people get.

The other part of the question was whether you needed to go for an x-ray and what would happen if you got numbness or difficulty passing urine or bowel movements. This is a condition called Cauda Equina Syndrome, where a disc bulges out and presses against the nerves in the spinal canal. This is a very rare condition but it is something you need to get help for that day – you don't wait for any appointments with your doctor, you go straight to hospital in that situation, but I must emphasise this a very rare condition. You might feel numbness between your legs and, as we discussed, you might not know when you need to go to the toilet and you might pass urine without realising it. In this case, you need to go for an urgent MRI scan and then go on to see a neurosurgeon perhaps for surgery very quickly but you will know if this happens.

It is a very rare condition, the vast majority of people with back pain have simple, or mechanical, back pain and the main thing to do is to relax and to try and keep on the go, gradually increase your activity and to reduce your painkillers as you're getting better.

Calloway: Dr Steve Gilbert. The next question is from a 20 year old who says, 'I've been diagnosed with dehydrated discs. I'm currently on a lot of medication and have been for the last two years. I've had physiotherapy, epidural injections and acupuncture. I've recently had a massive flare up and I'm in so much pain I just don't know what to do.'

Gilbert: Often, when we are looking at back pain, we tend to focus on the physical structures inside the back, particularly discs. Now, discs naturally dry out a little bit as you get a little bit older but I wouldn't think there would be any significant changes in your discs at age 20. There might be a little bit of bulging but if the disc is bulging out and that's causing a problem, it doesn't usually cause back pain – it causes a nerve pain all the way into your foot, all the way down your leg.

So I think you have been given an explanation about your back pain which is a little bit worrying if you're only 20 and your discs are already dehydrated and damaged – what's going to happen when you get older? It's not a very encouraging message for you. Discs are not usually the cause of back pain. You have had lots of different kinds of medication, injections and your acupuncture, and none of that has made any difference and it's most likely that everything in your back is very tightened up and very sensitive. That's to do with

the way that your whole nervous system, including your central nervous system or your brain, is working.

So what we have to do to try and get your back pain better is to, first of all, understand what the problem is with your back, why is there so much tightening and sensitivity there. Often there are spasms, because the muscles are contracting without any conscious control and that gives you a lot of pain. You need to try and get things to relax, which is not something you can do consciously, you need to try and increase your exercise tolerance to decrease the sensitivity and this is what we call a rehabilitation approach.

First of all, I think it would be worthwhile finding out more about chronic pain, and why it goes on and on, and why you get so many different opinions about back pain, and I would recommend a really good book about pain and pain mechanisms and pain management called *Explain Pain* by David Butler and Lorimer Moseley. This a book which explains why pain happens, it's got a lot about the nervous system and complex clever stuff, so by the end of reading this book you will be an expert on pain. This is something anybody can understand. It's traditionally been thought that back pain is a serious medical problem, it is clever and complicated – it's not. It is very straightforward, anyone can understand it, The evidence is that understanding is the key to getting better.

Calloway: Dr Steve Gilbert of Queen Margaret Hospital in Fife.

If you want more advice with dealing with, or preventing back pain, then an excellent resource is the back care helpline at backcare.org.uk. And finally if you would like to put a question to our panel of experts or just make a comment about the programme, then please do so via our blog, message board, email, Facebook, Twitter or even pen and paper, in which case the address you need to write to is [see Contact Details below]. All this information is on our website at painconcern.org.uk where you can also download all the past editions of ***Airing Pain.***

We will end this edition with some advice from Phil Sizer of Pain Association Scotland for those being diagnosed with chronic pain but are at a loss on what to do next.

Sizer: Well, the first thing is to get the best medical help you can, because I think people won't engage with self-management until they feel like they have got the right answers from the medical world. Once, they have done that, I think to find your way to some kind of self, or pain management programme would be important. There's horses for courses really, there are the intensive pain management programmes that only clinicians can send you on. There is the work we provide, which I think is very appropriate, there are also other sorts of self-management but I think the key thing is not to rely on medication because the picture of chronic pain is complicated because of the way people try, or try and fail to adapt, so these are key things being looked at, and self- management offers a way forward with that.

Contributors

- Prof Blair Smith – Generation Scotland
- Prof Sir Michael Bond – Pain management in developing countries
- Dr Steve Gilbert – Q+As on back pain
- Phil Sizer – Pain Association Scotland
- Dr Shilpa Patel – Culture and pain
- Dr Sue Peacock – Culture, gender and pain

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