

Airing Pain Programme 69: People not patients

Sharing decisions and why pain management needs psychology.

Can a doctor ever be too sympathetic? Health psychologist Professor Tamar Pincus explains why this might be the case – patients with long term conditions can feel like they are being 'looked after' rather than taking responsibility for their own health. Pincus also clears up some myths about the role of psychology in chronic pain and makes the case for acceptance and commitment therapy (ACT) as a key part of the pain management toolkit.

Acceptance can be difficult when people in pain are under pressure from those around them to be 'the person they were before the pain'. GP Frances Cole's rehabilitation service puts the people – not 'patients' – she sees in control of guiding their own treatment with the aim of being the best they can be with the pain. She asks them to focus on what matters most to them and helps them connect to 'a new world' where they can learn skills and knowledge from other people who've faced the same challenges.

Paul Evans: Hello, I'm Paul Evans and you're listening to **Airing Pain**, the programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and healthcare professionals.

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And I'm returning to a subject that was explored in depth by health professionals and some patient groups in the British Pain Society's Annual Scientific Meeting of 2014. Shared decision making in the context of a doctor patient relationship, implies that the patient's viewpoint, expectations and circumstances are essential components for a successful treatment plan.

Might seem fairly obvious, a 'no brainer', in fact, that the patient's expert – and *I do* think that's an appropriate word – the patient's expert knowledge of how persistent pain is impacting on his or her daily life, should be taken into account. But the fact that shared decision making is an issue highlighted in this British Pain Society meeting and elsewhere indicates, that the concept is not universally accepted or understood.

Tamara Pincus, a Professor in health psychology specialising in pain at Royal Holloway, University of London has looked at what GP's can say to patients when they present for the first time with low back pain or other conditions, of which very little is understood in terms of their cause and outcome.

Tamar Pincus: The problem is the GP is supposed to reassure these patients. How do you reassure when you don't actually know? How do you reassure in the context of uncertainty? So in the workshop that I presented here, we looked at evidence that suggests very strongly, that what helps patients is good information – giving a good explanation in simple words that a patient can understand. Discussing with them the possibilities of which treatments they are going to get, which treatments they want, that's very useful.

The question is where does the empathy and the building of the relationship and the 'it's going to be ok you can trust me' come into it, because the evidence on this was very surprising. You'd think – and I certainly thought when I went into it – that this would be essential, that nobody would even tell their GP what their problem was until they trusted them and they really had a relationship with them. And I think that's probably the case. But, it seems that if their GP is *over* affective and by that I mean very, very reassuring at those later stages of the consultation. The stages where they're actually educating, giving information, agreeing treatment, if at *that* point it's too much of a personal motive engagement, it actually isn't good for the patients.

Evans: Do you mean, if that reassurance comes late in the cycle of treatment, it's almost like saying 'Listen, we've been through everything, let's sit down and talk about what's on your mind.'

Pincus: That's a really good question. First of all, what's on your mind should be at the early stages. There's no question that early stages are about the patient talking and the patient should do the majority of talking and the practitioner should elicit their concerns as well as facts. The problem of doing the touchy feely stuff not just then, but also at the end, is that what you're actually giving is a message of 'You can trust me. You don't need to work or take things on board. I'll take care of you.' And that actually doesn't give patients tools to cope with their problem. So three weeks down the line when the pain hits them again, they haven't been given any new tools to work with it.

So they need to disengage from this 'It's ok, I'm going to be taken care of' in order to take on a different role, which is, I'm now going to listen and learn how to take care of myself. I think that is what the research is pointing at, but I have to stress that the evidence is from primary care in general and *not* pain specifically.

Evans: So, when you started your research, what was the question?

Pincus: I started the research because I believe that we've neglected a very important element in our research. We've looked a lot at what the patient brings to the consultation, so we look at whether they're depressed or anxious, fearful, working not working... and that does predict their health.

What we haven't looked at, is what the clinician brings to the consultation and my research in the past few years, has indicated that clinicians' beliefs really affect their decision making. So, for example, many clinicians tell patients they need to take a short break from work. That's against guidelines. The guidelines suggest you need to go back to work as soon as possible, even if you have to modify what you do at work. And you need to be engaged with your life for as much as you possibly can. If a clinician doesn't believe that, they're not going to obey the guidelines, they're not going to be in line with the guidelines.

So I was really interested in clinicians' beliefs and once you start looking at clinicians' beliefs, and patients' beliefs, you have to start looking at the interaction between those two. And that's when I thought about how to reassure patients, how to educate patients and how to enable patients to take care of their own problems.

Evans: A theme through this British Pain Society, Annual Scientific Meeting seems to be joint decision making – each has an equal part. Is that what you're getting at, that the doctor doesn't seem to be engaging with this?

Pincus: I think it's more complex, because it would be lovely if we had one thing that fitted everybody – joint decision, fifty-fifty, that's it. It's just not like that, some people come in to a consultation and they really do want 90 per cent of the decision making to be handled by the doctor. That's their *need*. We need to respect those wishes. They'll probably do better if we do. Others come in and want to actually tell the practitioner what they want and they will feel offended and patronised when a practitioner will turn around and argue, because they feel that they know – they know their body, they know their problem. Again, probably they should be doing more of the decision making, providing it's not harming them and there is more of a discussion there.

Different styles suit different patients. My argument is that we've just assumed that we can do consultations, but we haven't researched how to do them right for different types of patients at different stages of the consultation. So we really don't know enough about how to do this thing correctly.

Evans: So how would you identify those people who come in who just want a doctor to make me better and those people you want to take a larger part of it? It might not be as obvious as you're saying.

Pincus: There's absolutely no way currently, that we can identify those empirically. I'm sure that some doctors have very good intuition about it. Some doctors might even ask, 'Would you like me to make all the decisions here?' I've never been asked that by a doctor. Maybe there are others that ask it out there. But the empirical data about the consultation is a myth. The idea that we know how to do it as a myth, the data isn't out there.

Evans: You did a workshop today with health professionals, what were the barriers?

Pincus: There are many different opinions about psychology in pain. There are many fractions and factions and they're all pulling in different directions, so where are we now in terms of psychology and pain? We've done trials for the last fifteen years and we know that psychology is quite effective, but the effect is small. It's really disappointing because we thought that we could really, really change things when we targeted psychology. That means there's a group of people sitting there saying 'No more psychological trials'. There are another group who are pragmatists and they look at the NHS and they go 'There's hardly any psychologists working in pain, so why on earth would we want to do trials on psychology when we can't even roll it out afterwards to patients?'

There's another group who are psychologists who are going 'You've never given it a chance. All the trials that you've done were not done with psychologists delivering enough good psychology to people who needed psychological intervention.' Put all of those in a room and you'll see that delivering a talk, [laughs] can be stressful.

Evans: I thought it was well established that pain was a biopsychosocial phenomenon. Take the psychology out of that and what's left? You're taking the mind out of it.

Pincus: In the keynote that I've just given, I've outlined at least three myths that I think have really hindered us from moving forward. The first one is the idea that if you remove the pain, all the psychology would just go away. Now that is a myth for several reasons: at late stages of chronic pain, it's very unlikely that you'll remove the pain, and even if you did, the behaviours are entrenched already. Behaviours like disengaging from life, protecting yourself – you have to actually tackle those, not just the pain. Even in earlier stages, if you ignore risk factors such as depression and anxiety, you might remove the pain, but my suspicion is there will be another health problem that will manifest itself because you haven't tackled the risk factors.

So that's myth number one. Another myth is that if it's too complicated and hard to do then we won't be able to roll it out in the NHS to patients, so let's not even do a trial on it. That's a really sad one, because you wouldn't do that on open heart surgery, for example. You would never say 'Oh this is so expensive and needs so much specialist training that we won't even research it.' But somehow in psychology, that's exactly what has happened and instead what we get is watered down psychology by non-psychologists in tiny doses. So even if the model has been accepted, it's not actually been given a chance.

Evans: Well I'm confused now, because I thought psychological approaches – talking therapies, if you like – I thought they were well established as being meaningful and essential to managing chronic pain.

Pincus: You will come across some psychologists in pain programmes. Sometimes you will come across pain programmes that say there is psychology in it, but there isn't psychology in it. Often psychology is given by non-psychologists. And, yes, I think there is a recognition that we need to tackle psychology, especially in chronic pain, but there are not the resources, there is not the training, the psychologists aren't out there and in terms of funding, research is turning its back on it, which is very worrying.

Evans: I would have thought that chronic pain in psychology would have been a very, very sexy subject for a young psychologist to think about.

Pincus: It's a fantastic area to research but we are simply are in a situation where people are saying, we've got enough, we don't need any more, thank you very much. We know psychology works but it doesn't work as well as we hoped it would. We do not need to find out more about psychology now, we know everything we need to know and we're just going to offer a little bit of everybody.

The real shame about it is that means you never research the mechanisms, you never really identify the needs of sub groups, the more complicated issues of how to match treatment exactly to the needs of specific individuals. Instead you do a generic 'Oh, ok, anybody who scores more than five on this particular questionnaire, will get to see a physiotherapist who has also studied psychology for a couple of weekends and we're going to call that a 'psychological intervention'.

Evans: So in an ideal world, what could a psychologist offer that isn't offered now?

Pincus: In an ideal world, we'd really start thinking about theory-driven psychology.

Evans: Meaning?

Pincus: I particularly like acceptance and commitment therapy. Cognitive behavioural therapy often has this idea that there's a dysfunctional cognition involved in depression and pain. Actually, if you've had pain for a very, very long time, a lot of your fears and sadness are depression are not dysfunctional, they're realistic – you really have lost a lot. Acceptance and commitment therapy doesn't even go there. Instead it's about being flexible enough to embrace what you have got in your life and live with what you can't change and I like that very much. And I would like to see that trialled in a large trial here in the UK.

Evans: Acceptance and commitment therapy is getting established, but you're saying there's not enough of it around.

Pincus: There's not enough of it around and there's not enough empirical evidence for it. Currently, there isn't a single large trial on act for pain. It's coming, but it's not quite there yet. The other interesting thing from my pilot we've just finished on this, which was funded by Arthritis Research UK suggests patients actually want a combination of act with physiotherapy. They feel very strongly that the pain is in their body, not just their mind, they love the ACT and they use it, but they also want something in the body, some exercises, maybe some manual therapy, maybe some prodding and pulling. Whatever it is, they want this combination – a synergy.

Evans: But that is accepted theory now, perhaps that's the right word, accepted theory.

Pincus: Exactly.

Evans: But not the accepted practice.

Pincus: I think that's true and one reason is that there are simply not enough psychologists out there. Clinical psychologist are gold dust at best and they don't go into the pain services.

Evans: Did you come across any blank faces in the audience?

Pincus: I don't tend to have blank faces in the audience, um, possibly because I tend to be quite controversial and provoke a lot. I had smiles, but I didn't have any blank faces.

Evans: I would think that you have been controversial and I would expect doctors would stand up and 'No, you're wrong, we are doing this and we do take this seriously.'

Pincus: The evidence on the ground is that they don't and the evidence I produce from trials is that they don't. A lot of trials, because there are not psychologists there, have trained physiotherapists to deliver CBT and they call it a 'CBT approach'. One of the things I said in the plenary – and I was joking, but only semi joking – 'My husband has back pain and sometimes I give him a massage. I've learned to give a massage by observing the physiotherapists who work next to me and by looking at YouTube, who also show you beautiful little videos of training. And I don't call it physiotherapy, I call it a 'physiotherapy approach'.

Evans: That's Tamar Pincus, Professor in Health Psychology at Royal Holloway, University of London. This seems like a good time to remind you that whilst we believe the information and opinions on *Airing Pain* are accurate and sound, 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, your circumstances and therefore the appropriate action to take on your behalf.

Going back to acceptance and commitment therapy, if you want to learn more about it, listen to **Airing Pain** programmes numbers 16 and 45 which like all editions of **Airing Pain**, you can download or obtain copies direct from Pain Concern. If you'd like to put a question to Pain Concern's panel of experts or just make a comment about these programmes, then please do via our website, blog, message board, email, Twitter, Facebook or even pen and paper. All the contact details are at our website which is painconcern.or.uk.

Now, staying with the theme of shared decision making Francis Cole is a GP in West Yorkshire. She's a pain rehabilitation specialist, so what is that?

Francis Cole: I mean by pain rehabilitation, enabling people with long term pain to begin to understand that they are dealing with not only the pain itself but the way it impacts on them physically, emotionally, on their lives, socially, activities with their family and their future. And then from beginning to understand that, looking at how to minimise the distress and upset that the pain causes. Reduce and minimise the disability, the limitations and maximise that individual's health and wellbeing, so they can connect, give, notice what's going on around them, be much more active and keep learning.

Evans: The word 'rehabilitated' to me means 'I've had an illness and now I'm going to get better'. That's not the case in all cases of chronic pain is it?

Cole: No. I think that's quite interesting because sometimes people use the word 'recovery', but, actually, we're not talking about recovery. But what it means is, that when you have any long term condition – and pain is one of the long term conditions – then actually we're about enabling that person both their physical body, their mind and their lives to be as good as is possible, still with the condition being part of them. That's part of an acceptance that I'm different from what I was but I can be as best as I can possibly be in all those areas.

Evans: That's putting the pain somewhere else in your life?

Cole: In your life, in yourself, in your mind. So that you're in control in where *it is*, in your minute to minute, hour to hour, day to day... It does not limit, determine or shape who you are. It's the other way around, you shape you, and your life and the pain is shaped how you want it to be to live the life you would value.

Evans: So you're a GP?

Cole: Uh hum.

Evans: So how do you tell a patient how to do that?

Cole: Well over the years, interestingly enough, I've worked out a kind of system that works. First of all we don't rush, so we may see the person several times, over three to six, 10 to 15 minute sessions over a period of probably 10 to 20 weeks. I work with the individual to help them to identify what they would value changing, what would be most important for them to change at the moment about the way the pain is affecting them. Either body-wise, mind-wise, work-wise, relationship-wise, money-wise, whatever their issues are.

Help them to become aware actually of the bigger picture, so there is quite a lot of information about this condition called 'long term pain'. And then share with them the hope that there are things locally – as where I work we have lots of self-management support and resources – that we've got quite a lot of possibilities and some choices. And that would be session one.

They have the time between the first and second session to think, perhaps talk at home with somebody or ring someone, check out something, come back and share with me what they've discovered. They then say ok, 'How do we take that forward? So it's very much a kind of conversation. 'What is it that you need to do? What is it that I need to do as a GP to help this keep going ok?'

Evans: So you share in that decision making?

Cole: Absolutely, to me it's almost second nature, we're in this together. It's confusing. I've got some information, some knowledge, some experience and networks and links. You've got the same. We've got to pool it. And we've got to see what options there are, what options you're coming to see me with, what options we've *really* got, what options other people think you should be looking at ok and then we need to kind of pool it here on the table and have a kind of discussion around it. And then I'll leave you go away and have a think about the pluses and minuses of each of those three or four key areas. Often there are a lot of options and you try and help the person to focus on two or three that they can at least start with.

Then we just do some reviews and kind of keep them on track, using questions to guide their discovery about is this the journey they'd like to take. Is this the way it's going. And what I've discovered is that actually once you start them off, about four session down the line – and we're just talking four consultations – they're off because they've found and linked into a whole series and a new world where actually they can learn more knowledge, skills, tools and resources. They can connect with other people like themselves. They can begin to see those new people have got a new self identity and are beginning to explore how they did it, how they could do it and therefore how they can shape it.

I heard this past week a lovely story of how this young thirty-six-year-old, having had three spinal operations and most of the time spent in bed or in a wheelchair, has through three shared decision process consultations, is now on the expert patient programme, is doing Pilates and presented to Kirklees health and wellbeing board, his experience of the journey of the last six months, where he stood up and said where he was and where he is now and how he's done it and how more confident he is. And now he can see a future. And his future is that he is now going to become an expert patient trainer. So he now has a new sense of self. And that's what it's all about. Not complex, but it's about being a human-to-human together about the really important discovery of guided conversation.

Evans: Not all patients, not all doctors I guess, want to be part of shared decision making. Let's talk about patients first – a patient who comes to you and says 'Doctor, I'm ill, fix me.'

Cole: Aha.

Evans: Where do you start?

Cole: Just again, clarifying what it is that they see needs to be fixed. Clarifying what their ideas about what they think could do it, to fix it. And then open their minds up to the fact that actually sometimes in life, some things can't be fixed and we may need to look at other options.

Evans: Ok, there's only one thing my patient wants and it's get rid of my pain.

Cole: Ok, that's absolutely fine but we're stuck with a puzzle. The puzzle we have is that even if we remove the limb that has the pain embedded in it, when the limb is removed the pain is still there. So we aren't in a situation where we can physically fix what is a system processing problem – that the whole pain, nerve network system is unfixable, but can be at least managed in a way to shrink some of the pain. But it's not totally removable. And that's what that pain puzzle tells us and there're lots of others like that. So that's some information, some knowledge for you to go away and think about. The other thing I often find in people, who come with that very fixed kind of choice, is that actually it's not them necessarily, but actually the people around them – their partners, often their parents, their children... so very important influencing factors.

One of the things that's not recognised in shared in decision making is *who* is influencing your decision and how much. Okay, that's really important because most clinicians don't think about that and when people are fixed and still seeking total solution for their pain, it's a puzzle. You still see patients with three hundred pain injections, three spinal operations, two dorsal column stimulators and they still have pain, if not worse. What's that tell us? You wouldn't offer that to a dog.

Evans: What that tells me is that they haven't accepted in the first place that the pain is there and actually it's affecting other parts of their lives.

Cole: I think it's also sharing that they actually have a lot of pressure around them to be who they were and they can't be that person, and so that actually is impacting on relationships, and those relationships haven't adjusted and accepted. So that impedes or impairs the progress that that person could make. It also reflects on their GPs or other clinicians think there's a solution, but actually there isn't and that's because of lack of knowledge. So it's actually quite complex.

Evans: So how do you re-educate those GPs then, those medical practitioners who may not see shared decision making as a good option?

Cole: Very simply by enabling people, whatever their long term condition, to have access to more knowledge, more skills, more tools and resources, in a variety of ways. So they can have access to knowledge, which can be from peer support, it can be from websites, it can be from a local particular pain or other condition-related group. It may be some information that's available in amongst their healthcare professionals that they're seeing, be it a practice nurse or their physio. But discover that. Then they need to discover that they need a different set of skills, tools and so on.

By the patient saying we need a different conversation, then some of the clinicians who maybe wavering, not quite certain, a bit scared, a bit threatened, it may take more time. Some of those will go in the area of shared decision making, others will not. It's the nature of us as human beings and the human mind.

Evans: But you just used a valuable word in my book anyway, you've used the word conversation rather than consultation.

Cole: Yes, and if you notice I've been saying on the whole 'people'.

Evans: Not 'patients'.

Cole: Yes, with pain ok, so I've changed my language slowly and consistently because actually we are not patients, we are people, who have pain problems, who have a health condition or cardiac condition and the moment you start to change the language, you then have a different conversation.

Evans: And we, the people with pain, have a right to be part of the decision making.

Cole: Absolutely, very much so. It's your lives, it's your journey, it's your future. And the excitement of this work in pain rehabilitation, in pain management, the excitement is what the person with pain achieves. What *life* they grow. Like the example I gave earlier – I would never have believed that this lad, this Yorkshire lad with a bit of a tee-shirt on, a gap between his tee-shirt and his trousers, struggled in to the consultation room, never did I think six months later, that he'd be standing up before the Kirklees Joint Health and Wellbeing Board to share how he had taken control of his life. That's magic, because that's nothing to do with what we've done, it's everything about guiding a new direction of travel, a new journey, new possibilities, so exciting.

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