

Airing Pain 122: The Many Faces of Research

Visiting the forefront of research into pain conditions

*This edition of **Airing Pain** has been supported with a grant from The Mirianog Trust donated for this purpose. It was recorded at the end of April 2020, the second month of the UK's Covid-19 lockdown. All interviews were recorded prior to the crisis.*

*As research for a Covid-19 vaccine is a priority for the scientific community, this edition of **Airing Pain** focuses on the roles of researchers, and in particular the many disciplines that come together to increase the understanding, and therefore the management of chronic pain.*

First up, Paul Evans speaks to neurologist Claudia Sommer, whose research into fibromyalgia opens debate as to whether the condition should be treated as neuropathic pain.

Physiotherapist David Easton then talks about the research-led ESCAPE PAIN rehabilitation exercise programme for people with osteoarthritis in their hips or knees.

And finally, Paul visits the University of Bristol, where neuroscientist Bridget Lumb talks of the need for further research into the link between familiar contact and social interaction with chronic pain – particularly relevant at a time of social distancing – and social anthropologist Rachael Goberman-Hill explains the role of the anthropologist in health and pain research.

Issues covered in this programme include: Fibromyalgia, arthritic pain, neuropathic pain, nociceptive pain, loss of nerve fibres, anthropology, societal and behavioural aspects of pain treatment, qualitative research, acute pain, exercise, and joint pain.

Paul Evans: This is **Airing Pain**, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain, and for those who care for us. I'm Paul Evans, and this edition of **Airing Pain** has been supported with a grant from the Mirianog Trust.

Bridget Lumb: It's well recognised that pain can be alleviated by familiar contact with people. I've put in an application to actually try and look at the mechanisms that will underlie social interactions and relief from pain.

Evans: We're making this programme in week five of the COVID-19 lockdown, that's at the end of April 2020, at a time when research for a vaccine, diagnostic and antibody tests are at

the forefront of the scientific community. So whilst all these interviews were conducted before the present crisis, I want to focus on the role of research, and in particular, the many – sometimes surprising to me, at least – disciplines that come together to make living with chronic pain more manageable.

According to Versus Arthritis, fibromyalgia affects about 5% of the UK population. The name means pain in the muscles and fibrous connective tissues, the ligaments and tendons, but it's not actually a joint condition, but a syndrome with a set of signs and symptoms that include moderate to severe fatigue or lack of energy, sleep disturbances, headaches, decreased endurance for exercise, widespread muscle aches, and much, much more. As such, many people are treated under the rheumatology umbrella, a rheumatologist being a doctor who specialises in diagnosing and treating arthritis and related conditions. A neurologist, on the other hand, specialises in treating diseases of the nervous system. Download or read online Pain Concern's excellent leaflet on [Neuropathic Pain](#) to find out more about that. So if fibromyalgia is a rheumatic condition, what interest does it have for a neurologist?

Dr Claudia Sommer is Professor of Neurology at the University of Würzburg in Germany. And one of her research interests is fibromyalgia.

Claudia Sommer: A colleague of mine, an anaesthesiologist, [the] head of the pain clinic next door who had many fibromyalgia patients, one day he asked me, 'We must find out something about the cause of fibromyalgia'. And indeed, we were thinking of rheumatological causes, and he had some hypotheses along these lines. So with him, I started to look at cytokines, which are immune products – how do I say it, pro-inflammatory products of the body. And we had the hypothesis that these were increased in the fibromyalgia patients. This came only partially true. In the end, like, like all the hypotheses, they may be true for part of the patients. But after I had started this research, I became very intrigued because it's such a – I know it's a devastating disorder, but it's also a fascinating disorder, because it has so many aspects. There are so many open questions. This is what intrigued me to dig into this.

Evans: So is fibromyalgia a neuropathic condition?

Sommer: That's a question we cannot answer yet. What we can say is that it shares a number of features with other neuropathic conditions. For example, loss of nerve fibres in the skin; disturbed function of nerve fibres and their tracts; and changes in brain structure and function. But that can also happen in non-neuropathic conditions.

Evans: I'm confused, what do you mean by loss of nerve fibres in the skin? I mean, what my knowledge, as small as it is, is that fibromyalgia is just a brain condition. It's just a misbalance of chemicals or something.

Sommer: This is what most people thought, until a few years ago. But then we and others examined groups of fibromyalgia patients very closely. And we found that indeed, these patients have reduced nerve fibres in their skin and the remaining fibres obviously don't function as well as they did. And when we first published it, some people didn't believe it, of course, [and] others said, 'Oh, what a great finding, finally somebody is showing something for fibromyalgia'. And then we were very happy that several other groups from different parts of the world – so we're in Germany – but then a group from Italy, from Spain, Greece, from the US, they all had very similar findings in a very short time. So I think the time was just ripe for this finding that there is, at least in a subgroup of patients with fibromyalgia, a peripheral nerve basis to this syndrome.

Evans: So do you think that's the cause of fibromyalgia or the result of having fibromyalgia?

Sommer: Again, I don't know, as in human research, it's very difficult to see cause-result, because you only describe something. I find it difficult to see it as the result, which doesn't mean that this cannot be. But it's difficult to imagine how a pain syndrome that initiates in the brain would lead to loss of nerve fibres in the skin. For me, it's easier to understand it the other way around; that there is some defect – it may be genetic, it may be of the environment, it may be immunological – that damages nociceptors. And that this, together with other factors, triggers this whole syndrome.

Evans: You're going to have to explain to me now, what you mean by nociceptors. What is nociceptive pain, as opposed to neuropathic pain?

Sommer: [They are] two different things. A nociceptor is the word that we use for a peripheral nerve and its nerve cell, so the neuron that signals pain. And we have two types of them, we call them C fibres and A-delta fibres, and they serve different functions, but they both signal pain. So when we activate them, you notice pain, and we call them nociceptors. The term nociceptive pain means pain induced by activation of a nociceptor. So, for example, if I put my hand on a hot plate, this will activate my nociceptors and I will feel pain. Neuropathic pain, by contrast, is pain caused by an injury disease somewhere in the nervous system. So, if I injure a nerve, for example, by having an accident, and then these nerve fibres are hyper-excitabile, I can have pain without any stimulus from the outside. And this is what we call neuropathic pain.

Evans: Okay, going back to the nociceptors and fibromyalgia – is what you're saying that an injury to somebody, say, hand or leg or limb or anywhere else, may have started the fibromyalgia?

Sommer: We have no evidence for this. And in fact, this has been looked at, there have been large statistics on whether there is a connection between accidents and fibromyalgia and the connection was negative. What has been shown some time ago, was a connection between numerous myofascial pains and fibromyalgia. So myofascial pain is, for example, the usual neck pain you get when you sit for too long or type too long. So it seems that people who have these kinds of pain, which we would generally consider nociceptive, because we don't move properly and we stimulate our muscle nociceptors the wrong way. So people who have these kinds of pain they have a higher risk of developing fibromyalgia.

Evans: Dr Claudia Sommer, Professor of Neurology at the University of Würzburg, in Germany.

For many people living with chronic or persistent pain conditions, myself included, we are aware of current treatments, that is, what we're using now to manage our conditions. But we're ignorant of the work researchers and scientists are doing away from the public glare, and also of the many different disciplines involved, including, to my surprise, anthropology. If like me, in my ignorance, you associate anthropologists with archaeologists and pre-historians in television series about the origins and ascent of man, you may be surprised to know that they can work very much in the present. Dr Rachael Goberman-Hill is Professor of Health and Anthropology at Bristol University, where she's also Director of the Elizabeth Blackwell Institute for Health Research. And she's a social anthropologist.

Dr Rachael Goberman-Hill: We look at what people do in their everyday lives, and that might be their everyday lives in their homes, or their everyday lives working in a hospital, or their everyday lives, for instance, in living with pain. So what we as anthropologists would do is bring the research techniques that we would use in all of anthropology, and apply them into a pain and healthcare context. So we do things like chat with people, have conversations with people about how they live with their pain, and their history of their pain. We do that in interviews, and we do that in focus groups. We also do research that involves a researcher spending time, maybe in a clinic or a hospital, watching what people do and how decisions are made about care, and all that kind of thing.

Evans: That sounds a bit like time and motion to me, almost.

Goberman-Hill: It is a bit because when we're collecting that kind of information, the researcher will write down what they see. And we'll look at that information and bring it all

together to explain why people do what they do and how people do what they do. And when we get it published, that means that decision makers and people who write guidance about care will take that research on board, and look at it and see how it can best inform guidelines for healthcare provision. For instance, National Institute for Health and Care Excellence looks at qualitative research, some of which will be anthropological in an approach, and uses that to inform the guidelines that they write. So largely, what we'd do when we'd apply for funding is we'd get together quite a big group of researchers, usually people with different backgrounds. And we'd work together, because we've identified that there's a gap in the research evidence. And when we work together and find that there's a gap, we then have to design a research project. And we work for many months, usually, to design a research project and the kind of people we would involve would be statisticians, health psychologists, sociologists, anthropologists, pain doctors, surgeons, etc., etc. And we all come together as a group. And we then write a proposal for research.

As I said, that will take many months, what we do then is we'll submit that to an organisation like the National Institute for Health Research. They then have a committee of experts who drill down on that research plan, and look at whether it's needed, whether it's robust, whether it's appropriate, and provide comments and feedback to us. And then we go through a long process in which the funder makes a decision about whether or not they would fund our proposed research project. So it takes a long time from deciding that there's a gap in knowledge, to actually starting a research project with funding.

Evans So how do you find those gaps in knowledge?

Gooberman-Hill: That's a really good question. We do something called systematic literature review. And we have experts in pulling together existing published literature into one place so that we know whether there's gaps in the existing knowledge or not. And only when we know that there is a gap, and there's a need for more knowledge, should we really then be thinking about doing more research.

Evans: Just explain to me what qualitative research means.

Gooberman-Hill: Qualitative research is research that usually happens on a small scale. It's interested in understanding why people do what they do or think what they think, and how people do what they do and think what they think. So a qualitative researcher is interested not in numbers, but usually in words. And that means that a qualitative researcher usually has a privilege of inviting people to come to interviews and focus groups and talking with them. And for instance, in pain, we would hold focus groups to talk with people about their experience of living with pain, and their experience of finding healthcare for that pain, or

what they've done in their family to live with pain and those kinds of questions. And that's what qualitative research essentially is, in a nutshell.

Evans: Why is it called qualitative research? Because asking opinions to me is not non-qualitative, but equally as important as numbers.

Goberman-Hill: So we call it qualitative because it's different to quantitative. Quantitative research is about numbers. So in a clinical trial, where we ask people to fill in questionnaires and, you know, assign scores of one to ten, or one to five against certain things, that generates number information. But qualitative research gives us information that isn't about numbers. It's about thoughts and feelings and words.

Evans: It's about what we feel, how we live.

Goberman-Hill: How we feel, and as you said, opinions as well, but also, what we do and why we do those things. So when we're doing qualitative research, we're asking people to talk with us in some depth, and that's a great privilege. It can take a couple of hours to do a qualitative research interview. And we're not judging those people in any way, we're simply asking them what their life is like and how they live and what their healthcare has been like. We also do research with people who provide healthcare. So we've done research with surgeons, and we've done research with GPs, for instance. So, a particularly interesting piece of research we did a few years ago was to find out why GPs prescribed, or did not prescribe, opioid medication for people living with joint pain. And so we interviewed twenty-seven practising GPs – general practitioners – and we asked them about the kind of medication they prescribed and why they prescribed it.

We spoke with them about the patients that they saw. And we spoke with them about their background and their training and their experience. And this was great because the GPs, were really willing to talk with us, and that was a great privilege. The thing which we found really interesting from that project was that some previous research had suggested that GPs were reluctant to prescribe certain kinds of opioid medication, because they were worried about addiction, tolerance and diversion of those medications. And so we explored that in interviews, and what we found was that GPs were thinking about those issues in some detail, but actually, what influenced their prescribing most was their own professional experience of prescribing opioid medication; for instance, whether they'd had experience in the past of working with groups who prescribe that kind of medication or not. So we then publish that kind of finding in an academic journal, and an academic publication, it sounds like it's something that's going to be very dense and difficult to read. But we try to write these things as clearly as possible. And that's published in the journal so that other scientists can read our work, and know that we've done it in a robust research-y way. It's gone through

peer review, the people who read it can then know that what we've done is actually a decent piece of research. And then it's up to the outside world to decide what they do with that research finding. The peer-review process in research means that research that's out there in the public realm is trustworthy.

Evans: Dr Rachael Gooberman-Hill, Professor of Health and Anthropology, and Director of the Elizabeth Blackwell Institute for Health Research at the University of Bristol.

So, from the study of what people do in their everyday lives, I like to think of it as the macro, to the micro, the study of what happens within people's brains and nervous systems. Dr Bridget Lumb is a Professor of Neuroscience at the University of Bristol, she's president of the Physiological Society, and her particular interest is in the understanding of the basic mechanisms of pain, in particular, how we make the transition from acute pain to chronic pain.

Lumb: Acute pain is that immediate pain of putting your hand too close to the fire. It's about the severity of the pain, and it's time-caused chronic pain. It's classified by the International Association for the Study of Pain [as] pain that lasts for more than three months. And a huge proportion of people will suffer from chronic pain at some point in their lives, it's about 40% of the population.

Evans: That's astounding. So, three months after the initial injury that caused the acute pain where that injury has healed or should have healed, pain carries on.

Lumb: Pain carries on. A process that was set up by that initial acute pain – the damage, the injury – has set up changes in the brain, which means that the brain no longer reacts normally to pain. There is no noxious stimulus, there is no injury, it can have resolved, but the individual might still be feeling ongoing pain, which could last for years.

Evans: So what's going on there, then?

Lumb: Well, if you answered that question, you'd probably win the Nobel Prize. We know that, when I say noxious stimulus, this is an input from the body in response to an injury. [It] arrives in the spinal cord as its first point of contact. And then that information is transmitted up to the brain. That initial process, whereby the injury, the signal from an injury, enters the spinal cord, begins to set up a process that we call sensitisation. And it's that that can continue once the injury has actually resolved.

Evans: So the brain is actually reading what's happened in the wrong way.

Lumb: In the wrong way. There are interesting parallels – and I think this is an area that will become a focus of attention – is that the way the brain learns, it has an experience and it

then has an expectation. So when the stimulus arrives again, it expects to experience it in a particular way. In most people, if there's a mismatch between the stimulus and what they experience, they resolve it, relearn it, they say, 'Ah, so when this happens, I now feel this. I don't feel my previous expectation'.

Evans: Is that a pain centre? If you could look inside my brain, my mind, and I'm in pain, where will that be?

Lumb: We don't know. If one looks in imaging studies in humans, for example, there is a network which classically lights up in painful situations. But that same network lights up if you apply a novel stimulus. So is it a pain matrix? Or is it a salience network? Is it something that detects the unexpected? Pain is a hugely complex experience. It's not just about the sensory experience is not just about 'ouch'; it has emotional context, it triggers learning and memory, it triggers release of hormones, it makes changes in your blood pressure [and] of the heart rate, and it has an emotional context. One can map the pain pathway, for example, from the periphery, from the hand, let's say, into the spinal cord up to the brain, it will go to the thalamus, it will go to the somatosensory cortex. If you delete parts of the somatosensory cortex, you don't remove pain, chronic pain. So as far as we know, there is no pain centre. And it probably relies on interaction between different centres within the brain.

And context can change it so much. I mean, social context can change it so much. I mean, I've just put in an application, for example, to actually try and look at the mechanisms that will underlie social interactions and relief from pain. Because if we can understand the mechanisms for that, we can perhaps tap into that. I mean, it's well recognised that pain can be alleviated by familiar contact with people. How does the brain do that? The brain's got to be doing it.

Evans: Professor Bridget Lumb. Well, familiar contact with people – social interaction or lack of it – during the COVID-19 lockdown, could have serious repercussions, mental and physical. For those not just with chronic pain, but the population at large. Going back to an [earlier edition of *Airing Pain*, number 109](#), which is still available to download along with all editions from the Pain Concern website. We focused on the European League against Rheumatism's revised recommendations for the management of fibromyalgia, and the role of exercise in the management of all arthritis-related conditions. In that edition, we explored the walk with ease programme developed by Versus Arthritis, the Arthritis Foundation, and Aberdeen University. Just put 'Walk with Ease UK' into your search engine to find out more.

Now the ESCAPE-pain rehabilitation programme is another UK-wide evidence-based programme for people affected with osteoarthritis in the hips or knees. David Easton is a

physiotherapist based in Cardigan in West Wales, working for the Hywel Dda University Health Board, where he's Clinical Champion for ESCAPE-pain.

David Easton: So ESCAPE-pain is an acronym. It's a bit of a mouthful, and it stands for enabling self-management and coping with arthritic pain through exercise. It's really giving people some knowledge and some skills about how best to adapt to the condition to minimise the impact, enabling them to become more active, reduce [the impact of pain] and improve their quality of life.

Evans: Well, the one thing about quality of life and exercise is, we all know, at least I think I know, that exercise is good for me. But exercise is not thrashing yourself in the gym.

Easton: No, it's not. And I think this is where a lot of people with chronic joint pain struggle. They sometimes hear this advice and think, 'Right, I'll get all my energies together, and I'm going to give it a go, and I'm going to try my hardest'. But if you take that approach, people tend to overdo it too quickly, they won't understand their current ability and compare themselves to how they used to be before the problem. And what ESCAPE-pain does, is it gives them the opportunity to change that perspective and use exercise as a strategy to reduce their stiffness, improve their mobility, and over time, improve their function, and their overall exercise tolerance. It may not necessarily be to the level that they used to be, or where they'd like it to be in an ideal world, but it's a better place. And there's a real skill to be able to exercise when you've got persisting pain, and that takes time and practice. When you use exercise as a as a strategy for joint pain. It's about choosing when to do it, how much to do of it, and to keep it up on a frequent basis. It's not always choosing to do it just because you feel like it. It's knowing how to do that and for me - certainly, listening to people [about] how they have used exercise and the skills on the ESCAPE-pain programme – they learn how to use that effectively, and that's a process.

Evans: How do you get through to somebody who knows, 'Historically, exercise has hurt me'.

Easton: I think that's what's so great about the programme and why I'm a strong advocate. Because as a physiotherapist I meet a lot of people on a one-to-one basis, and I have these conversations. And sometimes I can see their face and [see] the screen come up and think, 'Yeah, I haven't really reached them'. Sometimes it takes a little bit of time. And it's not always what I say or what I do, [rather] it's the group environment, where people can see other people coming at it from a different perspective, and sharing that perspective, and thinking, 'Okay, well, maybe I'll give it a go', and learning how to then, over the six weeks, refine that. So sometimes they'll come along quite well, and they'll have negative experience. But I don't see that negative experience in terms of an increase in their symptoms as

negative. It's actually a learning opportunity to think at the moment, that's too much. So how can I do that differently?

Evans: I know you're going to say it's a successful scheme, but is it?

Easton: Why it's become so prominent, and [why it's become] a national programme, and won an award within NHS England, is because the research base is very, very strong. It was a randomised control trial that had 418 people, comparing people with usual primary care and the ESCAPE-pain programme. And the outcomes were recorded six months, twelve months, eighteen months and thirty months following the programme. And under those conditions, they were able to demonstrate that there were sustained benefits for people that attended the programme.

Evans: Physiotherapist David Easton, of Hywel Dda University Health Board. Well, whilst walking in groups may be a great way of getting and enjoying your daily exercise, as we're making this addition of **Airing Pain** at the end of April 2020, during the COVID-19 lockdown, UK Government guidance stipulates just one form of exercise a day. For example, a run, walk or cycle, alone or with members of your household. Now of course, all this will change, it may even have changed by the time you're listening to this edition of **Airing Pain**, so please do check with your own national assembly or government guidelines. However, whilst ESCAPE-pain's 290-plus class programmes around the UK are currently suspended, there's an online version and plenty of resources at escape-pain.org/escape-pain-online. The Walk with Ease programme, whilst it recognises that walking can be done in groups and with company, it can also be done on your own. In fact, they're currently producing an audiobook for people to listen to as they walk. I'll just remind you that whilst we in Pain Concern believe the information and opinions on **Airing Pain** are accurate and sound based on the best judgments 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, the appropriate action to take on your behalf. You can find all the resources to support the management of chronic pain including details or videos, leaflets, all editions of **Airing Pain**, and **Pain Matters** magazine, and the links mentioned in this programme at painconcern.org.uk.

Well, I want to return to the subject of fibromyalgia to end this edition of **Airing Pain**.

Professor Claudia Sommer tantalisingly left us with who might be of higher risk of developing fibromyalgia. But I can't leave without asking the one question that people with the condition really want asked. Will her research lead the way to better management or even a cure for fibromyalgia?

Sommer: At the moment? All this gives us is a better explanation why – the few drugs that we have for fibromyalgia pain – why they work. Because these are drugs we use in neuropathic pain, like amitriptyline, pregabalin, duloxetine. These are the drugs that have been shown to have some effect in the big clinical trials, and they come from neuropathic pain. So, that fibromyalgia has a neuropathic component <https://painconcern.org.uk/airing-pain-109-fibromyalgia/> makes sense, when we know that these drugs that are used to treat neuropathic pain also work to some extent, in fibromyalgia. But the more important question would be, can we in some way reverse these findings? So can we make the nerve degeneration stop or even induce regeneration? People are working on it, and there might be drugs out in the next five to ten years.

Contributors:

- Dr Claudia Sommer, Professor of Neurology at the University of Würzburg in Germany and President-Elect of the International Association for the Study of Pain
- David Easton, Physiotherapist at the Hywel Dda University Health Board in West Wales
- Dr Bridget Lumb, Professor of Neuroscience at the University of Bristol
- Dr Rachael Goberman-Hill, Professor of Health and Anthropology and Director of the Elizabeth Blackwell Institute for Health Research at the University of Bristol.

More information:

- Fibromyalgia Action UK – fmauk.org
- Pain Concern's [Neuropathic Pain](#) leaflet.

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