Is chronic pain telling us something important about society?

or ….Is pain a feminist issue ?

 Patrick Hill

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Introduction

Various reports suggest that 70% of people presenting with chronic pain are women.

Having worked with people with chronic pain, particularly facilitating group based self-management programmes for about 30 years, I have known this for a long time.

I chose one recent published study, at random and looked at the gender ratio

Women 88% (175) Men 12% (23) Where N = 200 ( Lanario 2023) This ratio is actually nearer my experience of people attending self-management support groups.

In a recent government survey ‘*Women’s Health – Let’s talk about it’* UK survey March 2021 50% of respondents ( n = 110,000) felt that their pain was disregarded or overlooked. They reported being told that certain symptoms, particularly those related to menstrual health, were to be expected and should be accepted as a natural aspect of being a woman and thus did not deserve medical attention. In the same survey women reported….severe pain sustained for years… but were told; *“it was all in their head”.*

A Lancet Editorial (March 2024) Gendered pain: a call for recognition and health equity concluded : *The evidence is unmistakable: (across the world) women are enduring delays in diagnosis, inadequate pain management, and disparities in access to appropriate care for many conditions, in particular those related to gynaecological conditions*

Vicious Circles

My view is that this is likely to result in vicious circles, resulting in more chronic pain. If women are being told that certain symptoms, were a natural aspect of being a woman and thus did not deserve medical attention, its likely to promote the idea; *“I’m expected to cope”.* The behaviours thoughts and feelings linked to this might well increase vulnerability to chronic pain, which we will examine later but which we also know is already thought to be dismissed as *“all psychological”* by many health care professionals, hence the vicious circle.

What is pain?

The notes that came with the IASP 2020 revised definition of pain are important notably:

1. Pain is always a personal experience influenced to varying degrees by biological, psychological and social factors
2. Pain and nociception are different phenomena, pain cannot be inferred solely from activity in sensory neurons
3. Through their life experiences individuals learn the concept of pain
4. A person’s report of an experience as pain should be respected
5. *Pain is usually an adaptive response to threat*but may have adverse effects on function and social and psychological well-being

Why is pain created ?

Perhaps the most important of these notes is :*Pain is usually an adaptive response to threat.*

One argument I would like to make is that pain is alwaysa response to perceived threat and chronic pain is far from a useless or meaningless message, but it serves a different purpose to acute pain. Myself and others have proposed the idea that chronic pain (and fatigue) are general ‘STOP’ signals produced by an overwhelmed and dysregulated nervous system. (Hill 2019 and Davies et al 2020)

To explore this we need to accept what is now a general agreement among pain scientists, that pain is created by a ‘top down’ process, in other words pain is produced by the brain.

I don’t think a periphery-free model is quite right, but the simple idea that pain is created by a top down, rather than a ‘bottom up’ process is more helpful. We know there is no ‘pain centre’ in the brain and the whole brain gets involved in interpreting potential threat and producing pain. The range of biopsychosocial factors that influence the experience of pain is huge.

Psychologists

Psychologists study human behaviour and clinical psychologists ‘formulate’ rather than diagnose, in order to understand and change people’s behaviour.

 This means that rather than using a reductionist diagnostic model to try and identify some form of pathology, they tend to use a biopsychosocial model, which doesn’t necessarily identify a specific cause, but can produce a more comprehensive picture of a presentation.

This is particularly helpful when a diagnostic model is of limited use i.e. a specific cause has been more or less excluded in conditions such as chronic primary pain or fibromyalgia and there seems to be no way forward. Helping people change their behaviour from one of cure seeking to developing the skills and confidence to self-manage their condition can be life changing.

The Power - Threat - Meaning Framework (PTMF)

The PTMF was published in 2018 by the British Psychological Society as an alternative to psychiatric diagnosis by (Johnstone L et al 2018) and is useful to help psychologists formulate behaviour. The PTMF takes account of context, meaning that emotional distress and behaviour are seen as understandable responses to experiences of power abuse and circumstances.

Within the PTMF:

*Power is* seen the ability to influence your environment to meet your own needs and interests across a range of areas.

*Threats* could be to relationships with threats of rejection, abandonment, isolation or emotional threats e.g. overwhelming emotions, loss of control

*Meaning*: logical responses to such threats may be helplessness or trauma symptoms or other behaviours such as overwork or perfectionism, features seen as ‘normal’ or even desirable by society.

Psychologists using this framework are likely to ask these core questions:

* 'What has happened to you?’ (How is Power operating in your life?)
* ‘How did it affect you?’ (What kind of Threats does this pose?)
* ‘What sense did you make of it?’ (What is the Meaning of these experiences to you?)
* ‘What did you have to do to survive?’ (What kinds of Threat Response are you using?)

The PTMF can therefore be helpful in understanding the roots of behaviour which may have been adaptive in the past but are presenting as problematic, particularly in the context of chronic pain conditions.

A model for chronic pain

As we started to see more and more people appearing in Pain Clinics with pain and fatigue usually labelled as fibromyalgia in the 2010’s, I became interested in the earlier work that had been done with people with ME, later called chronic fatigue syndrome (CFS)

Wessely and colleagues (1991) proposed the first cognitive behavioural or psychological model of CFS. They suggested that an organic ‘insult’ such as a virus precipitates a cycle of psychological responses, which mediate between the acute organic illness and the chronic syndrome.

 Building on this work, in 1995 Surawy and colleagues observed behaviours in people with CFS and asked them about their thoughts and assumptions and produced a model which included predisposing, precipitating and perpetuating factors for CFS. Their model suggests that people predisposed to CFS are thought to be highly achievement orientated, basing their self-esteem and the respect from others on their abilities to live up to certain high standards.

When faced with precipitating factors which affect their ability to perform, such as a combination of excessive stress and an acute biological illness or injury, their initial reaction is to press on and keep coping. This was labelled ‘All or Nothing Behaviour’ by later researchers, as patterns of ‘boom and bust’ begin to emerge in the medium to long term. This behaviour leads to the experience of ongoing symptoms, ( STOP signals such as pain and fatigue) which may be more closely related to pushing too hard than to the initial insult or injury.

The PTMF provides a useful framework to explore the origins of the thoughts and behaviours suggested in Surawy’s

 model. For example someone’s experience of abuse of one aspect of Power, within close relationships, it makes sense that it might lead to all or nothing type behaviour ( even in the face of adversity such as illness) as a logical response to try and maintain the relationship.

Brooks et al 2017 have suggested that the Surawy model can be more widely applied to predict many long-term conditions including Irritable Bowel Syndrome, Post Concussion Syndrome and Chronic Fatigue Syndrome.

What does this mean in practice - Behaviours , thoughts and emotions

My experience of working with people with chronic pain and FMS is that the behaviours thoughts and feelingsproposed by Surawy are consistently present.

Behaviours

‘All or nothing’ behaviour, constant striving for high standards or Perfectionism, not complaining, not admitting to any weakness, neglecting their own needs and concentrating on others, bottling up feelings

 Thoughts

 *If I am to be acceptable to others, I must achieve high standards of performance and responsibility, I must be in control of my emotions and not display weakness, If I don’t meet my responsibilities, I am a failure, unless I’ve achieved all my goals, I am a failure*

Feelings

Worried, Angry, Frustrated, Anxious, Unhappy, Unloved, Inadequate

A mechanism - How does this work in the body ?

Lorimer Moseley suggested that rather than an increase in neurological activity in the body, chronic pain may be the result of a reduction in descending inhibition, in other words the brain’s ability to moderate or filter the inward flow of information from the body and the environment and make decisions about threat may become impaired.

The risk of a dysregulated a system, like the pain production system, that works on a ‘better safe than sorry’ basis is that many non-threatening stimuli ( such as loud noise or bright light) can be treated by the central nervous system ( CNS – the brain and spinal cord) as potentially dangerous and unhelpfully, produce a pain response.

The key elements of this are:

* The human CNS has evolved to detect and manage threat.
* This system is always on, constantly sending data from the periphery
* Descending inhibition from the higher brain modulates or filters this input
* This can be helpful, for example, this Inhibition is reduced in acute conditions, projecting pain and fatigue into consciousness to enforce rest while healing takes place
* But ‘vulnerable’ systems have less to draw on and become less able to filter or moderate
* Chronic pain results from significant impairment in the wider systems recruited into the process of modulation, resulting in a dysregulated system.

We know that a wide range of systems are recruited in the brain to help with threat management, so if people are struggling with disrupted sleep, find it difficult to pace themselves, express emotion, have low self esteem and reduced sense of control, the brain has less resource to draw on – the Surawy model suggests the absence of these psychosocial factors predisposes people to chronic conditions.

This might suggest why a system that is already vulnerable, an extra threat such as a sprained ankle, flu virus or COVID infection leaves lasting difficulties. These seemingly small difficulties become the ‘straw that broke the camel’s back’ because the system doesn’t have the resources to re-establish itself into a regulated state.

Social context

Considering the concept of Power as the ability to influence your environment to meet your own needs and interests across a range of areas, the inequalities imposed by structural sexism across the world ( Oxfam International) ie the abuse of power by the state, it is perhaps not surprising that women and girls live under more stressful conditions than men. What I am arguing is that this is likely to increase their vulnerability To chronic pain conditions  compared with men and boys.

More recently a study was published in December 2024 looking at Alzheimer’s Disease in the USA. Alzheimer’s Disease is more likely to be diagnosed in women and this was previously attributed to genetic differences and women living longer.

Researchers measured state-level structural sexism from 1900 to 1960 e.g. maternal mortality, number of women in state legislature and proportion of women in workforce. A study of 20,000 women in those deemed the most sexist US States (Alabama and Mississippi) found 9 more years of ‘cognitive ageing’ than in the least sexist states (Connecticut) and the negative impact on memory performance was stronger among black women .They concluded that the higher rates of dementia in sexist states were most likely due to women being denied educational and career opportunities and poorer healthcare, producing disparities in chronic physical health conditions and ultimately the onset of dementia

As a further contemporary example of the extra stresses endured by women and girls, Saoirse Ronan’s comment about women’s safety on The Graham Norton Show (25.10.24) went viral after she said using a phone as a weapon is something *“girls have to think about all the time”* to the astonishment of her male actor colleagues, who had never thought about this until they had been taught about it for a film role.

Discussion

*Thank you so much, Patrick. One of the things that I was wondering was, are women more likely to ask for help when they have pain than men? So it may be that they actually suffer more pain or maybe they're more likely to admit to it. Like, men won't ask for directions!. So I don't know whether there's a cultural bias against men.*

. I think there's probably a vicious circle thing going on there because, yes, women do ask for help for health issues more generally than men. But you saw the response in the survey, that women were saying that particularly women's health issues, they were being dismissed. So they're asking for more help, but being dismissed. And the point I was making at the beginning, I suppose, was that I can see that knot in the vicious circle getting tighter and tighter. Because if women asking for help being told, oh, that's just part of being a woman - go away. That's likely to tip them into the kind of behaviours and concepts we are talking about in terms of then thinking, right, okay, well, I've got to shut up about this and just keep quiet and carry on. That's likely to tip them into chronic pain. So what's likely to happen over time is that they're going to present either with episodes of acute pain, and .we've seen this happening. Or they'll present with chronic pain, which unfortunately just reinforces the kind of unhelpful stuff. So, yes, I think that's part of it. .

 Can I just mention something? Because it's just. It's just triggered a memory. I did a bit of work in Bath a few years ago now, where we looked at the frequent attenders in the A &E.
.What we found was that in the vast majority of the people who were attending A and E were attending with abdominal pain, and they were young women, between the ages of about 18 and 35. And all sorts of things came out of that. And a lot of it was because they had been repeatedly dismissed and sent home after a horrible time in A & E . . So they were hanging on at home forever with the pain gradually getting worse and worse and then eventually pressing the button at 2 o'clock on a Saturday morning and being brought in screaming the place down.. That was a real practical example of that whole vicious circle thing..

*And what was the diagnosis? I mean, what was it when they eventually got see somebody?*

They all had background of lots of stress essentially., but most of them had. Had their a appendices removed. And when we got the notes out to have a look, the notes typically said appendix normal but removed just in case.

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*That's so commonplace: both your observations from AE and what I see that every week, day in, day out. . With young women and pelvic pain abuse is not far away. . Maybe there's Inflammatory Bowel Disease (IBD). My question to you is: when it comes to explaining pain or negotiating meaning of pain, that's really difficult, but can be rewarding and you have the benefit of being in a probably secure position down the line of referrals.*
*But people like Jonathan and me (GPs) have to do it on the front line. Convincing people is often very difficult when they want to get somewhere and you know for sure that's the end of the rainbow. But they may have been be fobbed off by somebody else who said it's overgrowing intestinal bacterial growth or an ovarian cyst and you think, well no, all the background is pointing towards that this is not a biomedical issue when it is not. Even with endometriosis it's difficult because there might not be endometrial tissue, and people go long down that avenue even to an eventual hysterectomy. And then of course the pain is still there. I find it extremely frustrating.*

It's. It's probably no different to intervertebral discs. You've got bulging discs which may or may not be causing pain . We know that hundreds of people have them without pain for then some people, they seem to be the issue. To answer your question: .it is difficult, but I think it's about learning how to contract with people . We often call it changing the agenda. . I appreciate sitting at the end of the line in the pain clinic is maybe a privileged position, but quite often in pain clinics we have people who really don't feel they're at the end of the line. They still feel they're in the middle it , needing investigations and so on..
 What I always used to do with people was first of all to give them a different story, like the slide I flagged up earlier from Live well with Pain. I tried for a long time to work out how to tell the story of pain in a different way.; of it being a top down and rather than a bottom up process, in a way that people would listen to. And then it's about contracting with them to say: can we agree we're going to work with this for a couple of sessions or something, and introduce them to something that we know will help. The kind of thing I would do straight away after that was to introduce them to some relaxation type stuff. And when they start to feel physically different, because you can do that fairly rapidly, people will then start listening and come on board with you. So there's a whole kind of sequence of things to be done there which can really help. I mean, I appreciate what you're saying, but I think you can do that. .

 *Jens sort of stole my question or thought my thought ! by the time you walk through a door with psychologists written on the top, you've already accepted to at least to a reasonable degree that you're prepared to entertain a psychological approach. And of course you sit with both the sign saying pain is not all in your brain, but of course it is all about a failure of top down inhibition. So it actually is and it isn't*.

*My experience, , and I'm still interested in how to help me deal with it, is that I have about 740 patients with chronic pain at my practice. And I know that about 90% of them, at least from my personal knowledge or in their notes, have experienced significant adverse childhood experience or intimate partner violence. And every year, dozens of them go back to Turkey and get MRI scans because it's part of what they do there. And they come back and say, here, it's all in my spine. Or they get ultrasounds or have pelvic examinations and say, here, it's, there's, it's, you know, here's the reason. And you know full well the misery of their lives and experiences.
And so there's a constant and often fraught attempt to provide validation without succumbing to the simple kind of explanation of a thing on a scan which often gets in the way of good treatment. On the other hand, an effective answer to their trauma is a lifeline of healing when they think that a little nip and a tuck or a bit of laser could zap away the thing that they're most worried about.. Back surgery is no longer what it used to be a\nd bariatric surgery, thank God, is no longer what it used to be. My clinic is full of people who've had gallbladders removed, who've got chronic diarrhoea as an after effect and no relief to their pain.*

*I found that absolutely fascinating and sort of chimes in with a lot of my experiences and. thoughts . And I wonder whether you are - I'm guessing you are, but I won't put words in your mouth - on to something? So what does this tell us about society? Obviously we focused on the impact on women and you make a very compelling case for that, which I find very convincing. But would you sort of broaden that to other areas inequality and deprivation and the sort of stresses of a life, living in poor housing conditions with insecure employment, low wages, inadequate nutrition, all of those sorts of factors.*

 *I was reminded of a book I read quite recently, called the Spirit Level by Wilkinson and Pickett, which charts pretty much every negative or positive social indicator index that you can think of against inequality and finds that there's almost a one to one relationship and this is backed up by repeated international sort of trials. And all the evidence indicates that. it's essentially another facet of this sort of broader social problem.*

 *.And just one other quick point: I was very interested by the way the personality traits you describe, which I identified with 100%, in terms of perfectionism, et cetera.., but how that precisely correlates to this idea of some sort of underlying trauma or stress. But do you get those traits?*

So first of all, yes, absolutely, I've angled this towards women, but the model is universal. And I think if you look at deprivation across the board, it's back to the context of the mechanism I was suggesting, all those things are going to likely to have an effect and reduce people's resilience and therefore make them vulnerable. The second thing is that those traits do result in particular behaviours. So the all or nothing behaviour . the perfectionism and so on makes people push, push, push all the time. You know, if you've got a sprained ankle and you can't rest,, because you believe you're going to lose your job and so on , you push and push. It's going to become a chronic problem. This very simplistic. But there are behaviours that result from those traits that are unhelpful.

 How does that relate to trauma? If, for example, using the power threat meaning framework idea,; if you've had a childhood where parents have said to you effectively you're not lovable unless you work really hard at school. That could be the seed for the all or nothing behaviour that then goes on through life . So it's not necessarily trauma, but it can be sort of abusive parenting in a way , where you've been held to ransom over relationships,

*I've got a lot of questions, but I shall try and be brief. . I've been investigating this area because I'm a clinical psychologist working with chronic pain as well, and I have done for many decades. I'm interested in the process of catastrophization, which is also linked to perfectionism, where there's a chain of meaning: You start with, ‘oh my God, I've got something wrong with me’ . And oh my God, it's a tumour. And it always ends up down the line with death or fear of death, either to yourself or someone else, which is, of course what is lies at the heart of PTSD . So, so there's that personal meaning of it, meaning death, so it's really serious. But often the emotions that are involved in it from early childhood are so extreme they can't be expressed easily. There's a barrier holding them back, so you can't talk about them. And if you do, you use coded language. And the physician or the practitioner hasn't got access to the codes they're using and doesn't understand their language. Most people in pain clinics don't scream and shout whereas in A&E they may well do so. So it's learning to see that it's an expression of distress, but not in the way that we know it.*

I'm just thinking of the points that Jens and Jonathan were raising about how do you get someone to that place where they. Because ultimately, what we're saying is that you need to sit down and talk it through, work out what the causes of your distress and your behaviour are Now, the point Jonathan was making was you've got to want to sit in front of a psychologist or someone like us and want to do that. And that's tricky. And I think that journey of getting someone to the place where they need to be to start talking about these issues that we're talking about now is often a series of steps.

 And one of the things I didn't mention today, but is a thing I often talk about, is the rule of seven, which some of you may know. This comes from advertising and it's a thing that's been around in advertising since the 1930s where they came up with this idea. And it holds a bit of truth. If you've got a new product, you need to get it in front of your customer seven times before they say, oh, there's a new washing powder. In other words the first six times it kind of probably bounces off, but then you start to notice it. And so that's why you get bombarded with seeing the same things constantly because it takes a while to go in.
 Now, I've found that really helpful because when we think about people with chronic pain. When I used to run pain management programs, at week two or week three of a program, a little hand would sort of go up at the back and someone would say : “so are you telling me this pain isn't going to go away?” And I was always astonished by that because we'd spent the whole of the previous weeks talking about chronic pain and why it wasn't going to go away. Echoing some points that they made earlier, they'll have seen a pain doctor and probably a physio , and probably an orthopaedic surgeon and a GP .They've had this conversation multiple times already.
 And the rule of seven is quite helpful there because it tells us that in the NHS and in health generally, we generally have this kind of, I told you once - haven't you got it yet? And it's not that people are stupid. It's a really difficult message to get across as we know. And if we think that it takes seven hits before someone's going to notice a new brand of washing powder that means that probably there need to be 8, 9, 10 conversations before the person is going to say, oh, okay, so you're saying this isn't just because of the bulging disc that I got on my MRI in Turkey, there's other things involved.

 So that was one of the points I wanted to make, which is that I think there are multiple steps particularly for GPs. Often all you can do in the 10 minutes that you've got is complete another step, but you're not going to land it in that time. It's going to take several go arounds. I think one of the things that's important is consistency and of course that's why people go to Turkey is because they get different kind of messages. But if systems can give people a consistent message it will help them to get to the point where they can start to think, oh, hang on a minute, then maybe there's other things involved. Oh, maybe stress is important rather than the initial response, which is “bloody psychologist, what are you gonna do?”

*I work in a community pain service and we're fortunate to have an IAPP service that's officially just starting to treat complex trauma, which is quite useful and very remarkable. So we're trying to make a good firm connection with them because complex trauma and chronic pain obviously go together an awful lot. We also in the process of making links with our two site liaison services in our local general hospitals. Because there's so many people who unfortunately go to AE looking for solutions and answers with chronic pain we're hoping that if we were to have a presence of some kind in the AE departments people might want us to be there more .We would help with the high impact users, as they're called. We're looking at the complex trauma service, and hoping that we're be able to link between all three services, AEs and IAPPs . Do you know of any other pain team services that have linked with or do you know of any work that linked with AES by any chance? It's like liaisons, has that been tried or done in what ways?*

Well, okay, yes, it has. It's been tried in various ways over the years. I think in Birmingham particularly there was the - I've forgotten the acronym initiative where they had liaison psychs in general hospitals trying to do this kind of joined up work.. The problem is that often you've got different stories, and I'm going to use the word story in a very careful way going on. So you've got sort of layers, with psychiatry telling one story, like this is sort of depression or something and someone else saying, this is complex trauma and someone else saying, this is chronic pain from bulging discs. Often patients in that situation , have got multiple stories and what you hear from patients is them saying I go to a different person and I get a different story each time. I think what's really important is a story that makes sense to them, first of all, but that actually pulls it all together. So one of the risks is that people then start to feel overwhelmed. Because what the kind of diagnostic medical approach tends to do is say is you've got this and this and this. So people feel like they've got a sort of whole stack of different problems - a sort of the fragmenting reductionist approach. It actually just suddenly feels like they've got 10 problems rather than one problem. When the rest of us are saying, well, no, actually this is all joined up. The problem is often no one sits down with them and says, can we just talk about how this all fits together? And so one of the things that, in that situation, I've always found really useful and I just want to pass it on, are things like the pain cycle in the pain toolkit. where you can sit down with someone and say all these things: sleep, stress, fitness and weight, you can get it all on the table together and you can start to draw a vicious circle. Now when you do that, most people say, , tell me about it, they know it.

. And I think that's probably the most helpful thing because once people have got a clear model themselves they can then start asking the different professionals that want to help them for the right kind of help. Otherwise what happens is they turn up in each place and say, help me.

 *I wanted to go back to your comments about abdominal pain. I had a very unpleasant experience recently when I had to go into A&E with our daughter who had quite extreme abdominal pain. She'd been sent in by a female GP who was pretty convinced she had appendicitis and she'd rung ahead to say she's too unwell to sit in A&E. Seven hours later, were still sitting in A E and she was seen 4 o'clock in the morning by a male consultant who came in and said, I've seen your bloods and you haven't got appendicitis, you've got pancreatitis. And we're going to discharge you and bring you back in for an ultrasound because it's most likely you've got gallstones. And I had to stay with her because she was too unwell to stand up for herself. And it's only because I said, look, this doesn't really fit with her. She's a personal trainer, she's a nutritionist, she's fit, she's 36 years old, she's got a very good diet, she got no pain over her pancreas, her pains are all down over the right hand side and it doesn't fit. And he just would not listen. And fortunately they kept her in that night. And the next morning she was seen by a female consultant who said, I'm going to listen to what you. To your story and I'm going to give you a CT scan just to check. And sure enough, CT scan showed appendicitis and no sign of pancreatitis at all. And the question is;
has there any work been done to show that perhaps women are dismissed more by male clinicians than they are by female ones? Are the pressures in AE playing into this as well? Because they just wanted to get rid of her. She was another female who come in with abdominal pain and they just wanted to get rid of her.*

Have a look at the survey which is available online, the 2021 survey and the special edition of the Lancet. Because there's probably stuff in there. I don't know, but I suspect there will be some stuff in there. [Results of the ‘Women’s Health – Let’s talk about it’ survey - GOV.UK](https://www.gov.uk/government/calls-for-evidence/womens-health-strategy-call-for-evidence/outcome/3fa4a313-f7a5-429a-b68d-0eb0be15e696)

*They're having an argument at the bottom of her bed because even when they saw it as appendicitis, he still wanted to send her home with antibiotics. And the female consultant was saying, well, she's going to be in a very soon again and if I hadn't been there to stand up for her, she would have been sent home.*

I'm sorry you've been through that. But that's not untypical. And, and as I say, the samples we looked at in Bath had been through that exactly that kind of process and got more and more distressed. And so what was actually happening was that the script amongst the health professionals was, oh, they love coming in here and you know, to get morphine and stuff. And actually when you talk to the the women, they all said they hated going in there because they were always treated kind of a bit like that - like, oh, another woman with abdominal pain And of course it's really difficult to then have a sort of sensible, assertive conversation when you're bouncing off the walls with pain.

*After 20 years or more in pastoral primary care, I'm very sceptical about the concept of closure. It sounds like if you want to be a Winston Churchill biographer and you want to have the ultimate answer to Winston Churchill's life, which answers all the questions because you found it that he's a narcissist or whatever. And I found myself also being wrong for woman when I said, your right flunk pain is a manifestation of your trauma etc But eventually it occurred to me that I should check her renal function. And there was also a renal stone as well as the trauma and everything else. I I would say I know her very well and I trust her and she trusts me and she comes back.to me. My increased understanding has kind of shut this all down so that she doesn't feel existentially distressed. Maybe I feel less distressed when she's coming and I damped my emotional counter-transference down. But I'm really sceptical about a one diagnosis, one story closure. - ‘please, now you have learned about it, accept it and don't you ever come back again’ sort of attitude No –*do *come back again. And of course she will have questions. It's this descending inhibition control that is not working. Somebody else said the stresses of life are carrying on and pain is like hunger and thirst. Of course she will come back and back. My problem, I have to be relaxed that I'm not a ‘dog for Christmas’ closure. I'm a dog for life.*

I agree. I think we should always be very sceptical of a sort of single answer solution. I agree with you completely. But I when I talked about changing the agenda earlier on, what I was referring to was this idea that rather than hunting for the thing, whether it's a gallstone or childhood trauma, 'is the wrong way to do it. It's not about that. What I was trying to talk about is the idea that we say, look, okay, let's try and get all the different elements on the table and have a look. So you may well have this, that and the other that's showing up on the scan. But let's look at your sleep, at how stressed you are, at how fit you are etc. and put it all together so people get the idea that all of these different things have a part to play. In other words, you may have some physical abnormality going on, but actually if you're not sleeping and you're completely stressed and overweight and blah, blah, it's all going to be much worse. That's what I mean by changing the agenda. It says moving from a biomedical to more of a biopsychosocial concept of the whole thing. It gives people some agency in terms of self-management as well. Otherwise, if we don't do that they're going to keep coming back to the expert each time for, for answer.

*I think the agency needs to be coupled with,: ‘you can always come back to me’ , it's not dismissal, it's not a rejection*.

*We've not met before, Patrick, but I am a systemic psychotherapist. I've been thinking about this through the lens of relationships. And I took a photograph of one of your slides about the assumptions about if I'm to be acceptable myself, about high standards, being in control of emotions, don't complain, neglecting own needs. And I was wondering how much of that applies to those of us and our colleagues and how many of us have had adverse childhood experiences, which clearly we're not going to talk about here. But many of us could be in the same place as many of the chronic pain patients that we're talking about today. And I'm wondering what makes the difference between those of us who are one side of the desk and those of us who are on the other? What is the resilience that makes you the professional as opposed to the patient? And because I think knowing my colleagues as I do as friends, many of those assumptions could apply to many of my colleagues, the high achievers, the drivers and so on. And thinking about some of what's been said in the conversation so far, a lot of it seems to be about relational trauma and a lot of what drives people, as you said, Jens, you can always come back to me if you need me. That the repair and the resilience is really about solidifying relationships and giving people confidence in relationships or confidence. They can feel that concern either from a doctor, if they didn't get it from a parent or a partner, and so on. I don't have any nice tidy conclusion to this, but I was just thinking about what makes the difference between us and them, and some of the shared assumptions and drivers that we have that make some of us resilient and some of us.*

Yes, that's why I came up with the mechanism model, because I was trying to wrestle with exactly that point. If you've got a good stable job, perhaps in the public sector so you can get six months off and six months half pay - as opposed to being self-employed - you've got a good relationship and a family, al l those things help. We know that the absence of those things tends to tip people into more vulnerability. So I was wrestling with exactly those issues. And if you look at other literature those sort of cushions, are spelled out in other ways. So there is an argument that women are on the back foot to begin with because of all the structural stuff that they have to deal with, which men don't,. So is it any wonder that more women fall off the balance than men? The other point is that the issues that have been highlighted in the Sarawi model, things like the all or nothing behaviour , the perfectionism and so on. One of the big problems with those is that they're kind of socially desirable so that they're not pathologies, but we're talking about them in terms of pathology. It's, that's not like people having panic attacks. If you go right back, to the onset of the ME/ chronic fatigue thing, when people talked about yuppie flu, it suddenly all made sense to me. There are people who are over driving themselves and their bodies saying no, they're not doing this anymore. The paper that this came from was published in the British Journal of Pain in 2018 or 2019. <https://doi.org/10.1177/2049463718799784>

*So is the ultimate implication then that we go for prevention? And look at early parenting stuff, breastfeeding, bonding, having fathers in the delivery room; really early kind of stuff. I mean, it seems quite a long way from. …*

I guess this does apply to chronic pain. But exactly how are we ever going to do that? I mean we don’t have to stop doing that stuff. Going back to what I said earlier on, which is that I think it's about finding a way of having the conversations with people that moves them from the ‘oh my God, I need another scam’ sort of thoughts . They need a different model which allows us to have these conversations like: ‘might stress be part of this’ or ‘ Tell me a bit about what's happened to you ‘ - the stuff we can all learn from To have the right conversations with people when they're presenting which are probably more achievable.

. *The title of your talk is What Chronic Pain Tells Us About Society. I was born in 1971. Society is far less sexist now than at any other time in my life. And yet rates of chronic pain have gone up. Medicine has far more women than it's ever had. There's less sexism in medicine than there ever was. So I'd like you to answer the question you set yourself, given all of that. Why are the rates of chronic pain going up? What does chronic pain tell us about society and about medicine?*

You're right, of course, but I think when we started to look at this sort of structural. sexism in the institutions that maybe hasn't. changed, significantly. When we look at violence against women, that is still a real problem. I think maybe there are other forces at work that are combining to produce this. I mean I would combine that with other things, like medicalization of conditions that. weren't before but are now. So people are kind of looking for more medical explanations for things. So there's a whole range of forces going on there. But
I suppose what I was thinking with the title was maybe that . Perhaps the medicalization thing is important as well, in the sense that it's a kind of a way of expressing a lot of the inequalities that are in society at the moment across the board. Maybe we should pay attention to that rather than drilling down all the time into the biological, which still seems to be a dead end. That's kind of where I'm coming from.

 *I'm just about to run two non-medical pain self management courses and all the people that have signed up are females, which very much goes with what you were saying, which is a shame, but I am going to work on that. The other thing is that do we have self management of chronic pain too far down the line? Should self-management of chronic pain start in primary care and use - not necessarily the GP because they don't have the time - but health coaches who are sure to find to get that story.*

The simple answer to that Is yes, of course. But people have got to be ready to go down that road. And so I come back to the points I was making earlier on, about the seven times people have got to have those conversations to get them to a point where they're ready to think about self management. And that's the tricky bit.: getting people to a place where they're ready to engage with that earlier on. From my experience a number of people are just not ready until they've been there for some time.

*One of the things we've done is some taster days for pain cafes and at every single one of them we have a number of people that actually break down sobbing at the fact that suddenly - they've been through pain management courses with the same management team - they find that there are people who are prepared to believe them unconditionally and without judgment; and to offer them ongoing support, not just a course and then it's ended. I'm passionate about this. I bore myself to death with it, because we've seen it work so often , taking self management out to the community into where it's needed.*

We should be doing that. I agree with you, but I'm just saying that the problem is if you catch people too early in their journey a lot of people are just not ready to embrace it. But of course it should be out there, it shouldn't be stuck in the back end of a pain clinic at the back end of secondary care

*I was going to ask earlier, but somebody else pre-empted me, about the effects of socio - economic factors and whether they disproportionately impact on women. A long time ago now when we first started these seminars, somebody gave a presentation showing that there was a close correlation between areas of high poverty and inequality and deprivation and chronic pain. The third thing he showed was that in areas of high inequality there was not only a high incidence of chronic pain but also of abuse of the drugs used to treat it,. Do these factors impact more on women?*

 *I've published a lot on these issues: the correlation between job loss and abuse and chronic pain. And it's become very popular in the States ( I'm talking to you from Seattle) ‘ the deaths of despair’. There's an article in JAMA showing where auto plants close down in Detroit you're going to get more chronic pain. So there is a link in there complex. My point is that I have published on this a lot, some in good places and some not good places because the biomedical journals such as Pain tend not to take it. They have taken some of my articles but if they rejected* *them John Loeser and I published something in the Yale Journal of Biology and Medicine\* about many of these issues, particularly about spouse abuse, child abuse and of job and pain. It hasn't been picked up. My stuff is not cited. And I think that points to a larger issue is that the incentive is all biomedicalized. The incentive in it now is to look at pain clinics where they do biomedical interventions. That's what gets reimbursed. And patients want a biomedical diagnosis as you indicated. And I think that the problem is not only with Turkish patients, but here in the US as well and in China, by the way,, they're doing more and more blocks They see patients for about five or 10 minutes in China, which is a big deal because China's got a lot of the world's population.*

 *But I think you’re preaching to the converted. We all listening here agree with you, but I think that the medical model is pervasive. It sits at the top of the hierarchy. That's what patients and doctors want. They have the highest prestige. And I feel frustrated at this point in my career and I'm nearing its end. I just don't think we've made any impact. .*

\*What are the Origins of Chronic Back Pain of “Obscure Origins”? Turning Toward Family and Workplace Social Contexts

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I feel the same frustration. The reason I put Gabor Mate on the end of my presentation was just that I think the impact he's having - he's saying the same things - but the impact he is interesting because people seem to be listening to him.

 *I was in a department of anesthesiology most of my career, and the people that were. there were the ones who did procedures for pain. or else who did research on mice.*

*And I was very low in the hierarchy throughout my career, and I just think that it's the systemic problem of everything being medicalized.*

. It's the same problem in the UK. The. The interventionists in pain clinics are the people who earn the money, usually for a wider surgical specialty. So they're often attached to intensive care and so on. It's the only part of the specialty that earns any money. So it's the same problem. So that leaves a whole load of people with chronic pain wandering around out there who are not getting the right help. And then, of course, you tip into the opioid problem, which is coming here, which you've had to deal with in the States

 And as I say, the thing I referred to a couple of times is this whole idea that you have to present a different model, a different story to patients to get them to make different choices. And the thing that I worked really hard on for five to 10 years probably is learning how to do that. Learning how to talk about a top down pain system in a way that is accessible so that people are going, oh, okay, maybe there's a different way of looking at this. And then they start to ask different questions and go in a different direction. And I think that's really important because that's the thing we can do in the face of this because that other stuff's not going to go away.

*What was that advertising principle?*

The rule of seven.

*The rule of seven. I think that's brilliant. We should bring that into pain more. But again, these patients have 15 minutes with a doc.*

*In the U.S. It's often, probably usually, an anesthesiologist*.

 I think that's down the line. You can't unpack that story in a 15 minute consultation. Yeah, it's not going to happen. But what you can do is move them along the line. You know, the rule of seventh thing. You can move them along the line a bit to say maybe there are other things at play here that I need to be thinking about. That's what I'm suggesting, if that makes sense. You need people who are skilled to do that and it's not going to happen in a 15 minute medical clinic.

*Even 15 minutes in General Practice is an absolute luxury. It's 10 minutes. It was seven and a half minutes. Two every 15 minutes*

*. There's a very interesting psychologist, Steve Biddulph, an Australian guy who wrote Raising Babies and he talks about resilience. And his theme was that if the child can be given three years of warmth from someone or other within the team of people looking after him, then t he or she will be resilient to a whole lot of other hits and mishaps through life. And he got into big trouble because he said no child should be sent into a child care facility before the age of three. And all these feminists came down on his head like a ton of bricks.*

*Of course we're wondering why is there more chronic pain going on? Well, maybe it's because we're making women work rather than stay home. I know that's highly controversial, but the natural biological state of a child and a mother is to be together for the first couple of years.*

Can just interrupt there, Maureen? Because actually the evidence is just bonding with someone. It doesn't. have to be the mother.

*. It doesn't have to be with the mother. But clearly we stick mothers on their own with the baby in Britain. But with my Bangladeshi patients, it was the mother and the granny and the auntie and the sister who all shared the care of the child. But anyway, it was all about the first few years of that child's life has to be with a warm and a cultural caring. . And I wonder whether we're going down a funny track where we're pressurizing young women to go back to work. It's almost regarded as eccentric not to want to do that.*

It's, it's tricky, isn't it? Because of course, that links us into things like economics and young people wanting to buy their own home and, the cost of living and so on. So yes, absolutely.

*In the 1950s, one man's income would support a family of five and the mother wouldn't go out to work. Whether that was ideal or not, I don't know. But anyway, we're sending children into child care facilities which may not be very skilful and will leave the child crying for hours on end and then the mother comes and picks her up, or the granny or the mother or the father. And they hear that it's been fine all day. But these children become tolerant of neglect and that internalizes into traumatic early experiences. So I think we have to be very careful about our political politician or our politics and the way we advocate for early life café… And the Surestart thing went brilliantly until the Tories got rid of it.*

I agree, Sure Start going was a terrible thing. But I would come back to the point that I think we are where we are. And one of the things that's really important - reflecting on some of the conversations we've had this evening. - I'm going to repeat the point is that it's about getting people to to shift their model, their understanding about their health, about their pain: allowing the fact that things like their upbringing and so on and so forth might be relevant. .If they see it's just a medical problem, they're never going to actually seek the right kind of help to. unravel what might be going on they will stay stuck in this awful kind

*.*

 *I think as a very quick explanation of chronic pain, is that they've got a broken heart. Someone broke their heart or they were perceived to have broken their heart. So if a little girl and her daddy shouts at her, it breaks her heart. Now if that goes on and she's got no control over it and cannot defend herself, it becomes just internalized as something she can't do anything about and she can't tell anyone because she also loves her dad. So, she’s got that conflict. So that's. where the power/ threat/meaning framework is a helpful because it helps us to see what happens to turn that into chronic pain, if we follow that through. And the framework that helps us to say she experienced a kind of abuse of power in a relationship so she would have adopted certain coping strategies to deal with it. . Is that what's going on now? Maybe she needs to find a different way of dealing with rejection.. I'm a big fan of framework and models because otherwise it gets really messy. And sometimes it's difficult to feel your way, especially where there's a lot of stuff that people present with*

O*ne of the problems is that we can give people this understanding, but the services just aren't there to help them to deal with it. A lot of the people that I see are women who carry a lot of life loads that they can't do anything about. They may be looking after parents with dementia, or they can't afford child care, or they are trying to hold down a job and trying to pay a mortgage. These aren't things that they can actually directly do anything about and if they also have had a lot of childhood trauma, that's a long term issue to sort out and the services just aren't there and that. So even if we give them this insight, what we, what do we do about it?*

There's a brilliant paper:- It's called Beck never lived in Birmingham\* and it's a critique of CBT. Of course CBT is probably the most accessible form of psychological help that's out there. But it makes the point that it was developed for people whose lives are essentially t okay, but their thoughts are very negative about things and it's about correcting their thoughts against a backdrop of a life that's generally going well. So if people have a lot of stuff going on, CBT is not the answer. and correcting their thoughts, which is what CBT is all about, isn't going to help.

 That's the kind of route people get pushed down very often because that's what's available. there isn't necessarily this stuff there. Years and years ago I, when I started out in this field I thought the answer was going to get out and educate everybody about chronic pain and how to help it and so on, and we'll put on all sorts of workshops and training for health professionals. But I realized that this just wasn't working. And so I sort of switched my thinking to thinking actually maybe it's about empowering people. So maybe the thing we need to be thinking about is what can we all do to empower people in that kind of situation to start taking back a bit of control? And it could be quite small things, maybe things that are seemingly unconnected with their pain. But we know that if you improve people's sense of self efficacy or self control. You can shift the locus of control. This helps in terms of internal psychological mechanisms and is really important. . And so maybe there are lots of things we can't do something about. But I think working on empowering and giving people agency is never a waste of time.

 Sometimes it might mean doing something quite different, like for example helping people to access a food bank or improving their access to a hot meal or something which improves their wellbeing and their sense of agency which in turn is likely to be helpful for other stuff as well.

\*<https://www.researchgate.net/publication/271506332_Beck_never_lived_in_Birmingham_Why_CBT_may_be_a_less_useful_treatment_for_psychological_distress_than_is_often_supposed>