**The perils and possibilities of defining chronic pain as a disease.**

Webinar 16/10/2023

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JF: Thank you for inviting me to defend a position I don’t hold by nature; I am relating to the position held by NICE to make pain a reality and establish pain in the firmament of the medical infrastructure, and make it the experience of patients in pain needing support and give this a name to enable people to use it to gain access to welfare, benefits and state support. For this reason we need to give it a name. To give it a name and status it needs to be a disease. And that rests on the attempts of a whole different generation after the war who their education to treating pain and improving the situation of people experiencing pain, and to make this visible by way of classifying syndromes as we do in psychiatry, and doing animal physiological and pharmacological research to establish an infrastructure to deal with this predicament of the masses. I appreciate that in the process of making pain visible on a population level it loses the nuance of the individual doctor patient encounter, or how the individual can identify their predicament or give it a name. It is about population planning at the meta and the meso level, where I am arguing for support for people within the magical system and the realms and fortification of health and social care which rest on disease categorisation.

 I accept that this is a process that changes with time. Neurasthenia is not a good diagnosis anymore; fibromyalgia is a way people recognise their predicament and having fibro is a shorthand for their experiences, and something the doctor can write on an application for personal dependence payment. It is also as way to make their struggle with day-to-day activities visible. Chronic pain finally has a name in the firmament of diseases in the WHO [International Classification of Diseases (ICD)](https://www.bing.com/ck/a?!&&p=15bc20c83f459aa1JmltdHM9MTY5ODk2OTYwMCZpZ3VpZD0zZDE0MmE3OC1mZTk1LTY3ZjUtMWU0NC0zOTFjZmZlZDY2YjMmaW5zaWQ9NTIzOA&ptn=3&hsh=3&fclid=3d142a78-fe95-67f5-1e44-391cffed66b3&psq=icd+11&u=a1aHR0cHM6Ly93d3cud2hvLmludC9zdGFuZGFyZHMvY2xhc3NpZmljYXRpb25zL2NsYXNzaWZpY2F0aW9uLW9mLWRpc2Vhc2Vz&ntb=1) 11.

So my argument is that this mainly serves population purposes; not many people will find their suffering recognised by “I am having post-surgical pain”; but it is a way to establish their predicament in population planning, medical student teaching and all sorts of interventions to support these people.

JT: So your argument is that a diagnostic label supports an infrastructure which is to do with education, benefits, social recognition, and is enabling professionals to be informed and patients to access sympathy and support. My response to that would be that people are changed by their diagnosis. So it’s not an \act where you go to the doctor who gives you a diagnosis of something, and then ,like it or not, you take it on as part of your identity. This doesn’t necessarily happen but you don’t need or always have a choice. We all know of patients who will use their diagnosis as a shorthand to explain all their difficulties and problems and in so doing a diagnostic label can hide individual differences and mask certain ways of being that aren’t tied up with that diagnosis. I know of patients who have responded to a diagnosis of chronic pain by ascribing all of their problems to it, taking on a sick role and use that as a reason to step aside from the sort of NICE recommended proactive taking responsibility for your own care - ‘self-management’ – but rather to resort to a position of ‘now I need to be looked after’. And within complicated family dynamics that can become the case. It's also problematic because there is a tautological problem with chronic pain as a diagnosis in that it is both symptom and label or cause. There is one study of young people with chronic pain and their parents, when they were interviewed about their experiences of chronic pain, who often responded that it helped if the doctor didn’t know what was wrong with you: describing your illness in terms of symptoms but failing to explain them. A diagnosis that explains nothing unless it perhaps it is a scaffolding around the kind of neuroscientific interventions which some people are very keen on, but which empirical studies have not so far have not found to be very effective for that many people.

 So the experience of being diagnosed with chronic pain can risk people taking on a particular role that is unhelpful and doesn’t support their recovery but rather fixes them in a passive position with little hope of recovery or restitution. It also sends the message to patients that the doctor doesn’t know what is wrong with you and you are just stuck with it. and like in the study of young people who felt that this meant that there was little interest and specialists weren’t going to investigate them anymore, and they were left to get on with it. Notwithstanding whether or not that is true, it certainly is an effect of the labelling of chronic pain.

 Lastly in response to your ‘chronic pain is both meso and meta’ where meta diagnosis is used in public health accounting for the numbers of people with chronic pain, and meso benefits of a diagnosis which is to do with internal communication between specialists and other doctors and researchers dealing with chronic pain and helping them to recognise that they are dealing with the same condition. I would argue that chronic pain is a diagnosis that neither has sufficient validity - in other words clear boundaries between chronic pain and not chronic pain do not exist, nor reliability to distinguish between different doctors working in primary or secondary care: pain clinics, rheumatology, neurology, orthopaedic and all the other clinics that might use it as a diagnostic label. It doesn’t even reliably serve either its meta or its meso diagnostic function, because so many stakeholders have different ways of using it.

JF: Back to the stakeholders: I am interested that you mention the sick role, and secondary gain or the weaponisation of the label for particular interests. I can relate to this as a clinician where I am supporting people in a rather passive role. However that is not a problem of the disease label itself but of the people using it as proper politics on the meta, meso or local level. You are relating to the debate about the deserving or undeserving and feckless poor, and about a moral obligation to use the label wisely. This again is not the problem of the label but of the people using it in one way or the other. My agenda is to have a label even if it is a blunt one is to make it visible in a world where something is not a disease but simply a problem of functioning that robs it of kudos, status, visibility etc. so needs to have a name.

 It is sometimes ridiculous that our labels are sometimes used - for instance talking about arthritis to a teenager when you can also say what is their pain that doesn’t go away label is a … that doesn’t explain enough … of course these labels are often used in a rather haphazard way . For this reason I support the idea that they are blunt and descriptive labels but at least carry the notion that many people struggle with life because of their pain experience which is an invisible disability. So hopefully they can say “I have an invisible disability - thank you for giving it a name. 14 06

JT: You have at least acknowledged that the problem is not with the labels per se but the way in which they are used or with the labellers. Is the diagnosis in your opinion sufficiently robust and reliable that you can control it once it is let loose? I would argue that once it is let loose upon the medical profession, unlike, for example, ADHD, where you have to refer to a specialist clinic (notwithstanding all the problems revealed by the recent Panorama programme about the diagnosis being made on the basis of screening test without a full psychiatric history) Chronic pain is a label which has been let loose for any clinician to use. Did you or any of your colleagues at NICE let it go before it had been kind of sealed tested within a specialist setting. Could it - might it - have been safer where the label chronic pain had been reserved for specialists who were qualified to make that diagnosis? But now you have let this out of the box and allowed GPs like me with a vested interest, and rheumatologists who are keen to reduce their caseloads by excluding people without biomedically identifiable inflammatory disorders, or surgeons people they don’t like.

Is there a problem now that the genie has been let out of the bottle that the label has been used without discrimination, thus undermining your project to have it as a useful meta-diagnostic tool.

JF. I like this question but I don’t have a single answer to it. Of course you can say once you have popularised pain as a disease then you may water its traction down. If you say …. Pain sufferers in the UK, does it mean you don’t need to name it as everybody has it, but does this not also hold true for mental health? One in four of us suffer from mental health problems, and this traction of popularising disease labels is not reserved for chronic pain; you see that in every other aspect of life. Diabetes gets expanded to prediabetes. Every aspect of life becomes a pre-disease state; it is more the problem of looking at life through the prism of specialists and diseases. I want to say that the project ‘pain’ is only one aspect of a general medicalisation of life. Why should pain be exempt in this dynamic?

 JT: Extrapolating from that – what you allude to – the risk is that everybody is diagnosed with something. One of the problems is that depression is both a normal experience and a diagnostic label with criteria. He also memorably said “we all have mental health but fortunately relatively few of us have a mental illness”. And chronic pain is a good example of something that many of us suffer with but it’s not reaching the level of a diagnosis for most people, just as we all get depressed but wouldn’t be diagnosed with a mental illness and wouldn’t be prescribed medication. There is a risk that a diagnosis leads on to a particular treatment pathway and accelerates you down that route.

  Would you acknowledge that to suffer is to be human and chronic pain is or may be a normal part of human experience and a risk of diagnosing it is the adoption of a sick role tied to a diagnostic category, and then someone comes up with a new drug for the diagnosis and the identity becomes tied up with the medication, and we end up with an oxycodone or ketamine epidemic. How do we distinguish chronic pain from normal life experience ?

JF: That brings us back to politics. The question of whose pain deserves to be alleviated is always a political question. And, in a way, giving it a name serves the purpose that people who experience pain can access help for it. Unfortunately under the welfare system and the disease system you need to have a disorder to get help. The same with mental health: if you have reactive phenomena of sadness etc. you need a disorder to get help for it. What you are arguing for is a complete overhaul of the system to access support. I can sympathise with this; wouldn’t it be nice not to have to have a disorder to get help? That is my dream - to have a different welfare system with a free flat rate for all [*a universal basic income?]* without having the status of suffering. It might come as a problem for people like you and me as doctors whose raison d’être is be this person who selects deserving from undeserving people. I am mindful of your argument that it shouldn’t be watered down and there is a need for specialists to this is or is not a disease. However I am feeling really sorry for the people with functional problems who are not validated because their problems are not established in the normal grid. A chronic pain label may at least be a vessel - a category – to access help.

JT: There are a couple of problems with your line of argument : one would be that by using a diagnosis as the pathway for us to offer support, services and treatment and so on. It becomes very medicalised if what counts as help is through medical men. Or what Foucault described as a kind of medical game. And rather than that opening possibilities for support that narrows them down to what medicine can offer. People often experience this as rejection. They have seen chronic pain through the perspective of pain specialist medicine which may involve a relatively short term service before being discharged back to the person who referred them in the first place, rather than a social, developmental health justice view of things. We have certainly seen in mental health the patient led backlash against the medicalisation of mental illness . Is there a risk that the diagnosis of medicine controlling chronic pain restricts what is on offer to people rather than expanding it?

JF: I share this concern, but I need to bring it back to the diagnostic criteria for selecting the people that are in need of help by establishing whether this is a disease that there is an obligation to treat within the health system. Yes, you can see the same dynamics in mental health and pain medicine. I hear that you are questioning whether having pain specialists and psychiatrists is helping the greater cause. That is a debate we could have, but the way we have to work now, as doctors, specialists and experts is to make peoples’ invisible suffering visible by giving it a name; making sure that the invisible suffering can be characterised by concepts like fibromyalgia. I accept that we in the medical profession need to be mindful of where we play a social role in medicalising social experiences. Bu there is nothing we can do as a profession – we are part of a wider social fabric

JT: I would like to ask you something else about what diagnosis does for and too people. One thing I have seen in the increasing numbers of people coming to see me wanting to be diagnosed with ADHD and autism. This is a new phenomenon: people seeking a particular diagnosis, especially one that might have been associated with social stigma . Something that diagnosis also does. Leaving aside the assumption - although there may be some truth in it – the idea  that they need prescriptions and illness as identity, to create a sense of identity, community or belonging, in the same way that higher performance in higher education or in work can create a sense of identity, community or belonging; and I think that social media has an important role here. There are so-called social media celebrities or thought leaders that position themselves as leaders of people that have certain conditions, and have followers who see themselves in that way and will coalesce around them. And in an age when people have strong social connections online connecting through an identity happens more than it might have done in natural social circumstances where people connect, perhaps under a shared project or geography – or something other than an identity. A diagnostic label enables people to become associated with that group. I can think of support groups for all kinds of illnesses. I am aware that there are people here from Flipping Pain, Pain Toolkit  and Live Well with Pain who do find that their approach is enormously helpful for people with chronic pain, but it does depend on a degree of acceptance and self-determination – and here is my challenge to you -  very few of  my patients that I have diagnosed with chronic pain choose this as an identity or choose to access the kind of support it offers or to get any kind of benefit from the label in the way that many other guys with disabilities do, and shy away from that. Why do you think that is? Is it a problem with the label?

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JF: What springs to my mind are subsections of the chronic pain label; some of them attract very people with identity-forming characteristics, subgroups, self-help saying I have for example Ehlers Danlos not the musculoskeletal world which has a very different group of followers like osteoarthritis and their programmes are very different from the people who are diagnosed with rheumatoid arthritis and inflammatory conditions. Pain labels are a very heterogeneous umbrella for all sorts of population groups with different predicaments. I am very mindful of the social gradient for all of them. The less resorts you ask the more difficult it is to get access to help. And I think that if , depending on the different pain labels being part of this will help you access support and peer support.

 I’m not really answering your question because pain labels kind of stand for different projects. Project fibromyalgia is a different one from project sickle-cell disease or Ehlers-Danlos. They have very different population groups .

JT : We are coming to the point as I thought we would where we agree with each other. Harking back to Arthur Frank *[author of The Wounded Storyteller*] who influenced my thinking on chronic pain, accepting the labels implies a degree of acceptance is hard-won and takes a long time. I recently saw a patient that I had been looking after for a long time - much of the 20 years I have been in my practice - who looked happier than ever but had taken this long to accept her chronic pain. She said “my pain tells me that I am alive”. So she has moved from a model of restitution - seeking to find the cause and to be free of pain - to I’ve got to live with it. Many of the people with chronic pain are still seeking an explanation which isn’t chronic pain, and that may be part of the reason why acceptance is difficult and why belonging to a group, unlike those for people with neurodevelopmental disorders who know they are stuck with it, may not be helpful. And that can be very hard.

Discussion

*Whose pain deserves to be alleviated? Most medications or other treatments are ineffective*

JF: I relate to Keith Wailoo, an American Author who wrote about sickle cell disease to highlight pain in the Afro-Caribbean population or fibromyalgia which involves more white, middle-cast females; and all these projects which are linked to raising the voices of people who are otherwise not seen or can not speak up. That made me wonder where this fits in the UK; which political purpose does a disease label serve; whose voice needs to be heard; who is in need of more support? Of course medications etc are often ineffective but that’s not what it is about - it is about who gets support in the wider population. Medication is our black magic for doctors who need to survive without solving the problem.

 I remember that in Rydal Hall we debated whether the pain disease labels served any useful function at all if it is something that affects everybody.

JT: I wouldn’t say that to be alleviated but rather validated. One question I would ask is: if that is true and almost all the qualitative research I have read about patients’ perception of clinical interaction about chronic pain suggests that validation is critical. I would ask whether CP as a label really serves the purpose of validation. I think the evidence is pretty equivocal. It might be valid at a political level but is debatable at an individual level.

JF: That brings me back to NICE which put validation as a central ingredient in the patient/clinician interaction. The question I have is: how to you actually validate what is needed to do that? Everybody says listening etc. but exactly what makes a different invalidation? – “ that must have been very difficult for you” or “I can only imagine what you are going through” or “there is something very difficult in this central component”

*A problem with validating a patient’s pain or disability is that there is no objective measure of pain. You can say I realised you have a lot of trouble and suffering but I’m not optimistic that that will make any difference with the Department of Work and Pensions. A diagnosis can be very disabling. You talked about Ehlers Danlos, a terrible situation, but does at least provide some validation of the diagnosis. I think that there is a way of looking at patients with pain who have central sensitisation the majority of patients and can see it similar description lack of response to medication and social history in a way pain has affected things that cause any damage cause increased pain examination getting across to people nervous system out of balance experiencing too much sensitivity too much pain going on there is no medication that is going to make that go back to normal and stopping doing things is not going to help me either a terrible problem for people with pain for a long time*

*It occurred to me that some people may not be familiar with Charles Rosenburg’s essay The Tyranny of Diagnosis. You need a diagnosis to get help as a patient. We can look at this as a medicalisation of a social problem. So I go and seek help from a doctor but what are doctors trained to do? : to give medical help. So you need the diagnosis but on the other hand doctors give opioids, spinal injections and all sorts of things and even unnecessary major surgery. That is what the patients want;, they go to the doctor who will look for a more definite diagnosis than chronic pain. It’s kind of a conundrum and there is no easy way out of it.*

 *Another thing – as a complete outsider – is that you talk about chronic pain but no-one has mentioned emotional and physical function.; not being able to do activities like socialising, family, work etc. If you don’t treat the pain but you do treat the concomitants that might be helpful and give physicians a way out.*

 *Finally, I think many of you are GP’s and I think you can be tremendously helpful in allowing patients to do what they want to do. I don’t know whether there has ever been a randomised study of pain specialists versus GPs particularly where the patient has a long-established relationship with a GP*

*Regarding what you said about ADHD, Jonathon: I had a very interesting conversation with my middle son last week; he has a three-year-old. He was quite shocked by the number of parents he knew who were actively seeking a diagnosis of ADHD or autism. It seems to be down to social media depicting perfect family lives as opposed to normal ones. Parents feel guilty because they feel they are to blame for their children behaving badly – two-year-olds do sometimes! They go from doctor to doctor seeking this diagnosis and are relieved when the child gets a diagnosis of ADHD or autism because then they feel it’s not their fault, I they have a label they have access to support for when their child is behaving in difficult ways. This is interesting as you would have though that normally people would hate to have that kind of diagnosis.*

*Henry Beecher described soldiers on the beach in Anzio in WW2 who were severely wounded but who didn’t need or want pain relief, whereas people in A&E who had been smashed up in road accidents were desperate for pain relief. And the difference was the meaning attached to the pain; if you are wounded in battle you are out of this hell and can go home; whereas after an RTA you maty think it’s your fault, or worry about being disabled and unable to work. M any people in pain are seeking that feeling of being able to go home but they may come from a home where their trust in their parents has been betrayed. They may not realise that this is a normal part of life even if dysfunctional but they want perfection and you always lose against perfection.*

*Some of us may have read the book* Some of Us Just Fall  *by Polly Atkins (who is actually coming to Rydal next year; she lives in Grasmere) I found it quite a distressing book to read. She has suffered from – arguably not chronic pain but more like very frequent episodes of severe acute pain, often from fractures and dislocations with minimal trauma, and she has rarely been altogether free from pain all her life since childhood. She was desperately seeking for a diagnosis which she finally got in her mid-thirties of Ehlers Danlos syndrome and haemochromatosis. (I’m not sure if they are associated or coincidental) which she says greatly improved her life, not least because haemochromatosis is treatable. I found this very disturbing because when I was practicing pain medicine I had always taken the position that Jonathon was expounding about diagnosis and tried to help patients to escape from the futile search for a treatable one that had occupied so much of their waking lives. Had I been doing some of them a disservice? Polly Atkins avers that diagnosis had made a huge change to her life for the better, and her and others’ attitudes to her pain, particularly because her medical attendants took her pain more seriously.*

 *We actually had this as our main topic at our meeting in 2015 entitled The Tyranny of Diagnosis. If you are interested you can find the transcription on our website.*

JF: We are talking about three intertwined strands. One is the dilution of medical labels which often makes me angry. Every week I work in a hospital for learning disabilities. I go into secluded rooms where naked people with severe ADHD and autism are being given support; and I am seeing the extreme end and I find this hard to reconcile with requests for additional study time and so forth. Then we have social justice where disease labels may be either counterproductive or productive. Thirdly we have the deserving/undeserving debate which is at the cusp of what we do in the NHS where medical services should be free for all. We see people wo we think are deserving while others know the system and know how to accumulate labels. Personally, when I look at these three strands I don’t see a clear path and don’t have a clear agenda. I think I have a moral compass but as soon as that becomes a health and political compass I become quite dizzy! and that makes me look at the political and moral foundation of what we are doing. That gives me a bit of an agenda but that comes from being at work and having an emotional component.

*I am thinking of the … diagnosis of the problem … the effectiveness of treatment as well is really important … both the request for a diagnosis … the treatment ……. ?? in Sydney … have people go through that search … failed treatment and ends up with reduced function and excessive suffering …. Diagnosis has to be useful for people and from my point of view I would go for a description of the symptoms which is that they have increased pain and excess sensitivity and often muscle tightening, disturbed sleep and reduced activity and an effect on mood. All of these things are interactive and …. how we can prove that is not ..… medication …. any better. It’s not investigations ….looking at signals in the nervous system causing the problem. Can we figure out a practical plan to think about the things that are really important for the patient ……. need this diagnosis or this treatment.*

*It's complicated! …*

*… It’s not – it’s really very simple …*

*… but as a GP you have to investigate quite a lot so that you are not overlooking anything, like a tumour somewhere or a joint disorder; you can’t …*

*… I see people with chronic pain. One of the primary things I would say to patients … you get it from patients that the symptoms are worse after they have done something … chronic fatigue Ehlers Danlos, post-Covid … get a big flare-up of pain afterwards and settles down … variability up and down … key symptom of chronic pain. With progressive disease the symptoms go up and up and … injury they go down and down.*

*In my experience of patients most functional progress is made when there is a degree of acceptance rather than continual searching for answers or treatments. I also find acceptance more difficult to achieve without validation of the experience of pain. Sometimes diagnosis achieves this; other times it is a better understanding of the process underlying the experience that can provide that sense of validation.*

JT: Responding to contributors about meaning: Arthur Frank, the Canadian sociologist, says that one narrative that people have about pain is about restitution ; that when you find a diagnosis you will find a cure. Chaos is when you have a series of failed restitutions which is what our patients experience. Our chronic pain patients are stuck in chaos, and those are the ones that cause us the most difficulty. Frank describes the third type of illness narrative which is a quest for meaning. Returning to the comments about how injured soldiers refuse pain relief because their pain has meaning, and those who have experienced traumatic events like the earthquake in Haiti. People who stayed with their communities and contributed to the clear-up suffered minimal PTSD symptoms whereas people who were ‘rescued’ and taken away and given therapy had far worse symptoms. The lesson from this and other examples is that when people who have experienced trauma are given a purpose in resolving the things that caused the trauma they have fewer symptoms . That accords with the earlier comment about powerlessness and about how that relates to chronic pain. I would say that the search for a diagnostic label is something we see very frequently in medicine. I was struck by what a psychotherapist whom I heard speaking recently said: the patients that he sees who get to him eventually, having failed to receive the diagnosis that they have been seeking, are often the ones most resistant to exploring issues within the psychotherapeutic relationship. The desire for a diagnosis is often a desire for a simple explanation for a problem that needs serious examination of the psyche rather than of the blood or the bones or the neurons. My last example is someone I knew very well that I met when I first joined Twitter about ten years ago who is a prominent doctor who has chronic pain and advocate of research about it. He recovered: - you’re not supposed to recover from chronic pain – and received quite a lot of vicious attacks including accusing him of faking it. He had to leave social media and kind of go underground.

*[From the Chat] Could it be that the soldiers, in an acute event, are having sympathetic hypoalgesia?*

 *At the battle of Waterloo Lord Uxbridge said to Wellington “By Jove, sir, I think I’ve lost my leg!” to which Wellington replied “By God, sir, so you have! “ \**

*[From the Chat] Even taking a tablet prescribed by an authoritative figure means you are doing something*

*[From the Chat] Getting a diagnostic label provides validation not only for medical intervention but for the benefits that you can claim. Wanting a diagnostic label for these purposes can increase the symptoms of the diagnosis*

*I have had patients who were injured at work and the pain never went away until the court case was settled. They weren’t making it up but this has been called ‘compensation neurosis or something of the sort.*

*Among the things that came up for me during the discussion was one kind of practical and personal issue: I had a recent conversation with one of the clinical directors when I was asking to see patients for two to three hours’ appointments for assessment, talk through their problems – kind of a brief psychodynamic – give then advice. They were saying ‘why don’t you see them for half-an-hour and give them a diagnosis?’ A lot of people are helped by diagnosis and I was thinking that I could, after all, possibly help people more in this way. Another thing that came up in our conversation prompts me to ask: in what sense do you want someone to validate your experience? You see it’s not about validating the experience – or is it?*

\*https://en.wikipedia.org/wiki/Lord\_Uxbridge%27s*\_leg*

*For some people there is something about how much of what I am experiencing is real? - unless it is socially agreed upon or unless there is someone who can say ‘yes, that’s what you’ve got’. If obesity was body beautiful or caught by viruses as some people suggest*  *everyone would want the label so they could say ‘ I’ve got so many problems , I can’t go up the stairs … because I’m obese; it’s a problem and not my fault’. Likewise with pain? There is something there about validation - I am not quite sure how it fits in, - but there is something about one’s embeddedness in one’s own body. I always talk to people about the intelligence of the body or the incarnated psyche or whatever you want to call it; something that goes beyond that kind of episcopal logic. I tell them that something is trying to tell you something. But you are right that in this sense not everyone is interested in making meaning out of and moving through an experience but to encapsulate and say ‘I’ve got this – that’s my burden; I’m not interested in getting better’. I see people that have been twenty or thirty years in the system so it’s not the same kind of populace as people with CP who are only two or three years down the line. I wonder if there is something there in that kind of ramble at the end?*

*I am a psychoanalyst and I see patients three or four times a week for years, so we have plenty of time. My approach is to get to the experience of the experience, and I am approaching diagnosis from an experiential viewpoint. First of all I find pain patients, most of the time, don’t want to be diagnosed with depression for fear that their pain is not going to be taken seriously or treated. On the other hand people who have had a diagnosis of anxiety or/and depression and other things in psychotherapy sometimes come with somatic symptoms they don’t know what to call - for example Ehlers Danlos and ADHD which describe conditions that are very different. The former is on a somatic level and the latter more on an emotional level. Getting a diagnosis explains why these people experience life as they do, which is different from those that don’t have a diagnosis. It seems to relieve them when I send them to a doctor to get diagnosed, because it helps them to understand why they experience life as they do. They don’t come to me seeking a diagnosis – quite the opposite; they are wondering why their lives are so messed up or why they find it so difficult to concentrate or they have joint problems.*

JF: The big issue with assessment for PIP (Personal Independence**Payment) and Universal Credit is that by default they are functional assessments. They are asset-based so they often invite people to maximise what they cannot do to get points. But they are not based on diagnoses. That is very good, and as a rehabilitation doctor I like that. However there is the problem Jonathon alluded to that it rewards things you can *not* do but not the things you *can* do. And that brings a very different dynamic into the game.**

**JT: One of the social functions of diagnostic labels is to remove that sense of blame and perhaps of autonomy or control: ‘it’s not me its my illness’. I can’t get out of bed today because of my chronic pain – it’s not that I don’t want to do all the things I need to do. I didn’t get my assignment in in time because of my ADHD. It can become a sort of shorthand for lots of complex disorders and social obligations which you can’t otherwise fulfil. The fact that there is no diagnostic hat means that even the label of CP still arouses a certain level of suspicion and people don’t trust it the way they might trust something like chronic lime disease or Ehlers Danlos which sound very medical and may be a shorthand for saying there are a lot of things I can’t do. There is also a search for identity which has always been there but is kind of more acute these days. So for example I have patients coming in who ask me: ‘why I am like this’. So I ask them ‘did you ever think of therapy or travel or hallucinogenic drugs or whatever?. There are many ways of discovering who you are and why you are the way you are.’ They often come wanting a particular diagnosis as they have already decided that the way they are is dependent on it; they are not interested in any old diagnosis. Chronic pain is partially successful at best in providing a shorthand explanation of the way that ED or ADHD might. It’s not quite adequate to serve that function of explaining yourself or relieving yourself of that sense that you might be to blame or be held responsible for your behaviour.**

***Let me declare an interest: I have an autistic son and a daughter with Ehlers Danlos, now in their early thirties. It has been a huge learning curve for me. The whole point about learning … very often with chronic pain there seems to be a ‘learning disability’. People are not connecting the dots. What I mean that very often you will have someone who does the over-activity/underactivity cycle, like a woman who cleans the house from top to bottom one day and can’t get out of bed for pain the next. But she can’t seem to connect her overactivity with her pain - she seems to have rebelled against it - and the obvious answer is pacing. Why don’t they get that for themselves? It’s partly because their attention span is very narrow so they live in the now and can’t always access what happened earlier to cause something. If you tell them that it is a causal relationship they may come back and say “oh you’re blaming me now - it’s my fault?” And they miss what they could actually discover for themselves.***

 ***Another other thing we can learn from autism is about perfectionism. An autistic child believes in a world that is wonderful, beautiful and perfect, and they want to be perfect. So when they a start to do something and have a failure, they give up. Most of us have to go through life with quite a number of failure experiences to get where we are and know that you have to learn from your mistakes, rather than being put off by one mistake. If they can get quieter and begin to join the dots up and risk taking steps into the unknown; very often they can’t read people and they don’t know what is going on, and it’s risky to go out and meet people because no-one understands them. So it’s a tough one.***

***There is a spectrum of autism and different levels of disability. A lot of people with pain have had trauma …***

***The thing about Ehlers Danlos - my daughter has every single kind of pain going from physical pain when her joints dislocate or she falls, when things like opiates help her get through the night. Since the opioid epidemic and NICE her GP took away the only thing that works for her; she is incredibly responsible how she takes it and knows the dangers, but she needs it for physical pain and an opioid is the only thing that helps. She had to move to another practice where the GP had actually taken the trouble to research what ED syndrome was.***

***[from Chat] A lot of assessors don’t ask what are the consequences – the costs – of performing certain tasks in terms of baseline function remaining sustainable***

 ***[from Chat] I am sure I had CFS prior to a diagnosis. If I had never had had it would I have got out of bed taken the children to school? Would I have used it to not so the parental stuff?***

***It’s of very variable severity.***

***Anxiety is an important adaptive survival reaction which we have inherited from our ancestors***

***You see a lot of conflicting different diagnoses from different sources and specialities.***

***Can we ask Jens and Jonathan what they have taken away from our discussions this evening?***

**JF: I was just reflecting about what I should write about all this. My first response is that I feel confused because there are so many strands and some of the statements regarding the act of diagnosing were contradictory. So I take away that there is some usefulness for specialists to define where people are on the scale; However they should not be the sole people in epistemic dominance. As Charles Rosenburg [in *The Tyranny of Diagnosis]*  said, we are people that are shaped by diagnosis but should not be defined. So there are differences between the active work of diagnoses and the identity formation they provide – their psychoactive property. Altogether is makes me question at what point is my work useful and at what point is it stupid and counterproductive.**

**JT: My favourite critical diagnostician AnneMarie Jutel from New Zealand says that a diagnosis is a superpower, because of its power to transform people and with great power comes great responsibility. So doctors should be aware of the impact of a diagnosis in terms of its transformative potential as well as the good or harm it may do. So we should think deeply about this.**

 **I think a diagnosis should be written in pencil so it can be rubbed out and revised at a later date, and we should be aware that a diagnosis can be sticky and what seems appropriate and helpful now may not be later on. It is a process and not a point in time. Diagnoses don’t come fully formed but they take shape and evolve and continue to do so.**

 **Finally, with something as complex as chronic pain the labels should be co-produced as a joint endeavour and shaped and agreed with the patient.**

***1.17 20***