Pain and Disability Research

Tom Shakespeare

I wanted to talk to you tonight about Disability Studies because not all of you may be familiar with it. So lot me give you a run-down on what the term means and why pain, which is reported by so many disabled people, is a missing presence in that debate.

History

What happened in the UK was that in the 50s and 60s we saw the emergence of lots of pressure groups and campaigns like Shelter that were saying that the welfare state although great wasn’t meeting peoples’ needs . Alongside this there were waves of activism which you can trace these back to the civil rights, lesbian and gay movements; the disability movement came along very much in the wake of those, with similar tactics and direct action. A slogan that is familiar from the disability rights movement is ‘ Nothing about us without us’. That comes from a feeling that only non-disabled people, be they parents, professionals or volunteers, have spoken for disabled people. So from all around the world, not just Britain or America, came this self-organised movement of disabled people. There were lots of groups that sprung up in the 70’s and 80’s which were coalitions of disabled people. By coalition I mean that they were cross-impairment, so they didn’t go on diagnosis but just on being a disabled person. Just as the Black civil rights movement doesn’t care where peoples’ ancestors originated, the disability rights movement doesn’t care what your diagnosis is , and indeed whether you have got a physical or a mental health, or intellectual disability- it doesn’t matter. So trying to form these coalitions - in 1981 the British Council of Organisations of Disabled People (BCODP) was founded. In those initials the ’*Of’* is really important: they were not organisations *‘for’* disabled people, they were *of*  them. And very important in the UK movement was the discovery, invention or creation of the social model of disability. The idea will be familiar to many of you that peoples’ impairment is disabled by society, not by their bodies and minds – or in additions to their bodies and minds. I think you’ve got a slippage; if you look at the history of UPIAS (the Union of Physically Impaired against Segregation) which was a very militant group; they debated a question and came up with the answer and if you didn’t agree with them they expelled you. It was formed by Paul Hunt who was a resident in a Cheshire home in Hampshire and an exile from Apartheid in South Africa. He was very powerful in the Civil Rights movement although he never actually wrote anything. [Vic Finkelstein](https://en.wikipedia.org/wiki/Vic_Finkelstein) and Hunt and other people were founders of UPIAS which came up with the social model that people with impairment are disabled by society with social barriers, physical access barriers, attitudes, lack of signage, poverty and all the other problems which you will be familiar with.

Social Barriers

What is important is the shift of focus from peoples’ bodies to social barriers. You are not the problem but society is. And society is bound to have to remedy the problem. You will remember where in the 60’s and 70’s when many disabled people were institutionalised and those who were not often drove those terrible blue mobility vehicles; if you wanted to travel by train you gave advanced notice and literally travelled in the guard’s van. So everything made you feel like a second class citizen. At the same time lots of disabled people were surviving which they didn’t before, not solving their problems but helping them to rehabilitate. Suddenly there were a lot of possibilities for participating which led to the emergence not just of UPIAS but lots of different disability groups. Another one is called Deliberation Network for People with Disabilities.

My reason for mentioning the social models of disability is really to try to explain how the disability studies research approach came out of that. So when I started my PhD in 1989 there was very little written by disabled people taking this approach, although there were a few books. And then Michael Oliver came along with a book called *The Politics of Disablement* which was very much about how people are excluded by those barriers

What is interesting is the attention given to society and away from body and mind, and the focus is not on things like pain or not a lot on individual things. I remember back in the day 1996 I edited a book about sexuality and disability and even that was thought to be personal and not experiential. We are interested in barriers. Mike Oliver was quite rude about that book because he thought it was too personal and said he wasn’t interested in disabled people telling their stories. Feminists said there was a split between private and public. But what I think disability research did was to look at the public side: employment, education, public spaces – it didn’t really look at the personal, private side. It recapitulated that split. Looking at sexuality and identity and so forth wasn’t very popular among the radicals because it was too personal. Even the personal experience of pain was not itself considered something you could do nothing about; it was in the biological box and ‘we don’t want to talk about the medical box. We want to talk about the barriers for disabled people’

I remember a very wonderful disability activist in Norwich who was chair of the Norwich and Norfolk Coalition of Disabled People I was a personal friend of his. He had a late onset muscular dystrophy. He used a wheelchair and suffered a lot from pain, including that from ulcers on his feet . We talked about Gabapentin and Pregabalin; Willy Notcutt prescribed Sativex (cannabinoid) and even that didn’t help. So we talked a lot about our pain. Once when we had been moaning and groaning about pain and went on the stage to talk and for him it was all about barriers: social, public, political; that’s what needed to change. When we came off the stage I said to him: “Hang on a minute – when we met as two individuals we talked about all the problems with pain” He replied “I’m not going to tell them that, only about the barriers”. He was a great man and I’m not denigrating him but reflecting that the approach of activists was ‘that’s public and that’s personal and we are not going to talk about the latter because we can’t change it. Only society can change the barriers.’ As I have said, from the disability movement and studies and the research approach inspired by people like Mike Oliver and [Vic Finkelstein](https://en.wikipedia.org/wiki/Vic_Finkelstein) focussed on disabling barriers.

Impairment

But for me disability is about two things: it is about barriers but also about having an impairment. And some impairment hurts. Pain is the most commonly reported symptom. Pain is the problem, not just for me but for many, many disabled people. And managing pain effectively is very important. You know better than I do that pain is social; it’s not just individual because of the barriers. It’s both psychological *and* social. We can meet the needs of people in pain properly or not. Many countries in the world do not have pain killers in the same way that we do, and we can campaign to change that; we can campaign for all sorts of things socially: we can campaign for more doctors or nurses or OT’s or physios who know about pain. There is an awful lot we can do to help people that experience pain which is social; it’s not individual. The division the radicals make between the medical model and the social model doesn’t really add up.

A lot of you are doctors or other health professionals and you will have talked to far more people than I have. Disabled people or people with chronic conditions don’t box off this or box off that. They don’t think in terms of separate categories. The idea is very useful, which came from these studies, that there is a medical model and a social model but as soon as you talk to people qualitatively either as a health professional or as a social researcher, of course they talk about all sorts of stuff, some of which you could say is medical, some social, but most of which is a bit of both. I remember examining a PhD by a researcher who was unusual in that he had had experienced a brain injury, so he had a lot of insight into his subject which was about people with traumatic brain injuries. He had interviewed a lot of people with brain injuries he wrote them up. He wrote a chapter about impairment and another about disability and another about barriers. And then he had a bit left over so he wrote another one about everything else. Of course the everything else is quite a lot because if it can’t be classified as medical or social it’s always a bit of both. Most of life indeed is.

Disability Studies

Where are we now at with disability studies? I believe in what you do. I don’t believe in the social model as originally conceived. I don’t believe in the dichotomy. I make my living by talking to people. And if you talk to people they respond differently. Like my friend in Norwich: when you talk to him he talks about pain and other issues but publicly he is all about barriers, discrimination and rights. Now, in Britain, but probably globally, we have different tendencies in the disability research world. We have one, which I shall call materialist, which very much follows that dichotomy between experience and barriers etc. There is also an approach, which I shall call constructionist, which is concerned with asking how disability is constructed. It looks a lot at culture, how we form our ideas about disability, particularly impairment, and it is very theoretically driven. As a result, what this fails to do is to consider people. And the people who follow this approach are very good on these big social and cultural forces, but not very good about what individual people think. Individual people don’t often think about these big themes. There is third group and you are looking at one of it - not just me but lots of people – who want to explore everything. This has been called … realist 18 26 disability studies because we think there is a real thing out there. The trouble is that the constructionists often lose sight of the real thing out there. They lose sight of the individual disabled by a combination of social and biological factors. I think it is really important, as it were, to look at pain in its social context and to think about all these factors I have been talking about, such as the variability of support, therapy or understanding from your GP; or what makes your pain worse? – is it your sleeping or your wheelchair and the bumps in the pavement? Do you need help in the area of psychological medicine? As well as all that stuff about medication. I think that is really important and it is part of politization. The good thing about disability studies is that disability is politicized: it says these are political choices about people who are suffering pain because they don’t have the right information - about the lack of analgesics in some countries, about the opioid epidemic in the USA or whatever else it might be.

A personal anecdote

I went to Guy’s Hospital recently for surgery. I took with me my Pregabalin which I take for pain twice a day along with a tiny dose of amitriptyline. The nurses confiscated that despite my protestations that it had been prescribed and said that they would get a doctor to re-prescribe it. They put a cannula in my arm for patient-controlled morphine. So I said “hang on a minute you’re allowing me to give myself morphine but not my own Pregabalin”. So I lay awake late into the night in pain because they couldn’t find a doctor to do the prescription. Another example: I had a three level spinal decompression and I was in a lot of pain on the third day post-op. The nurse said almost nonchalantly “oh yeah – people do tend to have terrible pain on the second or third day” When she said that I thought “oh- it’s not just me – it’s not that the operation hasn’t worked, it’s normal and what people should expect “. As soon as I understood this the pain didn’t go away but having put it in context I could cope with it. And I knew that it would go away in a week which it has. But why wasn’t I told to expect this before the op? That is what I mean by the need for better education around pain. I don’t want to criticize individual nurses but they were a bit blasé about the individual experience and what they could do to help. They didn’t give me all the information and they didn’t give me any control.

What can you – we – do?

I want really good research about the experience of pain among various disabled people. I would love to do a project where we interview disabled people about their pain: how it has been treated, when or what makes it worse, and what they have learnt, because a lot of people learn experientially about pain. They learn what makes it worse or better. I speak to my best friend twice every day, morning and evening. Why? I think it is partly because he had suffered traumatic paraplegia in an accident and, like me, incomplete paralysis – in his case one leg. People experience more pain when they have flu . I get more neuropathic pain as soon as my temperature goes up. Awareness of this doesn’t solve the problem but it does explain it a bit. Or you constipated? That might not be good for your pain. Have you tried pregabalin or CBD? How and when do you take it? did you have side effects ? Like with my friend and I before we went on the platform - we talk about pain all the time. And of course that can make it worse by directing attention to it, but it might help to find something that works for you.

So I want to talk to disabled people about pain. I want to politicise it in the sense that good communication , good medication, good psychological treatment and more *awareness* …

A lot of disabled people are trying to work, to learn, to parent - and all the things that people do in the community and yet are suffering pain at the same time. As you know, suffering pain all the time can make you short-tempered and tired due to lack of sleep. It may make some things impossible to do. Understanding how pain affects peoples’ lives; what workarounds they have for dealing with pain; what they do when it flares up.. These are profoundly social and political things. And the reason I speak to my friend Nick every day is because we often suggest things that might work to each other. We understand each other and we have the solidarity of people affected by pain. For instance, a long time ago I found CBD oil on the net, so I bought some and sent him a couple of bottles and he found it really effective. I don’t know whether or not this was placebo but it made a big difference for him. Doctors do talk to us about such things and that is very helpful but we lay people do discuss what works or doesn’t work and how we feel about it. I think that is political and should be part of disability studies.

Finally, you guys who are so concerned with the philosophy and ethics of pain – I know you do put people with pain at the centre, but it would be lovely if you were also to collaborate with some disability researchers. We need an alliance between pain specialists and people who experience pain – not expecting to solve the problem which will never go away so that together we can help people to live with it better.

Discussion

*How do you define disabled?*

There are obviously lots of ways of doing that. The whole point of the movement is that it is self - organised. And that means that it is self -defined; a disabled person is someone who believes they are disabled. Having said that it is not good enough for statisticians or researchers like myself. Globally, the Washington Group’s six questions short set\* are good, but none of them are about pain; they about seeing, hearing, self-care etc. but not pain. In a survey, the census that asked ‘Have you had a condition which affects your life for more than six months’ … some people are more affected than others and some say it doesn’t affect my life, or that it is a sociological problem, not a medical one. That is not to say that it is not real, but is not a disability as such. So there are different ways of looking at this. In my talk I was thinking about people with intellectual, hearing visual and psychiatric disabilities as well as people with chronic illness. A lot of people do not identify as disabled at all. When assessed by the DWP (Dept. of Work and Pensions) 50% of people classed as disabled, that you and I would think of as disabled did not identify as such. Aa lot of older people don’t identify as disabled –‘ we’re just aging normally’ – nothing wrong with that. It’s quite stigmatising to be identified as disabled , and if they can hide it they do. Ervin Goffman wrote that brilliant book *Stigma* in 1953 which is all about how you [?] pass as non-disabled but every now and again you can’t pass 32 12 because your health condition is a real problem in this context and you have to say I can’t do this because of my health condition.

\*<https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>

Many people with chronic health conditions don’t think of themselves as disabled. But if they use crutches or a walker and a venue is up six flights of stairs they are disabled. If people look at them in strange ways as if they are not quite normal they are disabled. If they live on benefits which may be cut they are disabled. Even if they don’t think they are, objectively I would class them as disabled. I did research with people with my condition (skeletal dysplasia with restricted growth) and a lot of them denied that they were disabled until they had skeletal or mobility problems. Then they claimed their blue badge; then they wanted to be part of that club. There are a number of people, especially older people, that I have encountered not using very straightforward aids and adaptations like wheelchairs or crutches, or hearing aids because they don’t want to be seen as deaf.

*You missed the conversation before you arrived which was about mental health and schizophrenia where there is the same false dichotomy between the biomedical and social models and I am very familiar with the situation in mental health assessment when the social worker says ‘oh, you are using the social model,’ and the Psychiatrist is using the biomedical model. Like you, I don’t like this false dichotomy.*

*Which brings me to a problem I want to share with you. Once a week I look after a learning disability/psychiatry hospital as a GP. Many of the long-term residents, who are loved and cared for, are non-verbal and I am often asked, when they are agitated or distressed if there is some underlying problem – maybe they are in pain? Of course that could be the case and the reasons might be because their wheelchair needs adjusting or they are not mobilising. They may be disadvantaged or unhappy with autism and have different sensory windows etc. But what I am dealing with and what makes a difference links a little bit to the problem you had in hospital when the doctor says “Pregabalin? We need to look at this … perhaps this isn’t suitable for you .. pregabalin is a little bit addictive etc.” I really don’t know how to pitch it right with these patients. Some of them come silent from hospitals having been over- medicated on sedative drugs or under-medicated and denied drugs that might be helpful. Sometimes you may need to say ‘ like everybody else you have to suffer and put up with it’. But how to say that is such a problem and I don’t know how to get it right. It’s not for the lack of trying because they are looked after … you can’t say ‘suck it up’ to someone who is non-verbal and cannot articulate their inner world.*

I don’t know the answer. You are right; when people are non-verbal and cannot communicate they may experience pain and other problems and not be able to express it. That must be particularly bad. I don’t know if there is a way of prescribing analgesia or other drugs for a trial period and if it seems to make them seem better from their behaviour … We know that historically there are lots of groups like newborn babies, women and slaves who were not thought to suffer pain btu now we are more enlightened. But I wonder about your patients who cannot express themselves but as you say you don’t want polypharmacy or to silence them with sedatives.

*[partly audible - gabbled]*

*I have a disability myself and I’m a GP. I was involved with a disability rights group back in the 90s led by ?McDonaldl? … he was a great man…realist approach. [guessed meaning->] Obviously that means that there is a underlying reality to be socially structured upon. There is obviously pain associated with disability but what about pain as a pure condition in itself? Can chronic pain be a disability in itself ?*

If a condition has an impact on somebody’s life – if it renders them housebound or makes it difficult for them to participate then whether if is of psychological or sociological or biophysical aetiology which obviously matters for how you approach it, in terms of those person’s lives it is excluding and needs to be attended to and you would use different approaches. Remember, disability includes people who are thought to be disabled but aren’t. So there is a sense in which people who think they are disabled but aren’t and if you are trying to alleviate their distress it doesn’t matter where the distress comes from. But you would still say let’s get to the bottom of this and work it out and try help you with it, be it with counselling or drugs or whatever. Whatever the problem it is real and rendering them unable to participate. Surely it is our goal that people can participate or interact and are able to exercise choices about their lives in the same way as others. Of course lots of people can’t exercise their choices but if we put them on an equal basis to others - I in a similar situation other people are not limited - then we need to attend to them as if they are disabled.

*The theme of your talk seems to be about insiders and outsiders. Do disabled people have special insights that non-disabled people don’t?*

No, I don’t think that is true. Anybody can assess disability. But if you don’t have a disability … if any of you were to say tonight I want to acquire the necessary insights I would say you need to talk to a group of disabled people because they will have ideas and experiences that might be helpful ….

*…?… it’s in several languages…. You get special insights. You experience yourself …. A fundamental distinction in the social sciences …*

*What have you written about the subject of tonight’s talk?*

… a chapter on pain … and I am co-writing a book with my friend Nick Watson who also thinks this is important… I know pain in a particular way because I experience it but you folks know far more about it as you are specialists. I have many books on the subject - and I had a very helpful time with some of you in Cumbria – but I am still on a journey. I have my personal experience of pain which I can’t always put into words. But when read about it or see a specialist I sometimes think *that* person understands and can help me. I don’t think they need to have experienced pain; maybe they know a lot of pharmacology or neurology or psychology or whatever …

… *My point is that there are different kinds of knowledge*. *There is a trade-off between means of communicating; I think there is a false dichotomy between the medical model and the social model – there may be heuristically or conceptually but not in practice because the medical model, at least in the US holds sway. You can have chronic pain which might be highly associated with something like abuse or you have lost your job and are in economic despair so statistically you are likely to have chronic pain or a similar problem – it’s like rain: we know it’s falling be we don’t know who will get wet. So for instance if a plant folds in Detroit we know there is going to be a lot of pain there. In the US this will all too often be treated with opioids.*

*I do think there should be more interaction between people with chronic pain and people like you and me (an academic and a sociologist)*

*Can I make a plug for this book* Innovative  *Approaches to Chronic Pain which is a compilation of essays by former speakers at our SIG meetings including Tom ….*

… It’s a very good book! …

*… And the royalties go to the SIG funds*

*I am a GP trainee in North Wales. It is a strain for a GP, especially a trainee, that you are constantly trying to understand other peoples’ perspectives and where your patients are coming from. I think this session has highlighted how woefully ignorant I am of the whole swathe of history of social reform and movements.*

*I had an interesting experience – you mentioned your experience in hospital when the nurse said “this is normal for day two”. Having recently been a hospital doctor myself I definitely observed that phenomenon and wondered why we do that. I think it’s because when you see the same thing over and over again you think – forgive me – that by day four you are going to be fine so it doesn’t really matter; your pain on day two is inconsequential because on day four you’re going to be fine, on day five you will be home … so none of this pain really means anything. That is obviously not a kind way; people get desensitised – and I wonder whether with chronic pain we go “well, we have done the research, we’ve read the books, we know that these painkillers don’t work etc. And I wonder whether that is something you have reflected on yourself and whether we can better bring people along that journey with us so they recognise that we are not just saying come to me as quick as you can, I want you to be better, trust me it will be fine… as you walk with people on that journey.*

I wouldn’t want you to think I am criticizing any of my doctors whether GPs or specialists because I have always had very good treatment, particularly from GPs who really know their patients and see them regularly. My dad was a GP. But I think we need to empower patients. We need more health literacy among lay people. You are right - they probably were blasé – but at that time – I know I’m an academic – anybody would surely benefit to know that this is normal, it will pass, and it is because the body reacts so badly on day 3. If I know this is likely and know why it is happening I can think OK, I can deal with that. It is useful to know the trajectory. I have been in hospital for surgery in 2008 and again this year, and neither time did anyone, nurses or doctors, take the time to tell me what they knew.

An example: when I was in the spinal injuries unit (with a non-traumatic spinal injury) there was a folder on the wall behind me which said ‘sexuality and spinal cord injury’. I thought that’s very interesting and of course most men – indeed most people - will worry about that but nobody told us anything about it. So I asked if I could read it and the guy in the next bed wanted it after me. Of course we were worrying about it, and they should have had a session giving us some useful information. So my experience from being in hospital is that you are not given useful information.

*As I understand it your condition is both illness and identity, and for some people it’s more of one than the other. I have friends: a family who are pretty autistic but refuse it as an identity. But it is disabling because they are not quite functioning. I know other people who are politically active and fight for neurodiverse rights and so on, so for them it is firmly identity. And I know other people who feel that their disability is sometimes more of one than the other, and may feel quite different one week for another. You can feel highly conflicted if one week you need social accommodation and the next you have an illness which is making your life miserable and you want something to treat it. But my other experience is looking after people with chronic pain who strongly, and in some cases viciously reject my attempts to normalise their experiences of pain. They may say “are you trying to tell me that this is normal?” - usually when all their investigations have come back as completely fine. And they are still in pain. The last thing they want from you is a lecture about the neurology of pain experience. They want sine validation in the form of an illness. I am more inclined to a social model than an illness even though I am a doctor . These days I find increasingly that patients want their suffering validated from an illness model, which is why they are at the doctors but not at the hairdressers, when I am trying to keep it in the social. That is probably one of the hardest things I have to do as a doctor. And I wonder if you can help me from your perspective.*

I am interested in the ‘one week illness next week identity’ pattern. I think that’s right. My friend who exposed his pain and problems to me in private but wouldn’t talk about it in private probably has times where he will make a political statement and others where he wants to remain private. I haven’t given you his name as he was talking to me in confidence as a fellow sufferer. It is really difficult. You talked about two cases: I presume the autistic family would have some sort of certification of their autism? In the world of neurodiversity, many people say ‘we are just different – we are not ill, we are not disabled, there is nothing wrong with us. It’s the same with a lot of conditions. I remember having a big argument with the mother of a girl with Down’s syndrome who said “ Down’s syndrome isn’t a disease!” - I said “well it is”… “ it’s just a social … “ , “ but there is a difference: people with Downs have a higher risk of developing dementia which is a biological thing and the consequence of having an extra chromosome. In the Covid pandemic they were 30 times more likely to die than others.” There is a real biological basis here even though she was right to seek acceptance and inclusion for her daughter. I many of these situations there is an unhappy combination of, on the one hand a physical health condition wanting to have civil rights. I think we should have both; we should say people deserve civil rights in a better world whether or not they have an impairment. At the moment I work a lot with people with dementia which is a veery real biological process but they also fight for the right to be heard. These are obviously people with early stage dementia and it is amazing and inspriring what they do. But they never deny that dementia is an illness which is bad and they would rather not have it but having got it they want to be heard.

*The flip side is that there are probably at least as many people who demand too little in the way of treatment – people who are severely disabled who suffer without complaining out of pride or stoicism. There may be at least as many of those who perhaps I worry about more because I don’t see them than the people I do see.*

I think both sides of the equation need to discuss with us in some forum what’s going on. The people who are undermedicated are either too proud or don’t want to express a disability label or don ‘t want to bother the doctor should have a non-stigmatising opportunity to try medication. The people that want an organic diagnosis but may not have anything organic wrong with them: I would like them to explore why it is that their distress, their exclusion, their poverty, their lives, are manifested as somatic pain. Everybody with CP wants it to be biological, they don’t want it to be ‘in the mind’ which implies ‘not real’ . We have a job to do to explain that ‘in the mind’ is real, it’s important and needs to be addressed; there is nothing stigmatising or wrong with it being a psychological process. That doesn’t mean we are not going to try to solve it, but it does mean we might have to use different methods. The key is trying to get away from the stigma.

Remember we have a political system which tends to stigmatise people who claim benefits for disability, talking about ‘shirkers’, so many people feel immense guilt at receiving benefits or help. The welfare reform process … there was a project in Glasgow which looked the coverage in the papers of people who claim benefits, and talked to groups of disabled people who claim benefits. They found that the strong disapproval from society about receiving things that were thought not to be theirs. So there is such a lot of stigma. One of the people interviewed reported that they were about to get into their car which they had got through disability living rights or something, in a working class estate. A woman came past with a child in a pram and said: “I paid for that car! “ , meaning the benefits came out of her taxes The person was speechless and it was a horrible thing to have said, implying that he didn’t deserve it. Perhaps he should have looked at the baby and said “ I paid for that!” – she was claiming child benefit - nothing wrong with that and it is to do with the social contract in a society which helps people who need help.

*First a comment about ‘all in the mind’ - i.e. ‘psychological’ . You don’t even have to use that term because basically we don’t really know where the hell it is when we can’t find a pathological cause. We are creating this myth of the psychological. We should just accept the reality of the pain as a symptom and just admit that we don’t know the cause.*

*There is an interesting guy in Edinburgh called Jon Stone who is a neurologist with an interest in functional neurological disorders. He doesn’t say ‘this is all in your head’ ; he says ‘you’ve got this thing that we can’t find a nice tidy diagnosis for. It is somehow your nervous system malfunctioning giving you these symptoms, be they pain, ataxia or whatever\* So it lets everybody off the hook.*

*[gabbled – words guessed] …. Changed their concept of obesity to a disability … already there are moves to make it into a disease … and pharmaceutical companies would love it to be a disease … The problem is that if someone defines themselves disabled because of obesity that implies that other people have the disability. You can say that there are limitations for people with obesity but I would say that is to stigmatise them. I am going round in circles here but I am curious to hear your perspective on obesity as a disability.*

There was a paper ‘ Can a fat woman call herself themselves disabled’ By Charlotte Cooper\*\* I don’t know and I almost don’t want to go there because there is a problem with obesity and rights but I don ‘t know. But I would imagine that for people with morbid obesity there are, all sorts of social stigmata - lack of space etc – by which the lives of people with obesity are made harder many of which are …. and could be solved. I agree with you; I would want to help them to be less … and there might be ways to do that. But along the way we should be less stigmatising and more accepting.

\*<https://doi.org/10.1136/bmj.m3745>

*Written by Stone mainly for non-specialists and patients but well worth a read. Much of it applicable to chronic pain*

\*\* <https://doi.org/10.1080/09687599727443>

*Of course it’s in the mind the same way that the colour green is in the mind. The other aspect is the perception of blame; “I’m to blame for it am I ?” – without any idea how they might have been to blame because they can’t see a causal link. But if you step back you can probably see one. Many people in pan are focussed into a shorter time-frame and to link it in to a higher event way back … but if they feel blame as a personal attack or that they are somehow inadequate – they have no idea what to do about it. And unless we can give them something to do - and there are things - we have to be very careful about our language*

There are a lot of things on the margins of disability, and different opinions as to whether they should or should not be regarded as such and I would certainly include obesity in that.

Lots of things are medicalised nowadays like bad behaviour or grief and some of them might be so regarded with advantage.

*Going back to this business of saying ‘it’s all in the mind’ : the problem for the patient is that just saying that doesn’t help them; it doesn’t make the pain go away and doesn’t give them any clues as to what to do about it, or any control whatsoever …*

*… GPs wouldn’t say that …*

*… … I’ve heard of it lots of times …*

*Of course it’s in the mind the same way that the colour green is in the mind. The other aspect is the perception of blame; “I’m to blame for it am I ?” – without any idea how they might have been to blame because they can’t see a causal link. But if you step back you can probably see one. Many people in pan are focussed into a shorter time-frame and to link it in to a higher event way back … but if they feel blame as a personal attack or that they are somehow inadequate – they have no idea what to do about it. And unless we can give them something to do - and there are things - we have to be very careful about our language.*

We do need an alliance for people in the disability world and the pain world to talk to and learn from each other – an opportunity which you have given this evening and for which I am very grateful. I would love to have one of you to talk to a conference or seminar about the social context of pain.

j