

Webinar discussion 14th December 2020

Self management of Chronic Pain: a critical appraisal

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Her current DPhil research project is focussed on: - Exploring self management of chronic pain

First I want to tell you a little about myself. I am a physiotherapist, originally in MSK practice but I got a little disillusioned with that mostly biomedical approach. I was working in inner London and found that many of my patients had interesting stories that I couldn't use in my practice. At that point we started running pain management groups with a psychologist. But we were working in a culturally diverse area of London and found that we were having to translate; for instance, what the BPS were saying about format and what we should offer which was a bit sparing about detail, and our straight translation was not culturally competent. After about two years we started noticing that our therapists were not referring our main clientele to the group. Out of a diverse population they were only referring well-educated white British people. This didn't match up to the one-to-one sessions I was having which were often quite harrowing and about trauma and torture and poverty and all these complex issues.

At that time I did an MSc in pain, science and society to try to better understand this population; but on reflection I think I learned a lot about pain science but almost nothing about society. It was quite good to have that knowledge but I didn't know where it could fit with my lived experience with my patients.

In time I moved on to my current job which is with inpatients in UCH London. It is a rather bizarre kind of service where we offer a multidisciplinary approach - not just to pain - to patients with complex co-morbidities and are struggling with their admission. We follow them when they leave hospital which is unusual for a lot of my colleagues. We try to talk to GP's to gain some of their insights into ways we can support each other. Through that kind of process we can talk a lot about self-management. In MSK we used to write discharge letters to the GP's; I don't know if they ever read them but we thought they would be very helpful. They said "this patient has completed their sessions with us and are now successfully self-managing ..." I continued to do that even in my triage clinics. The goal of treatment was always self-management. I never really interrogated this until I was in tertiary care where I was working a lot more than before with my medical colleagues. They used to say - and still do - "this patient needs self-management; you take them." I was never sure quite what that meant but the term crops up a lot in our policy documents and NICE guidance and even documents from the BPS and the Faculty and the Physiotherapy Pain Association. It seems to be assumed that we all understand.

So I started asking questions about it and decided to do some clinical research around it. Because of my desire to understand complexity I have always been reluctant to do research on the usual model of trials and systematic reviews and stuff. I am more interested in people, their experiences and the messy reality of life.

Rather than removing variables I'm interested in including them so we can better understand people. I'm doing my Ph.D. now; the question I originally thought to explore was about self-management but over time I've gone back and asked 'what, actually, is this thing called pain management?' So I am starting to look at some of the narratives in the literature, in our daily lives and the policy; and around clinicians and patients ... not necessarily patients but people who have lived experience of distress and chronic pain. In the last couple of months I am starting to understand that we are not talking about the same thing in any shape or form. Even within my own team, when I have asked doctors what they mean by self-management, they say – you know, physio and psych. So I say those are professions with lots of different subspecialisations. I have started to look at discourse and language and how language can convey power, and where these ideas and assumptions have come from. Based on my preliminary work with qualitative data from interviews and observations and a lot of documentary analysis, the key thing that keeps coming up is that 'self-management' is used, for example within most pain clinics, as a proxy for anything that is non-medical. But even within what is supposed to be 'not-biomedicine', the structures are still focussed on neurobiology and pain science, which is still very much focussed on a biological understanding of the problem. You can still fit in behavioural and social perspectives but no-one ever talks about the other aspects ... you can try and understand these things within neurobiology but for me it's lacking something. Going down to the cell level is helpful but doesn't help me as a clinician with the person in front of me telling me about Universal Credit cuts and housing and healthcare and all the messy stuff. The reductionist neurobiological model isn't enough to help us understand the whole picture, but it is still very dominant within pain physiotherapy, for example.

Psychology within pain management is basically behavioural and based on personal responsibility and not necessarily on the societal structures that might have led someone to be in the position they find themselves in at that individual time. Things like cognitive therapy and contextual behavioural therapy are still very much focussed on changing an individual's behaviour and not everything else that is going on around them. This aligns with some newer critiques of the biopsychosocial model which suggest that we are using the name but have lost its essence, and that it is the wrong model for understanding complex chronic pain. There is a lack of scrutiny among clinicians so we are missing the things from that dialogue. The world outside quite a small bubble still adheres to a biomedical model of pain. But I have learnt from patient advocates, people with lived experience, who have gone through what we have labelled self-management programmes, that when we unpack that we find that people have experienced completely different kinds of interventions and interactions with professionals. We have lost the nuance of understanding what people are doing, and what is working best for whom, under this umbrella term of self-management.

When I looked further back into the history of the term self-management, I found that the literature never seemed to refer to it as a concept. What seemed to have happened was that sometime in the 2000's Green and White policy papers started to refer to 'self' approaches; self care, the self as an expert and 'personal' responsibility for things. Things like the NHS plan and the Chronic Conditions model all started talking about self-management. It turned out that the reason for this was that a group of politicians went over to the States and visited something called Kaiser Permanente where they found the Chronic Disease Self Management (CDSM) course which they liked the look of and imported it in its entirety into the NHS where it

was called the 'Expert Patient Programme'. Unfortunately that didn't seem to take off very well here, particularly because the context hadn't been attended to. The support was offered in the American context, and what was missing was lots of care co-ordinators and payment systems and so on. Here it was presented as a peer-led service for multiple conditions but without the required structural support. When we looked at it in terms of pain the outcomes were really poor. The message seems to be that you can't ask patients what to do because they are going to get it wrong; we have tried the expert patient model and it hasn't worked, so that kind of fizzled out. But what has emerged now is something really powerful, which is that as the evidence that things like medication: opioids, benzodiazepines and gabapentinoids appear to have become less 'clean' and acceptable. Injections and spinal cord stimulators are being scrutinised. So there is a shift beginning. Pain Clinics have gone from being perceived as the be-all and end-all to a model of care which is a little more humanistic. It is saying that we can think more about communities, the environment that people live in, their connections, their network, their histories, their futures; how so they think about their bodies and themselves.

So I think I am noticing a shift in the discourse but only in certain camps. If you ask anyone in a pain clinic the world is still lovely. If you ask people doing a more comprehensive programme their language is starting to change a little. We are questioning the orthodox professional powers - just because a psychologist or a physio says something it doesn't make it true. Then when you look at where the funding models are going; in the English context, anyway, providers are getting reluctant to dole out large sums of money to an intervention clinic that doesn't seem to be delivering at a population level. What struck me most is that even the tertiary clinic for pain I work in turns people away. There are loads of us but we don't have an OT in our clinic (I note that although others do but they are falling out of the discourse) When we get a complex referral with trauma and other difficult issues, and have multidisciplinary team meetings, sometimes people will say "not for us". So the question I would like to invite some interaction on is this: if the people who are supposed to be specialists are turning people away what then? I am also very aware that if we see people and they attend a programme or do an intervention then we discharge them and I don't know where they go; we never hear from them again unless they get a referral somehow through the system six years later. It's not like *any* other long-term condition like diabetes where you would someone to have ongoing contact with the health system throughout their lives to help them to truly manage their own condition in collaboration with skilled professionals.

So that's where I have ended up with pain. For some reason we have moved from a supportive environment to buying into a personal responsibility model that is aligned with other thinking like in preventive health and obesity.

Discussion

(Contributions from the 'floor' are in italics)

Is one of the problems with pain that it doesn't fall under any particular speciality? Physio and psychology have kind of taken it on but that excludes the fact that so much pain is neither musculoskeletal or psychological; most of my chronic pain

patients also have gastrological or autoimmune diseases as well. Is this your experience?

Yes. Most of the people in pain medicine are anaesthetists who train with biological systems and don't spend a lot of time talking to difficult patients. They do one year of pain training but in my institution they spend a lot of that time learning procedures and not a lot on medication, unlike rheumatologists who also see a lot of pain patients. A lot of our patients come from gastroenterology. The Faculty of Pain Medicine have released a statement saying they are the experts. There is also conflict between different branches of psychology. OT's are hardly in the conversation. Some people want a piece of the pie and some don't want any!

That is my experience [in General Practice]

When patients are discharged they go back to the GP

GP's do a lot of work extending the network, not necessarily using healthcare as a place to manage pain, to include something like a wellbeing clinic. There is a lot of local knowledge about things that aren't in the healthcare system.

I used to run a wellbeing clinic outside the NHS with a very valuable ongoing support group, but I found that they ended up with the people with the most complex problems who had been turned away by the pain clinic. It was soul-destroying for them. They were getting letters saying you don't fit our criteria.

I want to comment on the issue that there is something wrong with a clinic saying we don't have the ability to care for you. As a surgeon I don't think anybody wants me to provide care for somebody I know I can't help. We would consider that malpractice. If it's true for surgeons why not pain specialists? They might say that we don't have the resources; the rebuttal is of course that you should have the resources.

The biopsychosocial model was a giant step forward when it was first conceptualised but I think the time has come to change it around and call it the sociopsychobio model because putting bio first pre-empts the other two which are far more important.

Our service is a bit of an anomaly as we are not run by a psychologist nor a medic, which gives us the freedom to be more flexible. Even if we feel that someone might not be very suitable for a programme we hardly turn anybody away. It is ethically wrong to deny people rehabilitation whatever their background

There are funding issues and a power dynamic as to how services are run.

Changing the biopsychosocial to the sociopsychobio model (which I already tell my trainees to do) has huge implications. I presume most people here do work on a medical model which has limitations and affects the way we think about it but it is the culture we are enmeshed in. We have psychiatrists and psychologists within our pain centre and we do spend a lot of time discussing these issues. I'm one of these anaesthetists who came to this via injections and pills which I found of limited use. Some of our patients do have big social and psychiatric issues but if we throw

people back to their GP's they tell us that the demand for mental health resources is such, and giving everyone their own talking therapist is so labour-intensive and expensive, that the system is never going to provide for the need. A lot of my chronic pain patients would find that this model of psychological help for ongoing need just doesn't work, either in pain or mental health. So where do we begin with this? It's such a huge problem. No simple fixes are going to work. We don't have the resources.

People with a bio issue are well catered for and the system is geared to that. There is a huge triangle of pain in the population with the service provision as a tiny bit at the top. Is this a societal issue? Is pain a grand social challenge that we need to innervate in our thinking. Do we need to step outside of our purely healthcare space? Can we be more creative?

In defence of us anaesthetists I would say that we do have our uses but they become much more limited as time goes on. There are quite a lot of patients, mainly those with acute back pain, who might benefit from some sort of intervention early in their pain career, ideally to facilitate physiotherapeutic endeavours to halt the slide into chronicity. But even when you get referred to a pain clinic it may be at least a couple of years and often five or more before you get there by which time all the other problems we have been talking about and that some people are particularly vulnerable to are firmly established.

I'm doing an audit of all the patients with chronic pain in our 13,000 patient practice in East London. Only a tiny proportion – about 150-200 - of them are coded as having chronic pain in their medical records. There are another 600 who are on opiates, gabapentinoids, tricyclics, duloxetine and other medications which might suggest that they have chronic pain. So I am going through all their notes to try and work out which of them do actually have it. Typically you will see someone with acute back pain multiple times in their records over twenty years. Of my own patients, nearly 100 whom I know well, almost all have a background of complex trauma or toxic stress. But although they have chronic pain a lot don't have a psychological diagnosis. I think it is really important that pain is held in the body and the body keeps the score. They might have IBS or chronic pelvic pain or addiction problems, but they don't necessarily meet the criteria for any psychological disorder and there is no way of coding complex trauma or toxic stress.

So there is a real problem in identifying these people and I am very cautious about the idea that it [trauma] is framed as a psychological problem as it is almost always physiological.

The other thing is that I am becoming increasingly convinced that auto-immune dysfunction and autonomic dysfunction is a prominent feature in this, and again is sort of sub-diagnostic, so most chronic pain is hidden and we are trying to shine a light on it and find a way of helping people, but I don't think it is through psychology for most people.

I feel that as a physio I am a bit of a Trojan horse because people are more likely to talk to me because of my job title, so I can talk about embodied experiences. I may not talk about tissue damage but I am always talking about a person being in the world and doing things. My psychology colleagues don't have that luxury. There is

always the risk that 'you need to see a psychologist' will be heard as 'it's all in your head'

What are your thoughts on supported self-management?

I struggle with that at the moment. It is an evolving process. We don't even agree what we mean by self-management let alone by supported self-management. It's a construct that has been created to summarise a lot of complexity. The work they do in one centre might not resemble anything they do somewhere else. We miss out in the opportunity to share and compare what we are doing, or giving a choice. Is there an appetite for unpacking complexity? – or involving communities?

As a person living with pain, who has done a lot of work in community and run a mental health charity, I see the other side of it. I see people who can't get to pain clinics who have either never had much help or have had it and then been discharged. With all the societal and mental health problems and financial constraints.... there needs to be a look at the full picture. But it is such a huge problem.

Regarding community: the concept of the self as it has grown up in the West can be very limiting. One of the best things I have seen is the promotion of peer support groups. With proper support that can be long-term. A doctor they may not know a person's background and there is a power balance between doctor and patient. Now there is a great opportunity to use social media and the internet to get better support groups in which professionals are involved, and break down some of these barriers. There are lots of models in mental health we could take on board

Secondly, we are indeed all embodied beings, in our heads and our bodies. There are a lot of psychological and psychotherapeutic treatments to which embodiment is essential

I have worked a lot with peer support groups (with professional help) and agree as to their value and that we could learn a lot from mental health. But they don't work for everybody. People in pain are such a diverse group with different needs that it needs a diverse approach.

I am a liaison psychiatrist at the Royal London Hospital where we work with a lot of people with chronic body pain, and I see a more psychologically impaired sub-group of those people. They are starting a range of self-help interventions at the RLH. My understanding is that there is a budding sense of responsibility and ownership and even if it isn't a living aspect of me it is still something I can work, interact and live with and relate differently to. I am very interested in embodiment but there is something about the converse, for instance if I'm feeling great my posture will change ... it's a two-way thing. There is this possibility of one affecting the other to be exploited.

Regarding support for groups: they can get stuck and it needs someone to break the internal dynamics which can be helpful. But people respond differently; for instance some people I have sent to the pain management programme come back and tell me it was really good but they don't all change. It's very individual but there are some principles about relating to ourselves and other people which are important to keep in mind.

Can I draw your attention to this paper by Simon Fletcher and Stefan Kulnik from St. George's in London *The problem with Self-Management*, in the context of stroke rehabilitation. The problem is the power differential: I tell people to do what I have conceived in my world. This may work in the biomedical world where we need the experts but if we are attending to these human aspects of care we need to emphasize the 'human' more. If supported self-management is still 'here is a bunch of things *I want you* to do', even if this is grounded in solid reasoning, we need somehow to strip the power out of it.

The phrase self-management speaks to me of business models and the way in which efficiency is promoted, implying 'how do I manage myself in an efficient and timely way'

Regarding complexity and community: do we need a complex fabric to hold together the complexity of these individuals; do we look at people who come to tertiary care with too narrow a lens? The skills within those structures are brilliant but are they failing to serve these people because we are trying to fit a round peg into a square hole? Do we need to relinquish our tools and admit that we don't know? – and acknowledge that the skills we need are outside of our remit? But this is not to say that you can't access this service. Perhaps social prescribing of other services in the community would make the net bigger.

I am a somatic therapist and I work with embodiment. This is a skilful practice which is relational. As an individual therapist working with a client there is a willingness to open your own experience to that shared experience and be touched and moved by it; to create a safe container for that individual. I wonder, as a clinician, whether we are prepared to open ourselves to feel and moved by the response to some of the distress we are holding or coming into a relationship with. Embodiment is important because it disrupts the individualistic notion that the client is dealing with the issue on their own.

As Professor Loeser said, it is time, if we want to deliver high value pain care, we should be looking at sociopsychobio. There was an article in Pain Medicine in January from Phoenix Arizona on high value care recommending this.

More than 60% of pain clinics in secondary care are skeletally staffed – some with one consultant and one physio, and perhaps psychology as an intermittent bought-in service, and most psychologists are stuck with CBT or ACT [acceptance and commitment therapy] and unwilling to try anything else like grounding therapy or somatic therapy etc., all things used for trauma. A tertiary care service really ought to have every profession under one roof but may be geared only to neuromodulation. So I agree with Prof Loeser that if we don't have the skill set it is probably safer to say we are not in the right place to treat pain.

A strategy I might look at in my own service is to say to the commissioners: "Look – I have got this complex patient with a sociopsychobiological problem for whom opiates would not be a good idea and I don't have a suitable intervention. They need different and better care, be it social prescribing, health coaching, counselling at home, etc., and if you want me to provide it give me the resources."

Do we look only at individuals or accept that individuals live within a society or community? We need to get everybody singing from the same hymn sheet. I am embracing trauma informed care this end. There are risks if this is not done well. Perhaps the Frome model of a community based approach should be an aspirational

model. This originated in the town of Frome near Bath, some years ago now, where the GP surgery identified a lot of people they couldn't do anything for so they developed a network of groups for community health within the town, and also trained individuals to be community links. It was all centred on the practice and people with problems such as loneliness, which was very prevalent, or with mobility or other social difficulties, could be referred to an appropriate group or agency, such as a food bank. They reduced the acute hospital admission rate in the town by about 30%.

There is an inspiring podcast of an interview between Dr Rangan Chatterjee Dr Julian Abel (one of the co-founders of the Frome project, about compassion and social relationships. You can find it here - <https://drchatterjee.com/the-healing-power-of-compassion-with-dr-julian-abel/>

That's the most exciting thing I have heard in ages. Having worked in a pain clinic for years and become disillusioned with a lot of what goes on, the model you're describing is what we need throughout the country. Why have they not been able to roll that out to anyone else?

They are – all over the world!

It needs a cultural change – which that practice has achieved. I have tried over the last four years.... I know many of the social prescribers in my area and we have talked a lot. We have used community support groups. I have interacted with health coaches We have tried to work with Reading, Newbury and other councils in our area and organised charity events to promote patient awareness. But it takes time – it has taken me three and a half years to build that kind of network. One problem is the perception of the pain clinic as the province of 'pill mill' dispensers and needle jockeys. I want GP's to see that there is someone in the Reading pain clinic who can be trusted to do something more.

In our area they have decommissioned injections and come down hard on medication. I could have had the option of going off into private practice or medicolegal work, or taken a harder look at what the patients need or how I could be of any value to the community. I have taken the second option; it's not been easy ...

It's a very brave and moral thing to do.

It's a very hard fight for anyone who wants to do anything different.

We should all think about context. We keep hearing about local initiatives but there isn't a pot of money. The commissioners only know about what is presented to them but this is unfortunately often only the NICE guidance which is only based on a certain type of evidence, so these stories of success aren't being picked up at the policy level. So there is a responsibility for pain clinics as leaders in the field to connect with some of these services as Deepak has done. It's hard to change what you have always done particularly if it is prestigious and 'shiny'; the community stuff might not even be classed as an intervention. It may be valuable but not valued. Perhaps if we do different types of research, perhaps involving our public health colleagues. It's not a one size fits all ... we need to be open to all possibilities

We are often undoing false perceptions, or trying to reset the thermostat for the patient that are referred to us. Typically patients are told "I'll send you along to the pain clinic – you need some injections that will sort you out." So it is hardly surprising that people come expecting their pain to be managed by the clinician, not by themselves. So it is turning everything round. In a sense self-management means putting up with it and finding ways to cope. The textbooks don't say anything about that. Anaesthetists' training is all about the opposite to self-management and we need to undo a lot of that before we can make any impact. Following the NICE guidelines that I now can't refer people for injections - I never did very much anyway – has made me think about working very hard on helping patients with understanding their predicament. This often leads to the response "it sounds like I am going to have to put up with this?" My answer is "yes! - that's the whole point about chronic pain; so how can we help you to do that. So that is where these other strategies come in, be they psychological, physical or social or whatever; they are working from the point that chronic pain is chronic.

Self-hypnosis is an important component of self-management of pain. If you teach people to self-hypnotise and use their own creative imagery – and people come up with some fantastic metaphors – you can actually enable them to reduce their pain and suffering with something that is under their own control.

My background is in speech therapy and I work a lot with children with special needs Can I ask: if we have a complex young person we will often hold a multidisciplinary meeting of teachers, physios, OT's and doctors and social workers ... housing: all the professionals working together with that child and their family, and often with the child itself, to work out a way forward. But that doesn't seem to happen with adult care, does it?

It happens rarely. In my role ... the GP's have what are called agency meetings and we go and crash them and bring our people with us. For instance the ambulance service may ask: why does this person call the ambulance all the time. We bring in the troops from another side

We have those as well in secondary care. We have teams to work with people who frequently come into hospital and see how they can be supported. That is a more compassionate way to work.

As a pain patient one of my problems was a lack of co-ordination; none of my carers seemed to talk to each other. There was never a full multidisciplinary team involvement. If there had been it would be cheaper than the NHS.

My understanding of the MDT is that it is (a) a question of responsibility and (b) of environment. The patients I am involved with often have learning disabilities or problems with mental health. The feeling often is that it's not really their responsibility and we have to change things around them. That happens more with younger people with learning disabilities but also where there is significant risk of suicidality or homicidality.

It sounds like there are pockets of desirable practice but there seems to be something stopping the diffusion of innovation. Some people seem not to be in that

head space ... "that's a lovely idea for someone else to do ..." Is it possible to generate more discussion?

Where do you think this change should arise from? It's very difficult to get anyone in tertiary care to listen. I have been banging on about it but it seems to be beyond peoples' imagination. I suspect the drivers may come from primary care, patient groups or the community. It's not going to come from secondary care; we are all going to have to be dragged screaming into this brave new world and it's going to be a shock.

Even the team I am in was set up following a lot of work by primary care and charities and we get to do all the fun stuff but every time we recruit new people it reverts to "why are you going on a home visit?" Every time we have a staff turnover that initial innovation defaults back to 'they come and see us' instead of 'we go and see them'. We do creative, relational stuff.

The rise of patient advocacy over the last 18 months has been exciting. It needs to get GP's attention and drive commissioning. It has got to be a ground up approach. I have been talking to GP's in recent months saying I want to change the concept of the pain clinic which is seen as DFY (done for you) with a very little DIY to DWI (done with you). We can't suddenly try to go from DFY to DIY without instructions, videos etc and all the support systems. So we need to create an ecosystem that supports DWY and facilitates DIY in a comprehensive way. The resources brought by the pandemic to help this have been great and we need to capitalise on the new power of patient advocacy to achieve change.

The revolution starts here!

Points from Zoom chat

Does physio and psych locate the problems of pain in the certain parts of the body - MSK and psyche alienated from others e.g. neuro-endocrine-immune? Does self-management locate the problem in individuals alienated from relationships with others and society?

Are pain clinics like Felitti's obesity clinic? Effective only while people are there?*

Self-management does not take into account systemic problems, social deprivation is linked to higher levels of reported pain.

[recommended] paper from Peter Stillwell on enactivism: An enactive approach to pain: beyond the biopsychosocial model: <https://philpapers.org/rec/STIAEA->

Aren't there some patients though who do mostly have only bio needs? Perhaps because they have already worked through their psychosocial issues related to their pain.

For some people trauma leads to pain and just as common are autoimmune conditions like psoriasis, lupus, rheumatoid arthritis, colitis etc. For some, but not all, it leads to psychological disorders.

Lots of emphasis on the social this evening. Do we need much broader conversations about what philosophy, values, behaviours and structures our communities needs to support human flourishing?

We need Salutogenesis –

Complex pain is a wicked problem that needs a lot of different small projects to coalesce into a broader social movement and cultural change this means that local contexts will determine how services will evolve

I'm not sure it needs a charismatic leader so much as lots of people supporting one another

Organisational change models suggest you need change agents to diffuse the changes. Networks such as this (for me) are supportive in facilitating change

** Filletti established an obesity clinic in San Diego in the 1980's. He was puzzled by the large number of participants that lost weight when on the programme but soon regained it. He discovered that many of these people had a history of trauma*