

Breaking the barriers to self-management

Self-management – we know it's one of the things that can most improve the lives of people living with pain, but all too often it's not being put into practice successfully.

After speaking to people with pain and healthcare professionals, we've been able to put together a clearer picture of what is going wrong and how we might make things better.

Katy Gordon: We are working on a two-year project looking into the barriers to self-management of chronic pain in primary care. So the first year of that was a research project, gathering data and speaking to lots and lots of people to get some information on what they thought the barriers were. So we've kind of finished that now, and now we're looking into developing some resources that might help overcome some of the barriers.

We basically found four, kind of main categories of barriers and under each one of those categories there was various sub-themes. The first one was the patient and healthcare professional consultation. So things that happen as part of that consultation that maybe become a barrier to self-management.

The second one was what we called 'patient experience', so their experience of pain and the emotions that might be attached to having chronic pain might become a barrier.

The third category was called 'limited treatment options'. So that kind of covered the tendency for people, of doctors and patients as well, to expect their pain would be treated with medication and nothing else, so they didn't really look into some self-management strategies they might want to use.

And then the fourth category was organisational constraints. So that's the sort of thing like really short appointment times, very long waiting lists, that sort of thing that makes it harder for people to do self-management.

Dr Martin Johnson: Chronic pain self-management is still in its infancy, as the recent report has shown. People are not confident in actually giving that advice, which is unfortunately why a report today has shown that the use of opioid containing preparations has gone up ten per cent in the last year. Because it is the natural instinct for doctors to prescribe, it's the one area where drugs are relatively cheap, in terms of just normal analgesics, so it's easy to reach for your computer prescription pad and prescribe, without giving a lot of advice.

Because unfortunately access to a lot of other services is either difficult, or not appropriate. But I think GPs have a huge role to play in the self-management of chronic pain.

Gordon: It was really, really common for people to say, I was made to feel like it was all in my head. People saying that they felt like if they'd gone for a scan and they didn't find a lump or something, then it was basically, well there's nothing wrong with you, just go away, that sort of thing. Yeah, that was really common.

And on the flip side of that, the doctors said they often found it quite difficult to talk to patients, perhaps. So there's not maybe a specific medical reason that they can pinpoint for having their pain, so if the doctor started exploring wider aspects of their life and some of the psychological aspects, that was a very difficult conversation to have with the patient, because as soon as you start talking about that sort of thing the patient will be like, 'he doesn't believe me, he said it's all in my brain'.

So quite an interesting contrast between the two sets of focus groups that we ran. So the doctors were saying, 'we can understand why patients think that's what we're saying, but it's actually not what we're saying, but we do need to explore the kind of wider psychological aspects of pain'.

Dr Ollie Hart: Sometimes people perceive self-management as being the healthcare professional just fobbing you off and saying, 'no, back to you, you've got everything'. But I think what we're realising more and more as healthcare professionals is that we need to have this dynamic relationship, where we are supporting people to self-manage. And it's more of a partnership approach really, where a healthcare professional acts more like a coach really, you know.

We've got Jess Ennis in Sheffield, you know, so she does the work, the training, but the coach guides her and helps her how to manage injuries that come up and gauges how much, how often and when. But at the end of the day it's Jess Ennis that has to do the work. You can apply a similar sort of thing to self-management, with the relationship with the healthcare professional really. People have to make the decisions for themselves, we're not there to hold their hand all the time, but as healthcare professionals we can coach you in what sort of self-management decisions might be best for you at that particular time.

Gordon: Number two, we called it patient experience. So part of that, well a big one of that, was the sort of emotional impact of chronic pain. So patients spoke about feeling low, feeling depressed, sometimes feeling suicidal. And if that's how you're feeling, it becomes very difficult to think, 'well maybe I should go out for a walk because that'll help me manage my

pain, or maybe I need to pace', you know. To be in that mind frame it becomes very difficult to then start doing self-management techniques.

So part of it was that, the kind of emotional impact. And also, well this was more... the doctors sometimes talked about people's ability to self-manage. Because actually there probably is a whole host of people who are self-managing very, very effectively, and very rarely go to their doctors, so probably the people that do use primary care are people who are perhaps not as successfully self-managing. And the doctors kind of talked about some of the reasons that might be, perhaps they maybe have a very chaotic lifestyle and therefore find it very difficult to self-manage. There was a little bit about people's ability and understanding of self-management that perhaps was one of the reasons that they didn't do it as well.

Johnson: There are some very simple messages that we can empower people with. I equate it with obesity, so obesity years ago, doctors were not confident in managing it, but there's been a lot of training that's gone on. So people are a lot more used to dealing with that now and actually giving appropriate advice. And I think giving self-management training, or supported self-management, that's what we should be calling it. We know the research shows that patients do a lot better if they are supported by some form of healthcare practitioner. If we go down that route I'm sure that many of our chronic pain sufferers would get a far better deal.

Gordon: Number three was, we called it 'limited treatment options'. So, the big one of that was really, which we mentioned briefly before, was the medicalisation, so everyone thinks that it should get treated by painkillers. And that's almost what they were taught, a few doctors felt very strongly that at medical school you're taught there's a problem, here's a solution and the solution will be giving you medicine and there was no other thought of the kind of wider things that they could be doing. And also, again on the flipside, patients sometimes go to a doctor and expect to get a prescription and they're not really interested in perhaps talking about any of the other things.

So medicalisation was one of the ones that was a big one, but quite a cultural shift, I think, that we need to get to where people start to think, well it's not just about the doctor fixing me.

Hart: The skill as a healthcare professional and as a patient, you know, learning to trust each other and working together. The patient will know what their life is like and what's going on for them, what expectations and limitations they have on what they can and can't do. And the healthcare professional will know what things work for other people in similar situations.

So I guess it's about forming a relationship together and sharing your expertise, isn't it? And coming to a plan, setting some goals together, but it's a joint partnership thing.

Gordon: Even the doctors who were really bought into self-management would say, 'I actually don't have time to talk about chronic pain in the detail it needs, I don't have time to talk about self-management, so at the end of an appointment I give a prescription'. So even the ones who are really, really, bought into the idea quite often struggle to talk about it.

Hart: Traditionally GPs have ten minutes, don't we? And that's not a long time. And that ten minutes includes me looking at your notes before you come in to see me, doing what we do together and then writing up notes afterwards. And the note-keeping is important, because otherwise I won't remember everything we've talked about for the next appointment.

So a lot to do in ten minutes. I chunk things up, is the phrase. I'll often agree an agenda with the patients, right we've got ten minutes together, what can we usefully do today? But I might want to see you again in a couple of weeks, or a month's time. I think what is increasingly becoming the situation is that we're trying to get a little bit more sophisticated in how we do things, so sometimes we might need longer, you know, recognise that if someone's in a really difficult position, there's some complicated things going on, we might need twenty minutes, or half an hour. But there also might be other ways that we could interact.

Johnson: I think the patient barrier is they'll want a cure. I'm convinced that's the main barrier and therefore when they see self-management, 'well, aren't you going to try and cure me and send me for another test'. And they all go for all these tests and they're all negative, or they find something that they then catastrophize.

For the listeners, a very good example of that is an MRI scan, so you'll go for an MRI scan and I know that most people over the age of twenty are going to have a finding on an MRI scan, even if you don't have any pain. It is normal, absolutely normal, but then when, unfortunately some of my orthopaedic colleagues might say, 'oh, you've got a bit of crumbling in your spine, dear, that's all it is', so people then stop doing it.

I would like to start what I call 'the first message campaign'. What we tell people is so, so important. That if you do things, your spine isn't going to crumble, people are concerned that they're going to end up in a wheelchair, that's so common. So, to get this education and rationalisation to patients, that they can do something for themselves, I think is the biggest barrier.

Hart: Self-management is a real skill, of recognising what's right for you, perhaps going against, what your natural reflexes might be sometimes.

Gordon: Knowledge of what the barriers might be has to be the first step to overcoming some of those barriers. So hopefully the report will give the people the knowledge and they might be able to use it to overcome the barriers.

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