

BARRIERS TO SELF-MANAGEMENT

SELF-MANAGEMENT ISN'T WORKING – OR AT LEAST IT ISN'T WORKING FOR A LOT OF PEOPLE IN PAIN. PAIN CONCERN'S FIRST MAJOR RESEARCH PROJECT IS INVESTIGATING WHY THAT MIGHT BE THE CASE. KATY GORDON, PAIN CONCERN'S RESEARCH OFFICER, TELLS US ABOUT WHAT SHE'S FOUND OUT AND HOW WE MIGHT IMPROVE THE SITUATION

WHAT WERE YOU LOOKING TO FIND OUT?

Callers to the Pain Concern helpline often spoke of difficult consultations with healthcare professionals that left them feeling unsupported and struggling to manage their pain. We wanted to know why this may be the case and decided to undertake a research project looking into barriers to self-management of chronic pain in primary care. We felt that knowing what barriers might exist would be the first step to bringing about change and ultimately hoped that our report would help more people better to manage their pain.

WHAT DO YOU MEAN BY 'SELF-MANAGEMENT'?

It was difficult to find a definition of 'self-management' that was consistently used throughout existing research. We decided to adopt a definition from an earlier study:

'A single approach or combination of approaches that can be initially taught by any health professional or learned by an individual to enable them to minimise the impact their chronic pain can have on everyday life.'

We liked that this broad definition allows for people adopting any number of strategies that work for them. The term itself sometimes generated debate with some people feeling it carried negative associations of 'having to do it alone'. A few of the healthcare professionals in our study said they wouldn't use the term when talking with patients for this reason.

HOW DID YOU CARRY OUT THE RESEARCH?

We wanted to hear from people in pain, carers and a wide range of primary care healthcare professionals so we organised a number of focus groups and invited people to attend. Focus groups are basically a big group discussion where I posed some questions and let the conversation flow. All the groups were recorded and transcribed and two researchers analysed the data for the key themes. In total we spoke to 101 people at 18 different focus groups – 54 people with chronic pain, 9 carers, 16 GPs, 15 physiotherapists, 4 occupational therapists, 2 practice nurses and 1 community pharmacist. I felt very privileged to meet all these people and hear about their experiences and opinions.

WHAT GETS IN THE WAY OF PEOPLE MANAGING THEIR PAIN?

Good question! We found evidence of many barriers to self-management of chronic pain which we grouped under four categories: patient/healthcare professional consultation, patient experience, limited treatment options and organisational constraints. It's not to say that all these apply to everybody but there is potential for barriers to form at each of these points.

We heard how short appointment times, long waiting lists and a compartmentalised NHS made discussing and undertaking self-management challenging. One of the barriers, which we called 'over-medicalisation', was a tendency to focus on pills as the only method of

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treatment as opposed to thinking about other options that might help with pain management.

The emotional impact of chronic pain and a feeling of 'wanting to be the person I used to be' sometimes made self-management challenging. Finally, the consultation with healthcare professionals sometimes led to barriers – some people felt a discussion about self-management came too late or not at all and there were consistent examples of both parties misinterpreting messages.

YOU SPOKE TO BOTH HEALTHCARE PROFESSIONALS AND PEOPLE IN PAIN – WERE THERE DIFFERENCES BETWEEN THEIR PERCEPTIONS OF THE SITUATION?

Generally there were quite a lot of similarities between the issues discussed at the groups with people in pain and those with healthcare professionals. What we called 'organisational constraints', particularly the short appointment times with GPs, had a double-edged effect – even the GPs who were really behind the idea of self-management didn't have time to talk about it, so it was no wonder that the patients then said they felt unsupported with self-management.

It was a really interesting part of the project to compare the results from the two different populations. It was common for the people in pain to say 'they said it was all in my head'. But while the healthcare professionals know that is a common perception, sometimes they struggle to ask the questions that they need to without creating the impression of disbelief. It didn't happen often but sometimes there was a definite mismatch between the groups. For example, GPs thought they saw patients when they were at their worst, whereas people in pain talked about waiting for their pain to ease slightly before they were able to attend an appointment.

WAS THERE ANYTHING YOU FOUND OUT THAT PARTICULARLY SURPRISED YOU?

I wouldn't say any of the results were particularly surprising to me. They were definitely interesting but not surprising. Although, as I work for Pain Concern, I had some insight into possible issues prior to starting the data collection – they probably would be surprising to someone outside of the 'pain community'. I'm actually pleased that there were no major surprises as it demonstrates that the issues that we hear about on



the helpline and through our contacts in the NHS are widespread and therefore can be the focus of change. Having a report which brings together all of these issues – based upon discussions with real people – is really powerful, I think.

WHERE PEOPLE DID HAVE BETTER EXPERIENCES – WHAT MADE THE DIFFERENCE?

A good relationship between patient and healthcare professional was often fundamental to successful self-management. When people felt listened to and felt their healthcare professional had a caring attitude the foundations for good partnership working were there. Similarly, support from family, friends and other people in pain was invaluable for people learning how to manage their pain.

WHAT COULD WE DO TO MAKE THINGS BETTER?

I think we need to start talking about self-management more, really raising its profile so both people in pain and healthcare professionals embrace it as a legitimate and effective approach for helping people to live better with their pain. Chronic pain is extremely challenging for those who have it and also for healthcare professionals – many of whom are equally unable to accept there may not be a 'cure' – and the disappointment and disillusionment for both parties when a straightforward solution proved elusive was obvious. However, there is also genuine desire to overcome some of the challenges and I sensed positive momentum towards self-management – the more we can build on this the better.

To read the full report from the research study 'Barriers to self-management in primary care', please visit painconcern.org.uk.