

# People with chronic pain face complex dilemmas and life-changing decisions

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Coping with chronic pain can affect every aspect of a person's life and cause conflict between what their mind wants to achieve and what their body allows them to do, according to research in the December issue of the *Journal of Nursing and Healthcare of Chronic Illness*.

Swedish researchers carried out in-depth interviews with ten people who had experienced chronic pain for between four and 32 years and were taking part in an outpatient rehabilitation programme. Nine of the patients, who ranged from 22 to 50 with an average age of 38, were unable to work because of their pain.

"A recent research study found that chronic pain affected up to 30 per cent of adults across Europe, impacting on people's everyday lives and in many cases their ability to work" says lead author Asa Skjutar from the Karolinska Institutet.

"Although multidisciplinary rehabilitation programmes for people with chronic pain are well established in Sweden, they don't work for everyone. There can be a number of reasons for this, from failing to customise treatment to individual needs through to delayed intervention which makes people less amenable to change.

"What is clear is that many patients with chronic pain find that their needs are not being met by healthcare professionals. Previous research has found that patients' beliefs play an important role in how successful any interventions are. That is why we were keen to find out how people

felt chronic pain impacted on their lives."

Three key themes emerged during the interviews:

## **Adapting**

Patients expressed conflicts between what they wanted to do and what their body let them do and they were constantly weighing up the consequences of their actions.

One woman described how she had to set her pain aside, grit her [teeth](#) and let her mind take the lead as she got her children off to school and daycare. "Had I listened to what hurts, then I wouldn't have done it" she said. Another patient talked about how a fishing trip satisfied his lust for adventure, even though he was aware of the increased pain that might follow.

Others, however, talked about not making definite plans to avoid the guilt of cancelling. They also said that they had no problem in accepting help or stopping what they were doing if they felt their pain levels would escalate.

"The participants had gone through rehabilitation programmes that recommend a steady and moderate level of activity, but said that they had not found the best way to manage their pain" says Asa. "They moved between the two extremes of letting their body and their mind lead and repeated this cycle so that neither dominated."

## **Discovering**

Patients also spoke about their need to let go of the way they used to live - including their behaviour, daily routines and independence - and find

new ways to express themselves. "It's so strange for me to say no" said one participant. "I'm not used to it. Nobody else is used to it either." But she learnt how to say no and, although it was tough, it felt good.

Another patient talked about how he had managed to paint a wall on one side of the house, but was unable to paint the remaining walls. "I am very pleased that it looks so nice even though I know that the other ones aren't done" he said. "Before I wouldn't have looked at that wall, I would've looked at the other ones."

"These transformations didn't happen overnight, they happened bit by bit" says Asa. "But they made people realise that they had made the adjustments they needed to make to their lives to manage their pain."

## **Engaging**

People who took part in the study also realised that they needed to manage their pain in order to enjoy their lives. They initially focused their energy on work-related roles and finding a fast cure for their pain, but this often led to more pain and feelings of defeat.

Family time and friendships became very important, because social interaction could often be achieved without too much activity. "I'm seeing friends and family again, which means a lot to me" said one participant. It was also important to have a change of scene. "I went to a friend's and played a video game and talked and just had a good time, just relaxed" said another. "It was so nice to get out and do something."

"Doing something they enjoyed gave people energy and made them feel more optimistic and positive" says Asa.

"Understanding how people are affected by chronic pain enables healthcare professionals to give them the support they need to adapt their

lives, discover a new way forward and engage with friends and family in a way that enhances their quality of life" she concludes.

"Chronic pain is a very common health problem in adults and its management affects not just people's personal lives and relationships but their contribution to society and the economy. It is vital that we enhance our understanding of people's needs so we can provide more effective [chronic pain](#) management services that meet people's varied and changing needs."

**More information:** Adapt, discover and engage: a qualitative interview study with patents living with chronic pain. Skjutar A and Mullersdorf M. *Journal of Nursing and Healthcare of Chronic Illness*. 2, pp 254-261. (December 2010). [DOI:10.1111/j.1752-9824.2010.01066.x](https://doi.org/10.1111/j.1752-9824.2010.01066.x)

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