

A meta-ethnography of patients' experience of chronic non-malignant musculoskeletal pain

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Scientific summary

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Background

Many people suffer from chronic non-malignant musculoskeletal (MSK) pain, which affects how they feel and what they are able to do. This pain often has no medical explanation and does not go away. Some people find it so devastating that at times they would rather die than go on in pain. A greater understanding of patients' experience of pain could have an impact on health care in this group. Qualitative research aims to understand experience and is widely used in health-care research. However, the increasing number of qualitative studies can make it difficult to use this knowledge to inform clinical practice. There has been no attempt to systematically search for, and make sense of, this growing body of research. A synthesis of qualitative research would help us to understand what it is like to have chronic MSK pain. Specifically, it would help us understand peoples' experience of health care with the aim of improving it.

Objectives

The aim of this study was to:

- increase our understanding of patients' experience of chronic non-malignant pain and therefore have an impact on quality of care
- utilise existing research knowledge to improve understanding and, thus, best practice in patient care
- contribute to the development of methods for qualitative research synthesis.

Methods

We used the methods of meta-ethnography. Meta-ethnography aims to develop ideas that will help us to understand a particular experience, by bringing together research findings. We included qualitative studies that explored adults' experience of chronic non-malignant MSK pain. We searched six electronic bibliographic databases (including MEDLINE, EMBASE and PsycINFO) and included studies up until the final search in February 2012. We also hand-searched particular journals known to report qualitative studies and looked through reference lists. We then appraised each study to decide whether or not we felt that it was *good enough* to be included. After this, we read the studies and made a list of the ideas (or concepts) that were in them. We then separated these ideas into categories (or themes) with shared meanings. We did this by constantly comparing concepts to look for any similarities or differences between them. In meta-ethnography this process is called 'translating qualitative studies into one another'. The final stage of the analysis involved developing a model that 'makes sense' of all of the concepts in the study. The aim was to make a whole that is greater than the sum of its parts, and generate explanations to improve understanding.

Results

The full texts of 321 potentially relevant studies were screened, of which 77 were included in the meta-ethnography. Forty-nine papers explored the experience of chronic MSK pain and 28 papers explored the experience of fibromyalgia. Our model shows that people with chronic MSK pain face a constant daily struggle to affirm their self, reconstruct a sense of self through time, find an explanation, negotiate the health-care system and prove legitimacy. These themes are adversarial, giving a sense that a person with

chronic MSK pain struggles to prove that they are legitimate. However, in spite of this struggle there was also a sense that people can move forward alongside their pain. The following section describes the categories or 'themes' that were developed from the study.

Struggling with chronic musculoskeletal pain

1. *Struggling to affirm myself.* This describes the struggle to hold on to the 'real me'. Pain alters the fundamental relationship with my own body. My painful body is no longer *me*, but *it*. I am powerless against this alien body. I look back nostalgically to the 'real me' and struggle to hold on to what I was. However, although I fight to be the person that I was, I know that I am irreparably altered. Pain threatens the relationships that I once had, and isolates me from others. I don't tell anyone how I feel because I am trying to look like my old self. I sometimes feel angry and low, and I no longer feel like the person that I once was. Perhaps no one knows who I am any more.
2. *Construction of time altered; unpredictable now and future.* This describes how a person's perception of their self through time is altered by pain. My plans, expectations and dreams for the future are gone. I cannot predict what my pain will be like from minute to minute and therefore I cannot make any plans. I now live in an endless present where I am constantly aware of my body. I have become cautious and can no longer be spontaneous. Although I live in the present moment, I also look towards the future and know that things are not going to be how I had wanted. The sense of certainty for the future is gone, and I am sometimes anxious or sad about what the future holds. I am struggling to find some hope.
3. *Struggling to construct an explanation for suffering.* This describes the need to find an explanation for pain and the value placed on diagnosis. No one knows why I continue to have pain and I have failed all the 'medical tests'. Although I don't want to be ill, I need to know what is wrong with my body so that I can do something about it. If I don't have a diagnosis, people will not believe me. I don't think my family, colleagues and doctors believe that I am in pain. Even though the health-care system cannot tell me what is wrong, I will keep looking for an explanation and a remedy.
4. *Struggling to negotiate the health-care system.* This describes the person's ambiguous relationship with the health-care system. I feel *compelled* to go to the doctors even though no one has found an answer. I feel 'trapped in the system'. I am continually referred to different health professionals and feel 'like a shuttlecock'. I sometimes doubt whether the doctor knows what is wrong or what to do. Maybe nothing can be done. I do not feel valued as a person by my doctor. I need my doctor to listen to me, hear what I am saying and believe me. They do not understand how much this pain has changed my life.
5. *Struggling to prove legitimacy.* This focuses on the adversarial and contested nature of chronic pain. Because I do not have a medical diagnosis, I have to prove to everyone that I am a good and honest person who deserves their care. I struggle to find the right balance between hiding my pain and showing my pain to others. There seems to be a 'right way' of being in pain. If I appear 'too sick' or 'not sick enough' then people won't believe me. I hide my pain from others so that I seem like my normal self. I sometimes feel ashamed or guilty about having pain that no one can explain, and would rather hide it from everyone. However, because I am trying to look like my normal self, nobody believes me, especially because I have no medical proof. I want other people to recognise that I am a 'good' person who is not to blame for my pain or how it has affected me. How do I try to look like my old self and show other people how much this pain has changed me?

Moving forward alongside pain

We also found that the person with MSK sometimes found ways of moving forward with pain: listening to the body, redefining a new self, becoming part of a community, telling others about pain, realising that pain is here to stay and becoming the expert of his or her body.

1. *Listening to and integrating my painful body.* This describes a new relationship of trust and co-operation with the body. If I listen to what my body is saying and respect it, I can continue to do the things that I want to do. I am no longer at the mercy of my body. By co-operating with my body I

- can try and balance what I can and can't do. I can then live my life more fully even though I am different now.
2. *Redefining normal and less focus on lost self.* This describes how the person in pain no longer focuses on their losses but on reconstructing a new self. I accept that things are now different and I am trying to find ways of moving forward with pain. I can still be me even if I am different to what I once was. I can enjoy life differently and I am still me. I focus on things that I can do now, not what I used to be able to do. At times, I still feel really sad to have lost my old 'real self', but realise that I need to move forward.
 3. *Being part of a community of others with pain.* This describes the positive, yet ambivalent, impact of being part of a community of others with pain. When I meet others with chronic pain, I feel part of a community. I know that other people have the same thing so it must be real. I now feel that there are others who understand, believe and respect me. However, at the same time I feel that deep down I am different to the others. I do not want to go on about my pain all the time.
 4. *Telling others about my pain.* This describes the benefit that comes from letting other people know about my pain. I now tell people that I have pain, and let them know that I cannot do all the things that I used to be able to do. I will sometimes tell others that I cannot do what they want me to do and that I need their help. I don't always need to gain everyone's approval. Now that I tell people about my pain, I feel more connected to those around me. I can make choices about what I do and don't do so that I can still do the things that are important to me.
 5. *Realising that there is no cure for my pain.* This describes the realisation that pain is here to stay, and the benefits of stopping the search for a diagnosis and cure. I am beginning to realise that I will always have some pain and that no one has an answer. I am not going to spend my time trying to find out what is wrong. This has stopped me from moving on. I can now move forward and find a new way of living. However, some described staying in the health-care system as important too.
 6. *Becoming an expert.* This describes the process of becoming an expert. I don't rely on my doctor as much to tell me what to do to make my pain better. I now listen to my body. I know more about my own body than anyone else does. I am becoming confident to try things out. I can make my own choices about what I do. I don't need the doctor to say that it is OK because I am the expert of my own body.

Conclusions

This meta-ethnography provides a synthesis of concepts and suggests a model for pulling these concepts together. The concept of an adversarial struggle explained what it was like to have chronic MSK pain. This constant struggle for people with chronic MSK pain may distinguish it from other kinds of pain. For example, it seems unlikely that someone with cancer pain would feel the need to *prove* that they are in pain. This suggests a very different starting point for people with chronic MSK pain. In spite of this struggle our model suggests how a person can move forward alongside pain by listening to their body rather than fighting it, letting go of the old self and finding a new self, becoming part of a community and not feeling like the only one, telling others about pain and redefining relationships, realising that pain is here to stay rather than focusing on diagnosis and cure and becoming the expert and making choices.

Our findings call us to challenge some of the cultural notions about illness, in particular the expectation that the doctor will find a diagnosis and offer an effective treatment. These cultural expectations are deep-rooted and can affect the experience of pain. For example, not having a diagnosis can produce powerful feelings, such as worthlessness, fear, shame, guilt. Our model also shows that not feeling believed can have an impact on a person's participation in everyday life. For some years, qualitative research has shown that people with chronic MSK pain do not think that doctors believe them, and this finding has not changed in more recent studies. This has clear implications for clinical practice and education. Our model suggests that central to the relationship between patient and practitioner is the recognition of the patient as a person whose life has been deeply changed by pain. Our model suggests that *feeling valued* is not simply an adjunct to the therapy or an optional extra, but central to it.

In the context of recent developments in pain management, it would be useful for qualitative research to focus on the following experiences of chronic MSK pain:

- how a person in pain experiences his or her own body
- the meaning of *acceptance* for both patients and clinicians
- reconciling hope with acceptance that pain is here to stay
- other specific MSK pain conditions, for example shoulder pain.

Additional syntheses would also help us to understand the experience of chronic pain. For example, there is already a growing body of qualitative research exploring the experience of osteoarthritis. Efforts to synthesise qualitative research will help to make sure that qualitative research is accessible to a wider relevant audience.

Our research shows that meta-ethnography can be used to elicit concepts that increase our understanding of patients' experience and enable us to explain the context in which people make decisions about health care. Although developed from studies of MSK pain, our model may also be transferable to other long-term conditions. Conceptual models developed from meta-ethnography can have an impact on quality of care. Our model opens up possibilities for therapies that aim to help a person to move forward alongside pain.

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