

A Reflexive Account of using an Advisory Group to develop a 'Collected Definition' of Acceptance of Chronic Pain.

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Background

Acceptance that chronic pain is long term is pivotal in achieving better outcomes in health. However, qualitative literature suggests that acceptance is poorly understood and open to misinterpretation. To develop conceptualisation of acceptance of chronic pain based on knowledge from lived experience, a Meta-Ethnography is being conducted. This required development of the definition of acceptance of chronic pain to guide study selection. An advisory group model was used (NIHR INVOLVE, 2012; Hoens et al, 2020) which included clinicians, academics and people with lived experience as advisors, whose perspectives on the concept were combined into a 'collected definition.'

Aim

To develop a definition of "acceptance" of chronic pain for use in a Meta-Ethnography.

Method

Advisors were asked to provide their own definition of acceptance of chronic pain and subsequently, reflexive statements on this process. The definitions were combined into themes by two team members and coded using NVivo12 software.

Results

Nine definitions were provided by advisors reflecting their different perspectives, and the 'collected definition' of acceptance of chronic pain is presented. The reflexive statements show how advisors approached the process.

Conclusions and relevance for patient care

The advisory group model provided a way of engaging relevant experience and perspectives, essential in developing a realistic understanding of important concepts in pain research. We used it successfully here to develop a definition of acceptance that will allow our subsequent research to be relevant to people living with chronic pain. The process also provided a reflexive space in the research process which has proven helpful to the interpretive process of Meta-Ethnography.

The Collected Definition of Acceptance of Chronic Pain:

Acceptance of chronic pain is the ongoing, fluctuating process of coming to terms with pain and its impact which includes transition and journey to a new way of being.

The process has different aspects which can include a completed search, a pragmatic realisation of the reality of the condition/ diagnosis, understanding, believing, confidence, changing and maintaining behaviour.

The person in pain may require to learn and unlearn, be able and willing to make changes to accommodate the pain, move forwards from losses due to the pain, create a life with and alongside pain.

Acceptance of pain may be approached actively, or it may be passive as nothing else can be done.

It may be influenced by the life experiences of the individual and external factors including the approaches, skills, care, compassion and communication of HCPs. It may require trust in those giving an unpalatable outlook.

Acceptance is useful for day to day survival and facilitates being ready to explore ways of living well with pain, rather than fighting it, thus minimising the suffering that can be associated with pain, leading to the potential of a rich and full life with pain.



Image: Alexander Hatemann, unsplash

Reflexive perspective

Advisors required to stop and question themselves, thinking back on their own experiences.

'Acceptance' for me was a bit like 'Pain' – it's something that we all experience, to greater or lesser extent, we all know (or think we know) what it means, but it's something that we've never had to define until specifically asked... When you asked me to define 'Acceptance' I therefore felt very challenged!

'pain has taken so much away from me in terms of work and career options that I see an opportunity like this as a way of proving to myself that I am not worthless...I was wary of using the wrong language...For my contributions to be useful I needed to be genuine and real, not trying to write what I thought C wanted.'

'When coming up with my individual definition of acceptance in chronic pain, I initially found it hard. So I deliberately started with a non-pain related definition, and then related that to chronic pain.'

The roles, backgrounds and lived experiences of the advisors became blurred.

'On reflection, I think that my medical training left me in the same position as the vast majority of doctors in that I looked on my illness as a problem and problems were to be solved.'

'I was surprised by how I thought I knew what the definition was, but instead of visualising a text, I immediately considered it in the context of my own long-term pain. It took some time for me to compose my definition, which is interesting given I address the concept and principles of acceptance with people living with pain on a daily basis in my work.'

'I can see the process of academia influencing me – I had tried to sum it, neatly, using terms that would fit into the literature and could be added into the definition box on the prospero form.'