Revising the negative meaning of chronic pain – A phenomenological study

Tapio Ojala, Arja Häkkinen, Jaro Karppinen, Kirsi Sipilä, Timo Suutama and Arja Piirainen

Abstract

Objectives: Chronic pain may disable the body, depress the mind and ruin the quality of life. The aim of this study was to use the participants’ personal experiences to explore the meaning of the experience of chronic pain and to find successful ways to manage chronic pain.

Methods: Thirty-four participants with chronic pain were interviewed. The transcribed interviews were analysed using Giorgi’s phenomenological method consisting of four phases: (1) reading the transcriptions several times, (2) discriminating meaning units, (3) collecting meaning units into groups and (4) the synthesis.

Results: The participants stated that the key to managing chronic pain was to reconsider the individual meaning of the experience of pain. As a result of the interviews, seven subthemes were found based on the ‘Negativity of chronic pain’, namely, ‘State of reflection’, ‘Reconsidering values’, ‘Acceptance of pain’, ‘Support network’, ‘Altered self’, ‘Joys in life’ and ‘Pain dissociation’.

Conclusions: Pain is an aversive sensation, which leads to the conclusion that the meaning of the experience is also negative, but it can be reversed. In clinical practice, the focus should be on revising the subjective meaning of pain in order to manage pain and to restore positivity in personal life.
Keywords
Chronic pain, quality of life, life change events

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Introduction

Chronic pain is a major health care problem in Europe, which is poorly understood and managed. Chronic pain can be defined as a negative emotional experience that is affected by a variety of psychological factors through different inhibitory systems. Thus, chronic pain can be regarded as an illness in its own right resembling other chronic conditions. However, recent functional brain imaging data have revealed that the contradiction between the subject’s conscious knowledge that the pain is not associated with the environment and the brain circuitry that continuously make such associations may be the core cognitive–emotional source of the suffering that chronic pain patients experience. Nevertheless, pain is usually described according to its aversive sensation and consequences.

The consequences of pain can be divided into physical implications, such as disabilities and restrictions in moving, and psychological implications, such as distress, anxiety and depression. The painful part of the body is often excluded, and persons with chronic pain suffer also from loss of identity and loneliness, indicating negative effects of pain.

‘Pain is a more terrible lord of mankind than even death itself’ is Albert Schweitzer’s negative description of pain. Negativity is the opposite of positive, not desirable, regarding the consequences of pain and its aversive sensation, defined as a strong dislike or disinclination. One reason for the negative meaning of pain may be found from the etymology of pain, originating from the Greek word poena meaning punishment.

The negative meaning of pain may be partly related to modern medicine, which has changed our cultural attitude to fear of pain (algophobia) where ‘pain must not simply occur’ and must be abolished immediately, interpreted as indicating that today, we are less tolerant to discomfort and unwanted experiences than before. However, pain has an important protective role, and life would be unthinkable without pain; furthermore, the experience of pain is a potential kick off to something new.

Chronic pain, like other chronic conditions may not be cured but has to be coped with. One coping strategy for living with chronic pain is acceptance, which can be defined as willingness to experience chronic pain and to continue with normal life. Acceptance of chronic pain is associated with decreased pain, disability and pain-related fear and realising that chronic pain may be a part of life.

The biopsychosocial paradigm has its origin in Engel’s (1977) work and has proven to be the most complete understanding of chronic pain. However, it does not explain the phenomenon of chronic pain and the subjective meanings of pain. Therefore, alternative methods to explain and treat chronic pain should be discovered by hearing the patient’s voice. Sessle in his recent review also calls for more pain awareness and education for the management of chronic pain. From the phenomenological point of view, it is not the pain itself, but the meaning of it, which defines the individual effects and management of pain. The aim of this study was to explore the meaning of the experience of chronic pain and the essence of the management of chronic pain from the patient’s perspective.

Phenomenological method

Phenomenology has its scientific methodological foundations in Edmund Husserl’s
(1859–1938) work, and therefore, it is primarily a method but additionally a philosophy. As a holistic paradigm, phenomenology rejects dualism and supports the idea that the mind and body are whole.19

As a method, phenomenology studies human experiences and how a lived experience appears in the consciousness and what its meaning is. Phenomenological method is a qualitative method to study experiences that are difficult to reach with any other method.17,18

Giorgi’s method is a descriptive method, following Husserl’s tradition to describe the phenomenon as it presents itself to the participants. Giorgi’s method was initially developed and used in psychology, but as he has stated, it is applicable to any social science that works with human beings, e.g. in qualitative health research. Despite the flexibility of the method to be modified and used in a range of fields, the researcher has to assume the attitude of the specific discipline and show sensitivity to detect the phenomena of interest.17,18

Giorgi’s four-phase method was chosen and applied to determine the essential meanings of chronic pain for the following reasons: (a) Giorgi’s method employs a descriptive tradition, (b) phenomenology is a science of experiences, (c) experience consists of meanings and (d) the aim in phenomenology is to analyse the meanings of the experience, describe the structure of the experience and in analysis using an epoche’, bracketing previous knowledge of pain aside.17

**Study methods**

**Participants**

The participants with different types of chronic pain comprised 34 patients with chronic pain who were recruited from four various sources in Finland. Fifteen outpatients were from the Department of Physical and Rehabilitation Medicine, and six outpatients from the Pain Clinic at the same University Hospital. Four participants were obtained from the local back peer-support group and nine from the local pain peer-support group by the first author.

The participants in this study had (a) chronic pain of at least three months duration as defined by the patient’s own physician, (b) willingness to talk about the individual experience of chronic pain, (c) ability to read and write in Finnish and (d) a minimum age of 18 years.

The ages of the participants varied from 26 to 73 years with a mean age of 48 years. Nineteen of the participants were women and 21 were married. Half of the participants were retired, and a fifth worked full time. Most of the participants used a combination of medications. The individual characteristics of the participants and pain are presented in Table 1.

**Ethical considerations**

Ethical approval for the study was obtained from the Northern Ostrobothnia Hospital District Ethics Committee. During the recruitment session, the first author or the doctor explained the nature of the study and an informed consent was obtained from each participant.

**Data collection**

The first author (T.O.) collected the data by using open interviews in different locations (library café, coffee shop, participant’s home, treatment room at the Department of Physical and Rehabilitation Medicine or support group meeting room) from May to November 2011 after contacting each participant by telephone to ensure his or her willingness to participate. A copy of the signed informed consent was also given to each participant. Every interview started with a short conversation before recording the interview. Field notes were not made during the interview.
**Table 1. The sociodemographic and clinical characteristics of the participants.**

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**Note:** CRPS: complex regional pain syndrome; LBP: low back pain.
The interviews were as open as possible, using open-ended questions to allow the participants to tell as much as possible about the experience of chronic pain. The key statement was ‘Please, tell me about your 0–100 chronic pain and how it started’. Additional questions were used, depending on how much he or she revealed. Some examples of questions are presented in Table 2.

The individual interviews lasted from 45 to 90 min and the interviews were transcribed by a professional transcriber. The complete collection of interviews consisted of 631 transcribed pages, ranging from 11 to 31 pages per participant. The transcriptions were not returned to the participants for comments.

### Meaning analysis

The data were analysed using a phenomenological method according to Giorgi, which is briefly presented in Figure 1.

1. The first author read each interview carefully several times and wrote a complete description of each participant’s experience of chronic pain.
2. In the second phase, the first author discriminated meaning units of chronic pain from each participant’s transcription using his or her own words or expressions to find subjective meaning units for pain. Meaning units consisted of a few words up to a whole sentence and were noted every time a participant referred to pain.
3. Each participant’s meaning units that he or she used to describe, for example, personal mood during pain, were collected, and a meaning structure, as we entitled it, was formed. The meaning structures were arranged so that the most valuable, from the participant’s perspective was placed on top, and the others were placed below it and/or in parallel in an order that reflected how they were related to each other. The value of each meaning structure was defined by how the participant described the experience of it, and how he or she referred it to other meaning structures. This organised collection of meaning structures constituted a subjective meaning network. In addition, a meaning perspective was written representing the entire experience of chronic pain for the participant. In this phase, the language was changed to reflect a third-person perspective.
4. In the synthesis, determining the essential theme of chronic pain was extracted from the meaning structures of all 34 participants. Some meaning structures were combined and/or retitled to achieve precision and complexity following the phenomenological tradition.

Phases 1 and 2 of the meaning analysis were performed by the first author. The meaning structures were formed and the final synthesis performed by a multidisciplinary team under the direction of an experienced author (A.P.).

The study had an adequate number of the participants as no new meaning units were found in the 34th participant’s interview.
indicating a saturated data. In the meaning analysis, the team bracketed their previous knowledge of pain aside, and described the experience of chronic pain as it presented itself to the participants.

**Results**

The analysis focused on ‘Negativity of chronic pain’ with the subthemes ‘State of reflection’, ‘Reconsidering values’, ‘Acceptance of pain’, ‘Support network’, ‘Altered self’, ‘Joys in life’ and ‘Pain dissociation’, which define chronic pain and are explained in the following section. Figure 2 presents the eidetic structure of ‘Revised negative meaning of chronic pain’ and the relationship between the subthemes. The most valuable subtheme, ‘State of reflection’ is the perspective from which the figure opens and should be read. Determining the value of the subthemes was possible using the subjective network and the synthesis of all 34 participants’ networks. The results were not checked by the participants.

**State of reflection**

The participants perceived themselves as unnecessary and disabled persons not needed by anybody. According to the participants, everyone’s life is sometimes miserable, but it does not mean that life is always miserable either with or without chronic pain. The participants described that in the state of reflection they reflected on their pain, life and themselves as persons from another perspective so that they could accept themselves with their deficits, and despite their losses, they were able to see that chronic pain could have a meaning in their lives. The usual interpretation of chronic pain was that it was like any other illness or harm that could
happen to anyone, but it was not allowed to destroy life and it was not the whole life. Thus, from a critical point of view, negativity of pain should act against itself; a person thinking of pain mainly negatively may have more distress, anxiety and depression resulting in increased pain and lower quality of life. The participants tried to exchange the former, only negative meaning to an alternative one which was not a positive one but related to individual reality.

P15 (Participant 15 in Table 1): My son (sighs). He was so young at that time. Although it was very hard for me to retire due to pain (pause) I still thought that there must be some reason for it. My son needed me, and pain gave me time to be with him.

The participants claimed that in order for the therapy to be successful, the therapist should see the person behind the pain and thus use a holistic approach. They emphasised that it is important that a therapist is caring, supportive and conversational, because a therapist who has new insight of pain and, hence, life revises the attitude towards and notions of chronic pain.

P18: My physiotherapist sees me as a whole. She does not only hear me but she listens to me, what I have to say about my pain. Somehow, she has the ability to ask questions, which makes me think about myself and my pain. I feel it’s great.

Reconsidering values
The participants described that they had to reevaluate their values. For many of them, values such as good financial status, fashion and attractive appearance had lost their importance. Chronic pain led to a beginning

Figure 2. The eidetic structure of ‘Revised negative meaning of chronic pain’. This figure illustrates how the subthemes are related to each other and how they function in a chain. In reality, the related subthemes partly overlap, but they are presented separate for clarity.
of new life with newly prioritised values. Small and basic things in life, such as the presence of spouse and family, became very important, and especially children were the main reason to live and to cope with pain. Conversely, during the worst episodes of pain, some participants got divorced and ceded their children as their only option for coping with pain because they were too tired to take care of them.

P14: They happened at the same time (pause). It bothers me, but the pain was so intense that I couldn’t take care of them. Since then, the children have been living with their father.

Some of the male participants stated that they used alcohol with or without drugs to alleviate their distress and pain. Surprisingly, those having a long history of alcohol abuse stated that they had no withdrawal symptoms at all; only a decision to stop drinking was required. For them, more valuable things in life gave better consolation and satisfaction than alcohol.

P24: I had a terrible pain in my leg and I could not move. Therefore, I gained 40 kilos and felt sorry for myself. I started to use alcohol and drank everything I could and gradually my drinking affected my relationship with my wife. Our marriage was not as good as it used to be, and alcohol and medication was not a good combination, which I noticed as intensive hangovers. I had to decide if I wanted to keep our marriage and if there was there any sense in drinking and using medication.

P6: I have thought that this is my destiny which I have to accept. I have also thought that it could be much worse. I am grateful that I am still alive. In the support group we have members who use canes and have intense pain. I do not know if this is right, but (pause) I am glad that I am not one of those.

Support network

According to the participants, family was the best supporter in chronic pain. The participants sought professional support from health care providers with poor success. Instead, support was found in peer-support groups, but the presence of family gave the best support and also an understanding that a patient should not be left alone with pain. Understanding and consolation were expected from family, whereas care and treatment were expected from health care providers.

Acceptance of pain

The participants highlighted confronting the reality of chronic pain – once having it – it had to be coped with for rest of their lives, and some them stated that they could never accept chronic pain, but they would try to cope with it. The participants described how they fought against pain, avoided it, and denied it, with poor outcomes. The more pretending or self-betrayal the participants engaged in, the more pain and distress they experienced. The participants had searched for help for their pain from medicine, and later also from alternative medicine. Eventually, with no success, the only possible option was to admit the reality of permanent pain. However, in the acceptance, there was a contradiction between the admittance and the aversive experience. Admittance supported the reality of living with pain, but the aversive experience resisted the admittance and desire to become pain free. Everyone needed help from professionals, friends and family members, but they also argued that they had to suffer and cope with the pain alone. Others just walk with you and are present when needed.
P5: It is the family that I have, and I have a feeling of belonging to the family. We like our companionship and have a really good time together. My family and my grandchildren give me the support I need by only being there.

The participants were quite sure that without the peer-support groups, some of them would not be alive. In the groups, every sensation and emotion was accepted without scepticism or disbelief. Things that were not received from health care, such as understanding, psychological support and acceptance, were received in support groups. One participant (P18) stated: ‘Only another chronic pain patient can understand a chronic pain patient’.

P6: In a support group you can see where you stand. You are understood and believed, and you can be sure that everything is confidential. Those without pain have no idea what pain is and what it does to you.

**Altered self**

Those pain patients who had accepted their pain stated that their quality of life had improved and they had grown as persons. The participants also considered themselves calmer and more self-confident. The amount of medication had decreased and the participants had acquired other strategies to alleviate pain as described in ‘Pain dissociation’ section. Life was clearer and simpler, with mercy and permission to be optimistic about future. Permission and mercy extended to all aspects of life. The participants claimed that without the complete cessation of their former life, they might not have known that there could be a better life. There was also a difference between pain and health in the way that pain is only ‘pain’ that does not affect your health. This insight meant that faith and hope returned into life again.

P21: Yes, I am happy though sometimes my pain gets worse. I have no other health problems besides pain. I feel that I am healthy, and I am in good condition. I have my family members to support me, and I know what to do and who to turn to if needed. The future is in my hands.

**Joys in life**

The participants described that they enjoyed the same things in life as before pain. Normal life had a new definition where the participants were happy with things that had been taken for granted before the onset of pain, such as watching the sun set or driving a car. One of the biggest joys was a reformed relationship with their spouse and children, as they were the most important supporters and reasons to live for.

P9: I enjoy ordinary things. My children are very important to me, and I know that I am important to them. I also enjoy my husband, who is so important to me.

**Pain dissociation**

The participants described different strategies to dissociate from their pain, mostly thinking about something other than pain. Some participants described how they forgot their pain when painting, laughing with friends or making love, which all were performed spontaneously with passion, enthusiasm and joy.

P13: I love painting (happily). It is like (pause) the most wonderful thing in life. When painting I forget time, place and pain. I can start painting at noon and (pause) my dogs are the only things for
me to indicate time passing as they squeal for me to take them out. After walking the dogs and feeding them, I can paint until early next morning.

**Discussion**

The main conclusion of this study was that there is a distinction between the aversive sensation and the experience of pain. The aversive sensation of pain usually has a negative meaning, but it does not mean that the meaning of the experience is also negative. Therefore, in chronic pain, pain itself may not be the core problem, but instead, the individual responses to it, based on individual meanings, a claim which is supported by psychological and phenomenological research. \(^8,17,18\) This main finding supports the notion that the basis of therapy should be on the dialogue with the patient. In this meaning analysis, the key meaning was the ‘State of reflection’ which was the beginning of coping with chronic pain. Reflection cooperated with values, support from the others and all these together contributed to accepting, and eventually to managing chronic pain. In a change, thoughts need to be scrutinised first because they are very often negative, such as, blaming, catastrophizing and emotional reasoning. \(^21\) In health care, it is essential to assist the chronic pain patient to look away from the negative pain-centred world, to widen the perspective of life and to realise that the content of life is much more than pain, a finding that is supported by Benedetti et al. \(^22\) The reformation of life and values is subjective, supporting the notions of Reynolds, \(^23\) Kneck et al. \(^24\) and Broom \(^25\) that in long-term illnesses, the patient interprets the meanings of the experienced illness from a subjective perspective. Values and motives can be related to each other. In the meaning analysis, it was concluded that if values are clear and solid, motivation for changes in life is high, and values are correspondingly altered by those motives. \(^8,11\) Poor motivation and vague values might be one of the reasons for poor adherence to therapy. Therefore, therapists should have the courage to ask the patient ‘What does the pain mean to you’?

For individual reasons, acceptance of pain takes a varying period of time because it is an iterative process, as has been noted in other studies. \(^12,26\) Originally, acceptance was not a coping strategy. \(^27\) Based on our results, it can be concluded that it is a combination of coping and acceptance, a mixture of active and passive strategies. Thus, acceptance of pain in our study was not only a rational decision, but a protracted process involving a complex mixture of unpleasant emotions and uncertainty, but also a humble optimism about living with chronic pain in the future.

The participants stated that they grew as persons to enjoy life again. One of the joys was belonging to support groups, where everyone was accepted and believed with confidence. As Reynolds \(^23\) suggests, in health care, chronic pain patients may be disbelieved and health care does not provide the help that chronic pain patients need the most: caring, understanding, consolation and hope for the better. This can be interpreted as suggesting that the efficacy of, e.g. physiotherapy does not depend only on, for example, exercise repetitions or mobilisation technique, but also on the therapist’s personal characteristics. In general terms, it seems that all the technical devices to detect the cause of pain and all the interventions that are performed to alleviate pain are quite far from what a chronic pain patient mostly needs, i.e. a caring human being and the genuine presence of another person.

The present study showed that the formerly restricted persons had changed by gaining a liberal and tolerant understanding that pain belongs to life and is not worth dying for. Instead of what cannot be done, they found out what they could still do; they
may not be as physically capable as before, but they are not worse persons. The altered self, realised that the psychosocial well-being was related to a reduction in pain, supported by Steinhaug. Joy in life also appeared in discriminating between pain and health. Chronic pain was not an illness but only 'pain' that did not affect health and more importantly, chronic pain did not necessarily alone make life miserable, indicating realism and an optimistic coping belief.

The pain education had lessened the participants’ fear of pain and they had better instruments to cope with pain than pills. Linton reached similar conclusions, namely that pain education ignored false positive signs of pain and contributed to the ability to cope better with pain. The participants’ disability decreased, and they lived as normally as possible when pain was not an obstacle, for instance, to marital sex life or an increase in physical activity. This indicates that in therapy pain, education is an essential part of treatment to correct the patient’s misbeliefs or maladaptive thoughts of pain. Thus, issues that are dealt with on a couch, which is the case in physiotherapy, are less important than the issues that are addressed by face-to-face conversations.

In summary, the results of the current study indicate that management of chronic pain was done with the aid of professionals, but most importantly, with the support of family members and in support groups. Family members’ unconditional support was crucial for survival and deepened the relationship with close ones. Children were the highest priority for surviving and staying alive. Without any personal changes during chronic pain, life would have continued in an unreflective and unsatisfying way. Overall, optimism, faith and hope for a better future were the participants’ strategy to carry on. However, some participants regarded pain as a monster that nobody could do anything about. Thus, chronic pain is not a pain of only one member of the family, but a pain of the whole family, which calls for a new way of thinking about chronic pain and therapy applications.

**Strengths and limitations**

The strength of the present study is that it provides a deeper understanding of chronic pain by emphasising its experiential nature. Regarding the limitations, we do not claim that this is the only eidetic structure of ‘Revised negative meaning of chronic pain’. However, the team’s systematic analysis provided credibility to the results. Many of the participants were interviewed and listened to for the first time, which might have influenced some meaning units in exaggerating their significance. Although, the results agree with other studies, they should not be generalised to all chronic pain patients or extrapolated to other cultures.

**Implications for practice**

The results indicate the distinction between the meaning of aversive sensation and the experience of pain. Pain clinicians should assist a chronic pain patient to reflect on the experience of pain instead of the sensation of pain. The experience of chronic pain is also situational; therefore, chronic pain management must be individual, comprising family members and the situation, in other words holistic.

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