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# Observational study

# Although unseen, chronic pain is real—A phenomenological study

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#### HIGHLIGHTS

- The Cartesian legacy lives strong in treatment of chronic pain despite recommendations.
- The usual statements by health care providers indicated disbelief and denial of pain.
- The biopsychosocial approach is only rhetoric.

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## ABSTRACT

**Background:** Research has emphasised the essential role of psychosocial risk factors in chronic pain. In practice, pain is usually verified by identifying its physical cause. In patients without any distinct pathology, pain is easily defined as imaginary pain. The aim of this qualitative study was to explore the invisibility of chronic pain, from the patients' perspective.

**Methods:** Thirty-four participants with chronic pain were interviewed. The mean age of the participants was 48 years, and 19 of them were women. For 21 of the participants, the duration of pain was more than five years, and most of the participants had degenerative spinal pain. The transcribed interviews were analysed using Giorgi's four-phase phenomenological method.

**Results:** The participants' chronic pain was not necessarily believed by health care providers because of no identified pathology. The usual statements made by health care providers and family members indicated speculation, underrating, and denial of pain. The participants reported experience of feeling that they had been rejected by the health care and social security system, and this feeling had contributed to additional unnecessary mental health problems for the participants.

As a result from the interviews, subthemes such as "Being disbelieved", "Adolescents' pain is also disbelieved", "Denying pain", "Underrating symptoms", "The pain is in your head", "Second-class citizen", "Lazy pain patient", and "False beliefs demand passivity" were identified.

**Conclusions:** In health care, pain without any obvious pathology may be considered to be imaginary pain. Despite the recommendations, to see chronic pain as a biopsychosocial experience, chronic pain is still regarded as a symptom of an underlying disease. Although the holistic approach is well known and recommended, it is applied too sparsely in clinical practice.

**Implications:** The Cartesian legacy, keeping the mind and body apart, lives strong in treatment of chronic pain despite recommendations. The biopsychosocial approach seems to be rhetoric.

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#### 1. Introduction

Pain is defined by the IASP, International Association for the Study of Pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage". Chronic pain is defined as pain lasting for more than three months, and its cause is rarely identified [1]. One of every five person experiences some type of chronic pain, and chronic pain accounts for more than two-thirds of all visits to physicians [2]. The consequences of pain can be divided to physical implications such as disabilities and restrictions in movements, and psychological implications, such as distress, anxiety, and depression [3]. Persons with chronic pain also suffer from loss of identity [4] and social isolation [5,6]. At present, there is increasing evidence regarding the effects of chronic pain, but the phenomenon of chronic pain is still poorly understood [7], possibly, also reflecting poor management of chronic pain. In a European pain survey, one third of chronic pain patients had received no treatment at all, 40% of them received inadequate treatment that affected their social and working lives, and only 2% of them underwent treatment managed by a pain specialist [8]. In a recent review, Sessle [9] calls for more pain education and management of chronic pain, away from the traditional medicine.

The biopsychosocial paradigm, originated in the study of Engel (1977), has proven to be the most heuristic understanding of chronic pain [2]. However, it does not explain the phenomenon of chronic pain and the individual meanings of it which, from the phenomenological point of view, define individual affects and its management [10]. As the chronic pain patient views the personal life through pain, the experience of pain needs to be understood individually, in order to perform individually tailored managements [5].

Pain does not have any diagnosis of its own. The ICD (International Classification for Diseases) is used to describe identified pathological abnormalities that might implicitly mislead the care providers to treat false-positive physiological findings. If pathophysiology cannot be empirically verified, pain is defined as psychosomatic rather than real [11–13]. One of the primary features of chronic pain is its invisibility [6,14], being real to the patient, but due to lack of physical findings it seems unreal to the others [6,13]. The aim of this study was to explore the invisibility of chronic pain, from the patient's perspective.

# 2. Phenomenological method

Generally, phenomenological method is a method to study experiences that are difficult to study with any other method. 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 [15].

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 has 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 and describe the structure of the experience and in analysis using an epoche', bracketing previous knowledge of pain aside [15].

#### 2.1. Study methods

#### 2.1.1. Participants

Eligible patients were informed about the study and asked if they would be willing to participate. Fifteen outpatients were recruited 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 inclusion criterion were: (a) chronic pain of at least 3 months 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. All enrolled 34 volunteers met the inclusion criteria representing a heterogeneous sample of chronic pain patients.

The ages of the participants ranged from 26 to 73 years. Of the participants, 19 were women and 21 were married. Half of the participants were retired, and a fifth worked full-time. Each of the participants could walk without any assistance but many needed help in tasks including household work. Most of the participants used a combination of medications. The individual and pain-related characteristics of the participants are presented in Table 1.

#### 2.1.2. Ethical considerations

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

# 2.1.3. Data collection

The first author (TO) collected the data by using open interviews at library café, at coffee shop, at participant's home, in a treatment room of the hospital, or in a meeting room of a peer-support group from May to November 2011 after contacting each participant by telephone to ensure his/her willingness to participate. A copy of the signed informed consent was also given to the participant. Every interview started with a short conversation before recording the interview. Field notes were not made during the interview.

The interviews were as open as possible by using open-ended questions [16] to allow the participant to tell about the experience of chronic pain as much as possible. The key statement was as followed: "Please, tell me about your chronic pain and how it started". Additional questions were used, depending on how much he/she revealed. Fig. 1 presents questions, which were used in one interview.

The individual interviews lasted from 45 to 90 min, and they were transcribed by a professional transcriptionist. The complete collection of the interviews consisted of 631 transcribed pages,

> Please tell me about your chronic pain and how it started. How did you feel about it? What does the pain mean to you? What is the worst issue with living with chronic pain? Can you tell me something more about "not being believed"? How do you explain it? What do you mean by saying "for a second-class citizen"? Have you noticed if you ever forget your pain? What do you think your family thinks of your pain? How have you coped to live with pain? How is your mental well-being with chronic pain? What do you think your future will be like?

Fig. 1. An example of questions which were used in one interview.

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