



Clinical pain research

## Adolescents' experience of complex persistent pain

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## HIGHLIGHTS

- The adolescents experienced pain that developed from bad to worse.
- They reported unpleasant bodily expressions and altered emotional wellbeing.
- They experienced a threatened identity and a risk of being stigmatised.
- They strived to keep up with friends and preserve normality.

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## ABSTRACT

**Background and aims:** Persistent (chronic) pain is a common phenomenon in adolescents. When young people are referred to a pain clinic, they usually have amplified pain signals, with pain syndromes of unconfirmed etiology, such as fibromyalgia and complex regional pain syndrome (CRPS). Pain is complex and seems to be related to a combination of illness, injury, psychological distress, and environmental factors. These young people are found to have higher levels of distress, anxiety, sleep disturbance, and lower mood than their peers and may be in danger of entering adulthood with mental and physical problems. In order to understand the complexity of persistent pain in adolescents, there seems to be a need for further qualitative research into their lived experiences. The aim of this study was to explore adolescents' experiences of complex persistent pain and its impact on everyday life.

**Methods:** The study has an exploratory design with individual in-depth interviews with six youths aged 12–19, recruited from a pain clinic at a main referral hospital in Norway. A narrative approach allowed the informants to give voice to their experiences concerning complex persistent pain. A hermeneutic analysis was used, where the research question was the basis for a reflective interpretation.

**Results:** Three main themes were identified: (1) a life with pain and unpleasant bodily expressions; (2) an altered emotional wellbeing; and (3) the struggle to keep up with everyday life.

The pain was experienced as extremely strong, emerging from a minor injury or without any obvious causation, and not always being recognised by healthcare providers. The pain intensity increased as the suffering got worse, and the sensation was hard to describe with words. Parts of their body could change in appearance, and some described having pain-attacks or fainting. The feeling of anxiety was strongly connected to the pain. Despair and uncertainty contributed to physical disability, major sleep problems, school absence, and withdrawal from leisure activities. Their parents were supportive, but sometimes more emotionally affected than themselves. The adolescents described how they strived for normality and to not become an outsider. Being met with necessary facilitation from school was important, as well as keeping up with friends. These adolescents had all been treated by an interdisciplinary pain team, and stated that they had an optimistic view of the future, despite still having some symptoms.

**Conclusions:** The study provides new insights into adolescents' own experiences of complex persistent pain occurring unexpectedly, developing dramatically over time, and influencing all parts of their everyday lives. The adolescents entered vicious cycles, with despair and decreased physical and social functioning, with the risk of isolation and role-loss. However, these young people seem to have a strong motivation to strive for normalcy.

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**Implications:** These findings may encourage healthcare providers to perceive adolescents' persistent pain through the lenses of a biopsychosocial approach. We suggest that further research into adolescents with persistent pain should include longitudinal studies of quality of life and gender perspectives.

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## 1. Introduction

Persistent and recurrent (chronic) pain is a common phenomenon in adolescents [1,2], particularly musculoskeletal pains, which include different conditions, like arthritis, hypermobility, fibromyalgia, growing pains, and complex regional pain syndrome (CRPS) [3]. CRPS is a chronic condition that is characterised by spontaneous or evoked amplified pain usually starting in a distal extremity [3,4]. The understanding of CRPS remains incomplete with multiple mechanisms involving both central and peripheral nervous systems, inflammation, altered somatosensory representation in the brain, genetic factors, and psychophysiological interactions [3,4]. The pathogenesis of paediatric CRPS is possibly not entirely the same as adult CRPS [3]; it occurs more frequent in girls and the distal lower extremity is most commonly affected. The pain and allodynia is out of proportion to the inciting event, often a relatively minor trauma, like a sprain, twist, dislocation, or soft tissue injury, or even no previous injury to recall [5–8]. Symptoms associated with CRPS are pain, allodynia, hyperalgesia, swelling, and/or changes in skin colour of the affected limb, dry and mottled skin, hyperhidrosis, and trophic changes of the nails and hair [3].

When young people are referred to a pain clinic, they usually have amplified pain signals, with pain syndromes of unconfirmed ethology, such as fibromyalgia and CRPS. Pain is more complex than can be explained by tissue damage alone, and it seems to be related to a combination of illness, injury, psychological distress, and environmental factors [9]. The biopsychosocial model, introduced by Engel in 1977 [10], has become an accepted way of explaining and understanding illness, and describes how physical, psychological, and social aspects of pain interact with each other, can worsen one another, and even lead to pain syndromes [11,12]. Amplified musculoskeletal pain syndrome (AMP) is a generic and descriptive term used to describe a condition where the body registers mildly painful or non-painful stimuli as very painful [3]. The patient tries to avoid pain by avoiding provoking movement, which may lead to functional disability [9]. Adolescents with persistent pain commonly report higher levels of distress, anxiety, sleep disturbance, and lower mood than their peers, but depression is often masked in this population [13–16]. Experiences of social isolation and unwelcome dependency on parents are common, and they may be in danger of entering adulthood with mental and physical problems.

Qualitative research can provide important knowledge regarding the patient's perspective of life with persistent pain [17,18], which will also contribute to a better tailored treatment regimen. Meldrum et al. [19] suggested that interviewing children and adolescents with chronic pain using a narrative approach, also may provide positive changes towards a "better quality of life". A narrative review highlights the lack of research into the lived experience of chronic pain, particularly CRPS [17]. Thus there seems to be a need for further qualitative research into the lived experience of adolescents with persistent pain in particular. The aim of this study was to explore adolescents' experiences of complex persistent pain and better understand how it impacted on their everyday life.

## 2. Material and methods

A qualitative exploratory design with individual in-depth interviews was chosen, as this is a method considered well-suited to

provide insight into themes from the subjects' own perspectives [20].

### 2.1. Sample and setting

The participants were recruited from a pain clinic at a main referral hospital in Norway. The inclusion criteria were adolescents aged 12–19, speaking the Norwegian language, being treated for complex persistent pain using a multidisciplinary treatment approach within the last three years, and willing to participate. At the time of the study, the pain clinic treated about 10 patients in the targeted age group annually. A nurse at the clinic telephoned potential participants and asked if they were willing to receive written information about the study. Nine out of the ten youths who were contacted accepted the invitation. After one week, these nine were contacted again and six were able and willing to participate in the study. This purposive sample of six informants included four girls and two boys, of whom four (three girls and one boy) had been diagnosed with CRPS and two (one girl and one boy) suffered from extreme muscle pain. Their conditions had lasted from one to five years and the interviews were conducted over a period of six months.

### 2.2. Data collection

An interview guide was developed for the purpose of the study and contained open questions about how the adolescents experienced the pain, how it started, how the pain affected relations with family and friends, leisure and school activities, and how they felt about having these pains. The first author conducted all the interviews and the interview guide was used in varying degrees depending on how the interview proceeded. A narrative approach allowed the informants to give voice to their experiences concerning complex persistent pain [19]. To promote a good and secure setting the interviews were conducted in locations preferred by the informants, either at the hospital or in their home. Each interview was audio recorded and lasted for about one hour. In addition, main impressions were noted in a diary after each interview.

### 2.3. Data analysis

A hermeneutic approach was used, with the research question as basis for a reflective interpretation. The purpose of hermeneutical interpretation is to obtain a valid understanding of the meaning of the transcribed text [21]. The recorded interviews were transcribed verbatim and analysed as suggested by Malterud [22], and Kvale and Brinkmann [21]. The two authors analysed the transcribed text. This involved an initial reading of the transcribed text to acquire an overview, and a first impression and intuitive ideas and comments were noted in a diary. Meaning units were discussed, identified by colour coding and sorted into 11 categories across all the interviews. The third step was to develop and reorganise the content of the initial categories by identifying nuanced meanings, patterns, and variations. Lastly the main contents of three main themes presented in this paper were summarised. Verbatim quotations are used to underpin and exemplify our findings. The results were

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