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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 ethology, 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.

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

additionally assessed in light of previous empirical studies and theoretical publications.

2.4. Trustworthiness

Qualitative research must be seen as complementary to quantitative study designs, with different types of data used and questions to be answered. The principles of relevance, validity and reflexivity are seen as standards for qualitative research [20]. Validity evaluation is an on-going process and findings were scrutinised in light of the interview recordings and transcriptions of these [21]. The diary was a valuable tool for reflection throughout the analytic process as it helped the researchers to remember initial ideas and to maintain a critical viewpoint.

What finally emerges from the narratives also depends on the pre-understandings of the researchers. To avoid bias and to enhance rigour, the two authors discussed their main impressions and interpretations throughout the analytic process. Different interpretations are fruitful when doing interview research [21]. In qualitative research, generalisation is based on identifying recurrent social processes rather than sampling individuals [23], and small samples may sometimes produce rich insights. Even the small sample in this study contained enough variation along key demographic and theoretical dimensions to make it possible to draw some conclusions beyond the particular individuals being studied.

As the first author is a pain clinic nurse, her closeness to the field may have influenced her ability to reflect critically upon the findings. However, the first author's knowledge of the patient group and context helped to gain the informants' confidence and to recognise their stories as common among adolescents suffering from persistent pain. The treatment by the interdisciplinary pain team was more or less finished at the time of the interviews, which is reflected in the results.

3. Results

At the time of the interview these adolescents stated they had a good life and an optimistic view of the future, despite the fact that they still had some symptoms and were not fully recovered: "Well, I think it's going to be okay, I am at least not afraid to get a relapse or anything, I think this is going in the direction now" (Siri). The narratives being presented in this paper are the adolescents' personal stories, as they recall how the pain affected the physical, emotional, and social part of their lives.

3.1. A life with pain and unpleasant bodily expressions

These adolescents had considered themselves as healthy young people prior to occurrence of the pain. For some of them, the strong pain sensation emerged from a minor injury, for instance a sprained ankle or a broken bone, and from there it had developed over time. Others described the first pain event like a "cramping attack", or some kind of seizure impossible to relate to any specific event. One of the informants had a minor surgery prior to development of excruciating pain. A common denominator in the interviews was stories about experiencing the pain as increasing over time. Siri explained:

> "About 2 years ago, I had an ankle sprain in the gym – that started it all. I used crutches for at least two months. After about one year, when I started exercise more, it triggered severe pain – like I was roaring in pain every evening up to 7–8 hours."

The informants described their pain as the worst sensation they had ever experienced. All of them had experienced pain at the top level – 10 – when using the numeric rating scale (NRS), where 0 is *no pain* and 10 is *the worst possible pain*: ". . .at best, it was like a 7½ up to 8, and at the worst it was a 10". This girl also described how her assessment of pain changed as the pain developed, and became worse over weeks and months. Pain she earlier had described as a "10" become a "9", based on the total experience. It was hard to find words to describe the pain sensation. The adolescents said it was inconceivably strong and incomparable to any known feeling, and used words like *stab wounds, phantom-pain, extreme pressure, stinging, burning, like a pulse, like an ankle sprain for each step you take, like having your back continuously pounded.*

All the adolescents with CRPS had experienced that a leg or an arm had changed in appearance. They described the colour as bluish, with red spots, yellow or purple, and the limb could be oedematous or thin. One of the girls had to wear an orthosis to keep her foot in the right position, because she had lost control over her foot and could not move it. They also described increased sensitivity for cold and decreased feeling of the difference between cold and hot:

> "I did not feel temperatures at all, like the snow was cold or hot" (Hanne).

Even so, a common experience was that staying out in cold winter temperatures increased the pain intensity. This altered sensation for temperature, particularly cold, lasted long after the pain had abated and physical functioning was recovered.

The boys tended to describe bodily sensations differently from the girls. They mentioned hyperventilation, fainting attacks and cramping:

> "It is like I actually fall to the ground and I lose control and my entire body shakes" (Tom).

The girls said they expressed their feelings by crying, shouting, or roaring out their pain. A couple of them suffered minor episodes of breathing problems when the pain intensity was extreme, but this was different from the boy's description of shaking bodies. These various attacks could occur several times a day and last for hours.

The informants described gradually decreased physical functioning, mostly emerging with the onset of CRPS. Some had to use physical aids such as crutches, orthosis, or even a wheelchair for a while. The informants most seriously affected found it hard to wear shoes or even socks. They could not tolerate anything touching their foot or any movement at all, and after a while it affected the functioning of the entire body. The adolescents with muscle pain were still able to walk, but their functioning was decreased, as well. The unpredictability of what kind of activity would cause flare-ups, described as "pain attacks", was a challenge. Several hours a day their pain kept them from doing anything, and to lie down was the only way to find some relief:

> "Normally it gets better. Like last time I had pain, I laid down on the floor with a blanket over me, and it took about 1 to 2 hours before I managed to get up" (Anne).

Sleep disturbances were an important issue for all the informants. They spent a lot of time in bed or on a couch trying to get some rest, but they all reported lack of sleep and feeling tired:

> "I could stay awake all night. Once I hadn't slept in a week, I fell asleep in the middle of a lecture at school and slept for 2 to 3 hours. Similar things happened several times – it has been hard to get some sleep" (Tom).

Some used words like "a vicious cycle", when describing how they in spite of their effort to get some rest, experienced insomnia and gradual energy loss.

3.2. The feeling of an altered emotional wellbeing

Surprisingly the adolescents' emphasised the feeling of anxiety only to a limited degree in their narratives. Two informants had been afraid that they had a dangerous diagnosis. Some talked about fear of the pain itself, but described it as emotions in the past:

> "Well, earlier it was like I was afraid of having pain, but now I have another attitude, living normally. And if the pain comes it comes. . ." (Ola).

One told about fear in conjunction with a pain attack. He had experienced arms and legs being completely paralysed and said "that time I was really scared", meaning he was afraid of permanent paralysis.

The informants seemed to be more concerned about the despair they felt during episodes of severe pain. When examinations, blood tests, and X-rays offered no answer to their pain this caused them to feel alone and tended to increase their despair. It made them feel sad and sorry for themselves, and emphasised how rare and unfortunate their situation was:

> "They [the physicians] have never seen cases like this in Norway before, being as bad as me. They have seen girls with some stinging pain now and then, but nothing like what I have" (Kristine).

The feeling of anxiousness was amplified when they all described how they were given different explanations and advice from healthcare providers. The adolescents with CRPS had received conflicting advice such as "use crutches, don't move the foot" or "walk on the bad foot even if it hurts", and one adolescent was even put in a cast for a while.

All the adolescents had felt that the physicians disliked labelling their problems as CRPS, and the information they found on the Internet was negative, and even if they heard about others with the same diagnosis, they were sceptical as to whether it was true, since they never really had met anyone with a similar problem. One informant had lost all hope and mentioned feeling deep depression. It was hard to address the negative feelings that accompanied the pain, and they found different ways to cope with it: "I had this habit of punching a wall with my fists, just to get something out" (Ola). Some chose not to let their situation bother them, or at least pretend they were not bothered: "It hurts, but it's okay – I don't give a damn shit" (Tom). The girls did not let their surroundings see their negative feelings and managed to appear positive and smiling:

> "Because I am like a happy girl, an optimist, managing to be happy regardless of the situation I'm in. I try to think; this will pass . . ." (Siri).

One of the informants had to walk up a hill to get to school. She had to crawl to manage that hill and the feeling of embarrassment when everybody laughed at her was terrible. Instead of getting angry she blamed herself and laughed together with her peers and tried to see the situation as amusing.

Another common concern among the informants was that the pain might be all in their imagination, or that people might believe so. When physicians were not able to explain the pain by tissue damage alone and these young patients were sent to a psychologist, they felt they were giving up and that the pain was believed to be imagined:

> "They thought maybe this was something psychological, and I remember how it irritated me. I didn't feel that this was something imagined, but I felt they believed so" (Kristine).

3.3. The struggle to keep up with everyday life

Everyone mentioned absence from school. One of the interviewees had missed two years of school, and was starting high school for the third time. The adolescents were concerned about their education and worried considerably about their academic achievement. They invested much time and effort in trying to do homework, but had problems concentrating both at school and at home. However, they noted that teachers and school leadership made an effort to help when they were informed about their health problems. Individual facilitating included adapted school hours, permission to drop some tests, or staying inside the building during break times when it was cold outside. This contributed to regaining a better quality of life.

All the informants had been physically active young people participating in various kinds of sports like handball, football/soccer, skiing, swimming, dancing, etc. before the pain started. Although the pain limited their activity, some of them found it hard to stop and they strained to carry on. One of the girls even went skiing although she thought one of her legs was broken. Her pain became unbearable, but she did everything she could to be like everyone else. Sports also represented an important part of the adolescents' social lives and an important part of most of the informants' identity:

> "It was difficult not being able to do what I wanted to. But I went down and talked to them and they also visited me in the hospital. That was very nice! It was important to feel that I was still a part of the group, because I am still the same person, although I can't do all the normal activities" (Kristine).

Despite the fact that the informants worked hard to continue their normal activities, they had to stop. This meant an existence with low energy and few activities. To go shopping, enjoy the cinema, or meet with friends were for the most part out of their reach. They found that friends pulled away during difficult periods, something that made them feel forgotten. Invitations, telephone messages, and e-mails became few and far between. They tended to blame themselves for this, as they did not have the strength to keep in touch. Some had friends who did not give up on them, however:

> "Well, I managed to keep in touch with my friends by Internet and phone, so I didn't fall out of touch socially, although I was not directly together with them" (Siri).

The girls talked about how they tried to make their friends understand and keep in touch with them. It was a challenge to get sympathy and to be believed by friends and neighbours, especially if there was "no sign of the pain". The boys said that they did not talk with friends about their pain and negative experiences, as Ola pointed out: "Boys are boys, you know". Some managed to be "normal" without anyone knowing about their problem until they suffered a serious painful episode and fainted or had a seizure at school. One reason they did not want to be asked about their pain was the fact that it was hard to describe the experience and they were themselves uncertain about the reason for their pain.

It was hard to be an outsider, not being invited to parties or asked to join their peers. Even if they did not have the energy to join in, they would have preferred to have been asked and given the opportunity to say "no" rather than not be asked.

The relationship with parents and family were described as close, with a strong feeling of dependency and that their parents really tried to help: "Mummy gave me massages and dad lit the fire in the fireplace" (Kristine). But they also noticed their parents' anxiety: "They (the parents) were pretty hysterical the first time; they called the hospital, asked me to breathe in a bag and. . ." (Tom) and

some expressed that their parents suffered even worse than they themselves because they had to watch their child suffer without being able to help. Some told about the difference between mothers and fathers: as their daddies tried to make jokes and create distractions, "while mummy felt it as bad as I did my self" (Siri). After a while the youths tried to spare their parents by not always telling them about pain attacks or bad days, and tried to spare their siblings by encouraging them to live their lives as usual.

4. Discussion

4.1. The pain experience and its impact on the physical and emotional wellbeing

The findings show how extreme the pain sensations these adolescents, emerging from nowhere and without any obvious causation, were experienced. Even if they described their symptoms as very much similar to findings in other studies of severe pain syndromes, like CRPS [3,5–8], their conditions were not immediately recognised by healthcare professionals. The lack of medical validation may have been one of the contributing factors to their feeling of being different, alienation, and loneliness from the very beginning, which also escalated the pain. The fact that young people may use other words than adults to describe their pain sensations may furthermore represent a risk to be interpreted less seriously by the physicians. "Extreme pressure", "pulsation you can feel right down to your toe", or "like being hit in your back all the time", do not sound as precise as burning, shooting, stabbing, or electrical – expressions more often mentioned in literature [24]. This however is something to expect, as young people neither have that many prior experiences to compare with nor a medical vocabulary. The lack of experience may furthermore explain why they had to extend the scale of self-reported pain intensity as the suffering increased over time. When considering pain as a biopsychosocial phenomenon [11,12], reporting "10" will always represent the total experience of pain based on biological, psychological, and social factors interacting at a particular point in time.

The respondents talked about fear as something that of the past, strongly connected to the experience of pain, as well as concern of having a dangerous disease. This anxiety was reinforced when physicians claimed they had never seen any case like theirs before, or when they fainted, suffered cramping attacks etc., and no one could explain why. Some of the respondents recognised that they had been more worried about getting a new episode of pain than the amount of pain such episodes actually produced. This corresponds with previous research that found "fear of pain" being related to both anticipated and actual pain [25]. An elevated risk for anxiety when having persistent pain has also been found in the general population of adolescents as well as among patients with CRPS [26,27]. Fear of pain is described as a major component of the changed behaviour following complex persistent pain [27,28]. Findings in this study suggest that contradictory advice from healthcare providers whether rest or activity is the better option, probably contributed to increased uncertainty and fear of movement, which is a phenomenon described in Vlaeyen and Linton's "fear-avoidance model" [29]. The informants described how their functioning became reduced and the challenge of not knowing what activity might cause intensified pain. This contributed to the behaviour of lying down, attempts to rest and generally avoiding flare-ups or increased pain. Even though they felt some alleviation from pain, they also noticed how this behaviour brought them into vicious cycles of decreased energy over time. Such avoidance of movement is found to amplify pain over time as well as bring young people deeper into physical, social, and mental disability [9,30].

Even though they appreciated their parents' care and support, it also created some concerns as the youths wanted to spare their parents worry by not voicing all episodes of fainting or despair. The respondents mentioned how their mothers and fathers reacted differently. Previous research has found that mothers showed more ruminating thoughts about their child's chronic pain, while fathers displayed more distracting responses [31]. When parents strive to fulfil a nurturing parental role, it puts them into a position of being constantly "on call" for their children in pain [32]. Assessing adolescents' fear-avoidance beliefs is important because it is found to be a mediator of an association between parental protectiveness and activity limitations [30].

Sleep disturbances was common and severe among the adolescents, which for some resulted in a collapse, and a feeling of increased fatigue. This is a common phenomenon among adolescents with persistent pain [33], which is serious as insomnia is found to increase the risk of depression and functional disability [15,33,34].

4.2. The strive to keep up with friends and preserve normality

The respondents communicated how they, as long as possible, pushed themselves to participate in normal activities. Rather than telling their friends about the pain, they risked humiliation when crawling up a hill to school, or even fainting whilst doing normal activities. The struggle to keep normality and a desire to belong to their group seem vital in order to maintain identity. Young people with rheumatic disorders have described a similar profound sense of being different or unable to achieve their full potential [18], and when the pain is not apparent, the worst experience is not being believed. Being able to keep up with friends seems to influence positively upon the adolescent's self-image [35]. During the worst periods they kept in contact through social media which served as a resource for maintaining contact with friends. In recent years young people normally spend more time at home and use social media, internet games, and communicate by internet, rather than meeting each other face-to-face [36].

Altogether, the efforts to keep up with friends and strive for normality may be seen as a way to preserve their identity in the group, rather than becoming stigmatised [18]. When people fall out of what characterises a normal development of identity, they are, according to Goffman [37] at risk of losing the role as normal and gain a role as stigmatised. In healthy adolescents a good quality of life is described as a positive cycle; feeling good, having a positive self-image, good family relations, and most importantly, having friends. These are significant factors that reinforce each other [35,38]. Trends in today's society such as expectations of excelling in school, having a perfect body, the right kind of friends, doing well in sports and so on, may contribute to pressure and strain on young people [36]. Skarderud [39] highlights the fact that bodily expressions like pain may be seen as an accepted way to show the world that everything is not okay. When it comes to stigmatisation, the time from being included to becoming an outsider may be brief [37].

4.3. Serious consequences of limited attendance to school and social activities

Severe limitations of normal activity in daily life with high frequency of absence from school, dropping out of leisure activities, and lacking energy to meet friends, are significant problems for young people with persistent pain [40–42]. Having to change direction or being an outsider regarding school represents a double threat: becoming an outsider and not getting a good education. This is well-founded as frequent absences from school are particularly harmful to children and adolescents with pain, particularly as

this will affect their maturing significantly [14]. Staying away from school creates a threat of being misunderstood and discriminated against and may intensify children's feelings of stress and grief [9]. To help adolescents to complete their education has great social and economic advantages. Despite the struggle to keep up with school; the findings in this study showed that the adolescents received support, understanding, and the necessary facilitation from school, assuming the teachers were given information about managing the pain. Nevertheless, the youths in our study represent a group at risk of stigmatisation and dropping out of school because of poor self-esteem and possible loss of roles. This reflects findings among an adult population of chronic pain sufferers, indicating that adjustment problems and depression are partly associated with changes regarding social roles and identity [43].

5. Conclusions

The study provides insights into how adolescents may experience persistent pain that emerges from a simple injury or without any obvious causation. The findings indicate some differences in pain-behaviour and expressions of girls and boys, but this need to be further investigated in a larger study. Even though pain is an accepted bodily symptom, persistent, severe pain as with CRPS, may bring young people into a situation of threatened identity and risk of stigmatisation. The feeling of not being understood or taken seriously causes despair and decreased physical function, which may lead to vicious cycles, with a risk of isolation and role-loss. However, the adolescents in this study seem to have a strong motivation to strive for normalcy and identity preservation. In spite of the severe situation they had been in prior to treatment, these adolescents claimed to have a good life and an optimistic view on the future at the time of interview, even though they still had some pain.

6. Implications

Hopefully, these findings will encourage healthcare providers to take an interest in young people suffering from persistent pain, and perceive their situation through the lenses of a biopsychosocial approach. The benefits of understanding and facilitating treatment so that young people preserve normal lives are invaluable both for the person and the society. We suggest that further research into adolescents with persistent pain should include longitudinal studies of quality of life and gender perspectives.

Ethical issues

The Regional Committee of Medical Ethics approved this study. Both the adolescents and their parents gave informed consent. Patient confidentiality is secured from interviews to publication. The youths' stories were held in confidence from parents or healthcare professionals, and the informants are given fictive names. The participating adolescents' were informed that they were free to withdraw from the study at any time. This would not influence their standing with the hospital.

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Conflicts of interest

None.

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References

[1] Perquin CW, Hazebroek-Kampschreur AA, Hunfeld JA, Bohnen AM, van Suijlekom-Smit LW, Passchier J, van der Wouden JC. Pain in children and adolescents: a common experience. Pain 2000;87:51–8.
[2] Roth-Isigkeit A, Thyen U, Raspe HH, Stoven H, Schmucker P. Reports of pain among German children and adolescents: an epidemiological study. Acta Paediatr 2004;93:258–63.
[3] Weissmann R, Uziel Y. Pediatric complex regional pain syndrome: a review. Pediatr Rheumatol Online J 2016;14:29.
[4] Bruehl S. Complex regional pain syndrome. BMJ 2015;351:h2730.
[5] Sherry DD. Complex regional pain syndrome in children. UpTo Date [Internet]; 2013.
[6] Kachko L, Efrat R, Ben Ami S, Mukamel M, Katz J. Complex regional pain syndromes in children and adolescents. Pediatr Int 2008;50:523–7.
[7] Low AK, Ward K, Wines AP. Pediatric complex regional pain syndrome. J Pediatr Orthop 2007;27:567–72.
[8] Wilder RT. Management of pediatric patients with complex regional pain syndrome. Clin J Pain 2006;22:443–8.
[9] Clinch J, Eccleston C. Chronic musculoskeletal pain in children: assessment and management. Rheumatology 2009;48:466–74.
[10] Engel GL. The need for a new medical model: a challenge for biomedicine. Psychodyn Psychiatry 2012;40:377–96.
[11] Gatchel RJ, McGeary DD, McGeary CA, Lippe B. Interdisciplinary chronic pain management: past, present, and future. Am Psychol 2014;69:119–30.
[12] Twycross AWA. Pain: a biopsychosocial phenomenon. In: Twycross A, Dowden S, Stinson J, editors. Managing pain in children: a clinical guide for nurses and healthcare professionals. 2nd ed. Wiley Blackwell; 2014. p. 36–45.
[13] Cohen LL, Vowles KE, Eccleston C. The impact of adolescent chronic pain on functioning: disentangling the complex role of anxiety. J Pain 2010;11:1039–46.
[14] Eccleston C, Bruce E, Carter B. Chronic pain in children and adolescents. Paediatr Nurs 2006;18:30–3.
[15] Kanstrup M, Holmstrom L, Ringstrom R, Wicksell RK. Insomnia in paediatric chronic pain and its impact on depression and functional disability. Eur J Pain 2014;18:1094–102.
[16] Palermo TM. Impact of recurrent and chronic pain on child and family daily functioning: a critical review of the literature. J Dev Behav Pediatr 2000;21:58–69.
[17] Johnston CM, Oprescu FI, Gray M. Building the evidence for CRPS research from a lived experience perspective. Scand J Pain 2015;9:30–7.
[18] Tong A, Jones J, Craig JC, Singh-Grewal D. Children's experiences of living with juvenile idiopathic arthritis: a thematic synthesis of qualitative studies. Arthritis Care Res 2012;64:1392–404.
[19] Meldrum ML, Tsao JC, Zeltzer LK. I can't be what I want to be: children's narratives of chronic pain experiences and treatment outcomes. Pain Med 2009;10:1018–34.
[20] Malterud K. Qualitative research: standards, challenges, and guidelines. Lancet 2001;358:483–8.
[21] Kvale S, Brinkmann S. Det kvalitative forskningsintervju. Oslo: Gyldendal akademisk; 2010.
[22] Malterud K. Kvalitative metoder i medisinsk forskning: en innføring. Oslo: Universitetsforl; 2011.
[23] Silverman D. Interpreting qualitaive data. 5th ed. Los Angeles, London, New Delhi, Singapore, Washington, DC: Sage Publications; 2014.
[24] Borucki AN, Greco CD. An update on complex regional pain syndromes in children and adolescents. Curr Opin Pediatr 2015;27:448–52.
[25] Lyby PS, Aslaksen PM, Flaten MA. Is fear of pain related to placebo analgesia? J Psychosom Res 2010;68:369–77.
[26] Hoftun GB, Romundstad PR, Rygg M. Factors associated with adolescent chronic non-specific pain, chronic multisite pain, and chronic pain with high disability: the Young-HUNT Study 2008. J Pain 2012;13:874–83.
[27] Cruz N, O'Reilly J, Slomine BS, Salorio CF. Emotional and neuropsychological profiles of children with complex regional pain syndrome type-I in an inpatient rehabilitation setting. Clin J Pain 2011;27:27–34.
[28] Logan DE, Williams SE, Carullo VP, Claar RL, Bruehl S, Berde CB. Children and adolescents with complex regional pain syndrome: more psychologically distressed than other children in pain? Pain Res Manag 2013;18:87–93.
[29] Vlaeyen JW, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. Pain 2000;85:317–32.
[30] Wilson AC, Lewandowski AS, Palermo TM. Fear-avoidance beliefs and parental responses to pain in adolescents with chronic pain. Pain Res Manag 2011;16:178–82.
[31] Hechler T, Vervoort T, Hamann M, Tietze AL, Vocks S, Goubert L, Hermann C, Wager J, Blankenburg M, Schroeder S, Zernikow B. Parental catastrophizing about their child's chronic pain: are mothers and fathers different? Eur J Pain 2011;15:515–9.

[32] Maciver D, Jones D, Nicol M. Parents' experiences of caring for a child with chronic pain. Qual Health Res 2010;20:1272–82.
[33] Palermo TM, Toliver-Sokol M, Fonareva I, Koh JL. Objective and subjective assessment of sleep in adolescents with chronic pain compared to healthy adolescents. Clin J Pain 2007;23:812–20.
[34] Sivertsen B, Harvey AG, Lundervold AJ, Hysing M. Sleep problems and depression in adolescence: results from a large population-based study of Norwegian adolescents aged 16–18 years. Eur Child Adolesc Psychiatry 2014;23:681–9.
[35] Helseth S, Misvaer N. Adolescents' perceptions of quality of life: what it is and what matters. J Clin Nurs 2010;19:1454–61.
[36] Bakken A. Ungdata 2016, Nasjonale resultater. NOVA Rapport; 2016.
[37] Goffman E. Stigma: om afvigerens sociale identitet. Frederiksberg: Samfundslitteratur; 2009/1963.
[38] Haavet OR, Saugstad OD, Straand J. Positive factors associated with promoting health in low-risk and high-risk populations of 15- and 16-year-old pupils in Oslo, Norway. Acta Paediatr 2005;94:345–51.
[39] Skarderud F. [The communicating body – eating disorders and culture]. Tidsskr Nor Laegeforen 2004;124:2365–8.
[40] Haraldstad K, Sorum R, Eide H, Natvig GK, Helseth S. Pain in children and adolescents: prevalence, impact on daily life, and parents' perception, a school survey. Scand J Caring Sci 2011;25:27–36.
[41] Hunfeld JAM, Perquin CW, Duivenvoorden HJ, Hazebroek-Kampschreur AAJM, Passchier J, van Suijlekom-Smit LWA, van der Wouden JC. Chronic pain and its impact on quality of life in adolescents and their families. J Pediatr Psychol 2001;26:145–53.
[42] Roth-Isigkeit A, Thyen U, Stoven H, Schwarzenberger J, Schmucker P. Pain among children and adolescents: restrictions in daily living and triggering factors. Pediatrics 2005;115:e152–62.
[43] Harris S, Morley S, Barton SB. Role loss and emotional adjustment in chronic pain. Pain 2003;105:363–70.