

Characteristics of children and adolescents at the Switzerland-wide first ambulatory interdisciplinary pain clinic at the University Children's Hospital Basel – a retrospective study

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Summary

AIMS OF THE STUDY: Given the long history of underestimating chronic pain in children and adolescents, we lack valid data on its assessment and treatment. The psychological and economic burden for patients, their families and society is substantial. The aim of this study was to assess patient characteristics of the first ambulatory interdisciplinary clinic for children and adolescents with chronic pain in Switzerland and compare them with data from other international centres.

METHODS: All patients of the ambulatory interdisciplinary pain clinic at the University Children's Hospital in Basel during the period from 4 January 2012 to 4 July 2016 were included in this retrospective study. Data were collected from the patients' medical records and from a questionnaire, which the patients and their parents received and completed in advance of their first visit. Demographic information, pain, referral, social environment, therapies and school absences of the patients were statistically analysed with means, percentages, 95% confidence intervals (CIs) and standard deviations (SDs).

RESULTS: Of the 135 patients included in this study, 80% were female and the mean age of all patients was 13.95 years (95% CI 13.5–14.4). The commonest pain presentations were: musculoskeletal (38%, 95% CI 0.30–0.46), back (25%, 95% CI 0.18–0.33), multiple regions (21%, 95% CI 0.15–0.28) and headache (7%, 95% CI 0.03–0.12). Mean duration of pain until the patients came to the clinic was 24.5 months (95% CI 19.82–29.22). Physiotherapy (71%, 95% CI 0.63–0.79) and non-opioids (50%, 95% CI 0.42–0.59) were the most used therapies before the first meeting. Psychotherapy (52%, 95% CI 0.44–0.61), most often using a psychosomatic therapeutic approach (psychosomatic therapy) 34% (95% CI 0.26–0.42), physiotherapy (36%, 95% CI 0.27–0.44) and non-opioids (33%, 95% CI 0.25–0.42) afterwards. The

mean number of school absences during the last month before the first visit was 5.1 days per month (95% CI 3.48–6.73). The parents of our study participants suffered more often from psychiatric diseases than the mean Swiss population.

CONCLUSIONS: The average of more than 2 years of pain before referral to the clinic seems to be a long time. Assuming that specialised support is mandatory for young patients with complex pain syndromes, the referral time should be reduced. Furthermore, patients with headache were underrepresented in Basel compared with other centres. Interestingly, in our study, patients' parents suffered more often from psychiatric diseases than the mean Swiss population.

Keywords: chronic pain, children, adolescents, interdisciplinary, characteristics

Introduction

There is a long history of underestimating chronic pain in children and adolescents [1]. Several epidemiological studies have reported the prevalence to range from 5 to 30% [2–5]. Reasons for the width of this range include differences in the assessment of chronic pain, the definition of chronic pain, the type of the chronic pain condition and the investigated age group. The available literature suggests an increase over time in prevalence and burden caused by chronic pain in children and adolescents [6, 7]. This corresponds with our own clinical experience.

Children are particularly at risk for insufficiently controlled pain with poor short- and long-term outcome [8], as chronic pain, in contrast to acute pain, bears a considerable risk of being insensitive to therapy, especially to conventional therapy such as classic pain killers. This not only affects patients themselves, but also their families [9] and can prevent patients and their relatives from having a normal life. Furthermore, the cost of adolescent chronic

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pain presents a substantial economic burden to families and society [10]. Total costs to society for adolescents with moderate to severe chronic pain have been extrapolated to \$19.5 billion annually in the United States [10, 11].

Long-lasting absence from school is another issue. Konijnenberg et al. [12] reported that 51% of children with chronic pain had intermittent or long-lasting absence from school, and 72% suffered from impairment in sports activities. This underlines the increased need for specific therapeutic institutions. In 2012, the University Children's Hospital Basel (UKBB) established Switzerland's first ambulatory interdisciplinary clinic for children with chronic pain. Since its opening, this clinic has experienced a steadily increasing demand.

The aim of this retrospective study was to assess referral, patient characteristics, social environment, previous therapies and school absences of the patients seen in the ambulatory pain clinic during a 4.5-year observation period.

Materials and methods

Participants

All children and adolescents assessed and treated in the ambulatory interdisciplinary clinic for chronic pain at the UKBB during the 4.5-year period from 4 January 2012 to 4 July 2016 were included in the study.

Structure of the interdisciplinary clinic

The ambulatory interdisciplinary clinic at the UKBB consists of specialists from paediatric and adolescent psychiatry, psychology and pain therapy. To the best of our knowledge, this interdisciplinary clinic was the first one in Switzerland to be specifically designed for children and adolescents suffering from chronic pain. During the first consultation, patients are seen by a child and adolescent psychiatrist or psychologist together with a pain therapist. It is important that both the patient and the parents understand that pain is not only a biological phenomenon, but a complex interaction of biopsychosocial factors [13, 14]. To achieve this, as early as the initial consultation the patients and parents are provided with educational information on the relationship between psychology and pain. The consultants discuss different therapeutic strategies with the patients and their parents and provide recommendations including plans for and the arrangement of the next steps in therapy. Depending on the formulated therapy plan, subsequent appointments are with one of the consultants involved in the primary visit. If it is considered to be beneficial, in some cases subsequent visits are with the initial team. In the case of logistical problems, such as a long travel time from the patient's place of residence to the UKBB, connections to ambulant pain specialists are facilitated.

Procedure of data acquisition

In advance of the first clinic visit, the child or adolescent and his/her parents receive the German Pain Questionnaire for Children, Adolescents and Parents (DSF-KJ) developed at the German Paediatric Pain Centre, Datteln, Germany. There are three different questionnaires: for children (between the ages of 4 and 10), adolescents (from the age of 11) and parents. The DSF-KJ provides a standardised

assessment and comprehensive description of paediatric chronic pain problems and facilitates medical and psychological diagnostic and therapeutic decisions [15]. All the information for the study was extracted from these questionnaires and from the patients' medical records. Follow up was restricted to the second consultation (maximum two consultations: primary + follow up within 4 weeks). This period was chosen to check implementation of treatment recommendations during the primary consultation.

Measures

Demographic information

The demographic data included sex and age. For our study, the patients were categorised into three age groups that were based on the school levels in Basel. The first group included children in primary school (6–12 years); the second group children in secondary school (13–15 years); and the third group adolescents in an apprenticeship or in high school (≥ 16 years).

Pain

Pain presentation was classified into seven groups (head, back, abdomen, musculoskeletal, complex regional pain syndrome, multiple presentations and other presentations of pain). In the category "musculoskeletal", all causes of pain referred to the spine were excluded and were placed in the category "back pain".

The intensity of the pain was measured in the questionnaires and using the 11-step numeric rating scale (NRS) ranging from 0 = no pain to 10 = worst pain imaginable. The duration of the pain was measured in months, from the moment the patient described the pain for the first time to the day of the first appointment at the UKBB.

If a specific cause of the pain was clearly recognisable, it was sorted into one of three groups (accident, illness, iatrogenic); otherwise it was placed in the "unknown reason" group. The iatrogenic group included all patients with pain linked to a medical intervention such as surgery, chemotherapy and radiotherapy.

By means of four different graphical diagrams depicting level of pain over time [15], the questionnaire helped patients to describe the dynamic of their pain as continuous pain with intermittent pain attacks, intermittent pain attacks with transient pain-free periods (length not closer specified), continuous pain with small changes and continuous pain with fluctuating in strength.

Healthcare system utilisation and referral

In the questionnaire, patients reported the number of physicians they had consulted for their chronic pain. Patients and their parents were also asked how they were referred (by their general practitioner, paediatrician, or a specialist from a hospital or other institution) to the ambulatory interdisciplinary clinic at the UKBB.

Family

The questionnaire sought to determine whether parents or siblings of the patient suffered from chronic pain or psychiatric diseases. Marital status and place of birth of the parents was also queried.

School absences

Completed questionnaires also revealed the number of days a patient missed school during the last month prior to the first consultation at our ambulatory interdisciplinary pain clinic.

Therapy

Twelve different types of therapy (physiotherapy, non-opioids, opioids, osteopathy, surgery, psychotherapy, chiropractic, interventional pain procedures, lidocaine-ketamine infusions, transdermal analgesic patches, transcutaneous neuromuscular electrical stimulation (TENS), and alternative medical therapies) were surveyed. Disclosure of multiple types was possible. Non-opioids include nonsteroidal anti-inflammatory drugs (NSAIDs), paracetamol and metamizole. The type of therapy was recorded before the first meeting and after the last meeting (i.e., 4 July 2016) if the therapy was still ongoing. Reductions of the initial dosage of at least 50% of one drug as well as newly prescribed analgesics were recorded.

Ethics

The Ethics Committee of Northwest/Central Switzerland EKNZ approved the study on 25 October 2016 (No. 2016-01637). The judgement of the EKNZ included: because of the retrospective, encoded data analysis and according to para. 34 HFG (human research law of Switzerland), an additional written consent of every included patient/parent or legal guardian was not required.

Statistical methods

Descriptive statistical values were analysed and expressed as follows, unless otherwise stated. Continuous data are expressed as means with standard deviation (SD) or median with interquartile range (IQR) in (e.g., number of patients, age). Nominal data are expressed as absolute frequencies and percentages (e.g., gender distribution, pain presentation). Ordinal data (e.g., pain scale) are expressed as median with IQR. All results are presented here as estimates with 95% confidence intervals (CIs) unless other-

wise stated. GraphPad Prism Version 6.07 for Windows was used for statistical analysis.

In the case of missing values, patients were excluded from the analysis of that single comparison, but remained in the analysis for the other comparisons.

Results

During the 4.5-year period from 4 January 2012 to 4 July 2016, 135 patients were assessed at the ambulatory interdisciplinary pain clinic at the University Children's Hospital Basel. Most of the children were female ($n = 108$, 80%; 95% CI 0.73–0.87), and the mean age of all patients was 13.95 years (range 6–20 years, 95% CI 13.5–14.4; [fig. 1](#)).

The main presentation of pain in all children was musculoskeletal (38%, 95% CI 0.30–0.46), followed by back pain (25%, 95% CI 0.18–0.33) and multiple presentations of pain (21%, 95% CI 0.15–0.28). In the youngest (6–12 years) and middle (13–15 years) age groups, the most common pain presentation was musculoskeletal (57 and 36%, respectively). In the oldest (≥ 16 years) age group, back pain (39%) was the most common ([table 1](#)).

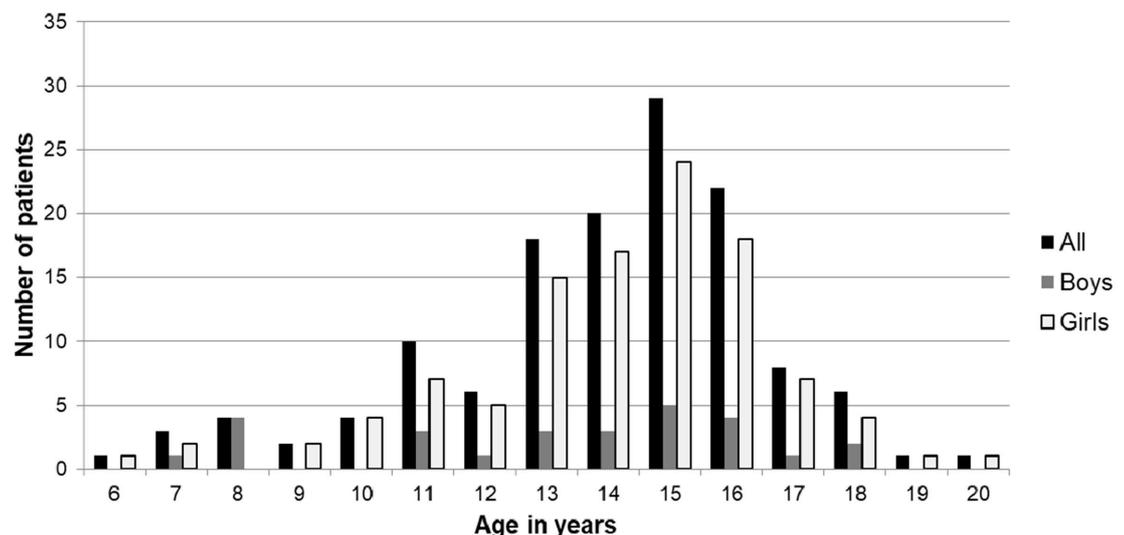
The mean duration of pain until patients had their first assessment at the UKBB was 24.5 months (SD 27.4, 95% CI 19.82–29.22). Appointment wait time until the first consultation ranged from 1–8 weeks. For the patients who were not referred by doctors of the UKBB, the mean duration of pain was 20.6 months (SD 21.34, 95% CI 12.55–28.65).

The median for maximum pain intensity was 8 (IQR 2; 95% CI 7.36–7.96) on the NRS (scale 0–10).

In 50% ($n = 67$, 95% CI 0.41–0.58), the initial cause of the pain was unknown. The most common known cause was an accident (26%, 95% CI 0.19–0.33), followed by illness (16%, 95% CI 0.10–0.23) and iatrogenic causes (7%, 95% CI 0.03–0.12).

Only one quarter of the children and adolescents ($n = 34$, 26%; 95% CI 0.19–0.34) reported pain-free periods prior to the first consultation.

Figure 1: Age distribution of patients in the chronic pain unit; 108 (80%) were female, mean age was 13.95 years (standard deviation 2.66, 95% confidence interval 13.5–14.4), with a range between 6 and 20 years.



The number of prior physician visits due to chronic pain before the consultation at our institution ranged from 1–15 (median 4, IQR 2, 95% CI 3.60–5.03).

One hundred and eight patients (80%, 95% CI 0.73–0.87) were referred by UKBB physicians. The remaining patients presented on the recommendation of the primary care paediatrician (n = 10, 7%; 95% CI 0.03–0.12), their general practitioner (n = 6, 4%; 95% CI 0.01–0.08), or from another institution (n = 11, 8%; 95% CI 0.04–0.13).

Forty-two of 133 patients (32%, 95% CI 0.24–0.39) had at least one parent with chronic pain. In 37 patients (28%, 95% CI 0.20–0.35), one parent suffered from chronic pain, and in 5 (4%, 95% CI 0.01–0.07) both parents suffered from chronic pain. Thirteen patients (10%, 95% CI 0.5–0.15) had siblings with chronic diseases.

For 24 patients, one parent, and for one patient both parents, had a history of a psychiatric disease (n_{total} = 134). Thus, 19% (95% CI 0.12–0.25) of patients had at least one parent with a psychiatric disease.

At the time of the survey, the majority (n = 77, 63%; 95% CI 0.55–0.72) of the parents lived together, 41 (34%, 95% CI 0.25–0.42) were separated and 4 (3%, 95% CI 0.001–0.06) were widows or widowers. Forty-three percent (95% CI 0.49–0.63) of the parents had a migrant background.

The mean number of school absences before the therapy was 5.1 (SD 8.83, 95% CI 3.48–6.73) days during the month prior to consultation (n = 116). Fifty-seven patients (49%, 95% CI 0.40–0.58) had no school absences. Ten (8%, 95% CI 0.04–0.14) patients did not attend school at all during the last month.

The two most common therapies before the first meeting were physiotherapy (71%, 95% CI 0.63–0.79) and non-

opioids (43%, 95% CI 0.40–0.57). Less frequent were osteopathy (17%, 95% CI 0.10–0.23), opioids (13.6%, 95% CI 0.08–0.20), surgery (13%, 95% CI 0.7–0.19), psychotherapy (12%, 95% CI 0.06–0.18), chiropractic therapy (12%, 95% CI 0.06–0.18), interventional pain management (5%, 95% CI 0.01–0.09), psychosomatic (1%, 95% CI -0.008–0.02) and alternative medical therapies (3%, 95% CI 0.001–0.06) (table 2).

After the first consultation, the therapies applied most often were psychotherapy (52%, 95% CI 0.44–0.61) most often with a psychosomatic therapeutic approach (psychosomatic therapy: 34%, 95% CI 0.26–0.42), physiotherapy (36%, 95% CI 0.27–0.44), non-opioids (33%, 95% CI 0.25–0.42) and transdermal analgesic patches containing local anaesthetics (lidocaine) or an NSAID (diclofenac) (31%, 95% CI 0.03–0.13). Further transcutaneous neuromuscular electrical stimulation (TENS) was prescribed in 14 cases (11%, 95% CI 0.06–0.17), opioids were continued in 12 (10%, 95% CI 0.04–0.15), interventional pain management was performed in 5 cases (4%, 95% CI 0.01–0.07), surgery in 4 cases (3%, 95% CI 0.001–0.06), intravenous lidocaine-ketamine infusions in 2 cases (2%, 95% CI -0.01 – 0.04), chiropractic therapy in one case (1%, 95% CI -0.008 – 0.02) and alternative medical therapies in two cases (2%, 95% CI -0.006 – 0.04). In 16 patients (13%, 95% CI 0.07–0.19) dosage of at least one medicament was reduced by at least 50% and in five cases (4%, 95% CI 0.01–0.04) all analgesics were stopped.

Discussion

In this study, we examined the paediatric chronic pain population assessed in the ambulatory chronic pain clinic at the UKBB in Basel.

Table 1: Presentations of the pain reported by the patients and their distribution on the different age groups.

Pain presentation	All (n = 135)	6–12 years (n = 30)	13–15 years (n = 67)	≥16 years (n = 38)
Musculoskeletal, n (%)	51 (38%)	17 (57%)	24 (35%)	10 (26%)
Back, n (%)	34 (25%)	6 (20%)	13 (19%)	15 (39%)
Multiple locations, n (%)	29 (21%)	5 (17%)	16 (24%)	8 (21%)
Head, n (%)	10 (7%)	–	7 (10%)	3 (8%)
Abdomen, n (%)	5 (4%)	–	4 (6%)	1 (3%)
Complex regional pain syndrome, n (%)	3 (2%)	1 (3%)	1 (1%)	1 (3%)
Other, n (%)	3 (2%)	1 (3%)	2 (3%)	–

Table 2: The type of therapy the patients received before the first meeting and after the first consultations (4 July 2016) if the therapy was still ongoing.

Therapy	Before first meeting (n = 125)	After first meeting (n = 126)
Physiotherapy, n (%)	89 (71%)	45 (36%)
Non-opioids, n (%)	54 (43%)	42 (33%)
Opioids, n (%)	17 (14%)	12 (10%)
Osteopathy, n (%)	21 (17%)	–
Surgery, n (%)	16 (13%)	4 (3%)
Psychotherapy, n (%)	15 (12%)	66 (52%)
Psychosomatic*, n (%)	1 (1%)	43 (34%)
Chiropractic, n (%)	15 (12%)	1 (1%)
Interventional pain management, n (%)	6 (5%)	5 (4%)
Transdermal analgesic patch, n (%)	–	39 (31%)
Transcutaneous neuromuscular electric stimulation (TENS), n (%)	–	14 (11%)
Intravenous lidocaine-ketamine, n (%)	–	2 (2%)
Alternative medical therapies, n (%)	4 (3%)	2 (2%)

* Psychotherapy includes psychosomatic therapy

The reasons leading to the development of chronic pain are multifactorial and complex. Somatic causes are not solely responsible. Psychosocial factors, in particular, have an effect on sustaining acute pain until it leads to chronic pain conditions. Moreover, stress-induced hyperalgesia can lead to chronic pain without a somatic or biological trigger [16]. Thus, chronic pain is best explained by the biopsychosocial model, which combines biological, psychological and social factors as important factors for the development and maintenance of chronic pain conditions [13, 14].

As chronic pain is generally not easy to treat and concepts are different from those of acute pain conditions, early specialised support for these patients is crucial. Chronic pain, particularly during childhood, increases the probability of pain-related morbidity in adult life [17, 18]. This is acknowledged and it is generally accepted that the treatment of children and adolescents with chronic pain requires a specialised multidisciplinary approach involving paediatricians, psychiatrists and psychologists, pain physicians, specialised nursing, physiotherapists and occupational therapists. However, young patients with chronic pain often initially receive unidimensional treatment options such as analgesics [19].

One of the most striking results of our study was that on average more than 2 years had elapsed before patients were referred to our pain clinic. This underlines the huge barrier that child and adolescent chronic pain sufferers face before they receive a treatment that focuses on their pain as a disease that requires special attention and treatment strategies. To our surprise, referral to our pain clinic took longer internally than externally. We can only assume that the primary care paediatricians tend to treat patients from the beginning with a more biopsychosocial approach than a specialist does, and this leads to earlier referrals. But we truly believe that there has been a learning curve for our internal colleagues over the past years. We hypothesise that, when we repeat the same study for the next 2 years, internal referral times would significantly shorten (data to be investigated...).

An important indicator of the severity of a chronic pain disease is school absences [20]. Fifty-one percent of the patients were not able to go to school for at least one day during the last month prior to first consultation because of their pain. Absences averaged 5.1 days (median 1, SD 8.83, 95% CI 3.48–6.73) during the last month (n = 116) prior to consultation. Days absent from school represents an important criterion for decisions about the treatment setting (ambulatory vs in-patient treatment) [21]. Other important determinants are the severity of pain, its disabling impact on daily life, failure of unimodal pain medication and failure of improvement under a chosen treatment option [20].

Another remarkable finding from our study is that only 24% of the included children and adolescents experienced pain-free periods. That means pain is a permanent stressor without periods of recovery and therefore has a major impact in daily life in the majority of children.

The biggest subgroup of patients in our study was the middle age group including patients aged 13–15 years (67, 50%). A possible explanation could be associated with the physical and psychological changes accompanying the beginning of adolescence. These changes can represent a

considerable burden on young people and can lead to decompensation.

Similarly to other reports [22, 23], this study showed that the majority of children and adolescents with chronic pain are female, 80% in our collective.

Psychiatric diseases of the parents can be a risk factor for chronic pain [16]. It is well known that children of parents with psychiatric disorders suffer more often from such disorders, experience more stress and have decreased resources to handle with complex situations such as illness and pain [16].

The parents of our study participants suffered more often from psychiatric diseases than the mean Swiss population: 7% of the fathers in this study compared with 4.2% of Swiss men and 10% of the mothers compared with 6.6% of Swiss women had a psychiatric disease [24]. This is an interesting finding and an important consideration, especially for young patients with chronic pain, as we know that children of psychiatrically ill parents have more stress and strain compared with other children with mentally healthy parents [25].

Compared with an average child in Switzerland, fewer of our patients, only 63% (95% CI 0.55–0.72) with all age groups combined, lived with both of their parents. In the general Swiss population, 87.2% of children aged 4–12 years and 79% of children aged of 13–17 years live together with both parents [26]. Living in a single-parent home could be a possible co-trigger for chronic pain diseases.

The fact that fewer medications were prescribed by our pain clinic and more psycho- and psychosomatic therapies were arranged after a patient's first consultation indicates that the therapeutic approach of our interdisciplinary clinic is strongly focussed on psychosocial triggers of the pain. Another important objective in our setting is the implementation of psychological and pain education. This approach corresponds with other multimodal and interdisciplinary concepts [27].

The follow up period in our study ranged from immediately after the first consultation until a possible second consultation (normally within 4 weeks). This may be a reason for the relatively small reduction in opioid and non-opioid analgesic prescriptions. From the experience and literature we know, tapering opioids and even non-opioids needs weeks to months, even in children and adolescents [28].

We used the retrospective data of Zernikow et al. [23] to compare the results from our clinic with another international tertiary paediatric clinic. The mean age of our patients was 13.95 years. This is more than two years older than patients in the German study by Zernikow (11.5 years). In addition, the percentage of female patients was higher in our study population (80 vs 61%). Pain presentations were also noticeably different. The German study population suffered mainly from headache (69%). In Basel, only 7% presented with headaches. The same was for abdominal pain (16.3% in the German study vs 4% in ours). The majority of pain in our study was musculoskeletal (38%) and back pain (25%). This is not very surprising because, due to the close collaboration, most of the referrals to our clinic came from the orthopaedic team of the UKBB. Patients in Basel came to our interdisciplinary pain clinic more than 6 months earlier than to the clinic in

Germany (24.5 vs 31.1 months, respectively). The patients in Basel also came earlier from external referrers (20.6 months); therefore, the roughly half-year difference was not due only to the convenient accessibility of the UKBB.

Conclusion and impact for future efforts of the interdisciplinary chronic pain unit for children and adolescents

To further improve the outcome of children and adolescents with chronic pain, the following are of importance. First, the length of time children suffer from pain until their initial visit at the clinic should be reduced. Two years is far too long. This could be achieved by providing information and through efforts to raise awareness of the issue among paediatricians and general practitioners. The fact that in-house referrals take even longer than external, demonstrates that continuous education and information is also mandatory in a University Children's Hospital.

Second, the parents in our study population suffered more often from psychiatric diseases than the mean Swiss population. This is an interesting and important finding and could have an important impact on the understanding of chronic pain in young people and in treatment options as well.

Third, reducing analgesic dosage, if possible, is one of the main concerns of an ambulatory pain clinic. It is a process that takes weeks and months, and is not always easy to realise, although it is one of the first aims. A longer observation period is necessary to evaluate how effect full a treatment could be.

Fourth, it is surprising that in Basel only 7% of the patients had headache, compared with 69% in the German study. This means that headache patients are not being referred to our clinic by their treating physicians. Research shows that these patients especially can profit from the biopsychosocial spiritual approach that we implemented in our pain clinic [29–31]. As stated above, informing and educating paediatricians and general practitioners is crucial.

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Potential competing interests

The authors report no conflict of interest relevant to this work.

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