UiT

THE ARCTIC
UNIVERSITY
OF NORWAY

Faculty of Health Sciences / Department of Community Medicine

Current situation of paediatric chronic pain in Switzerland: prevalence and paediatricians' experiences

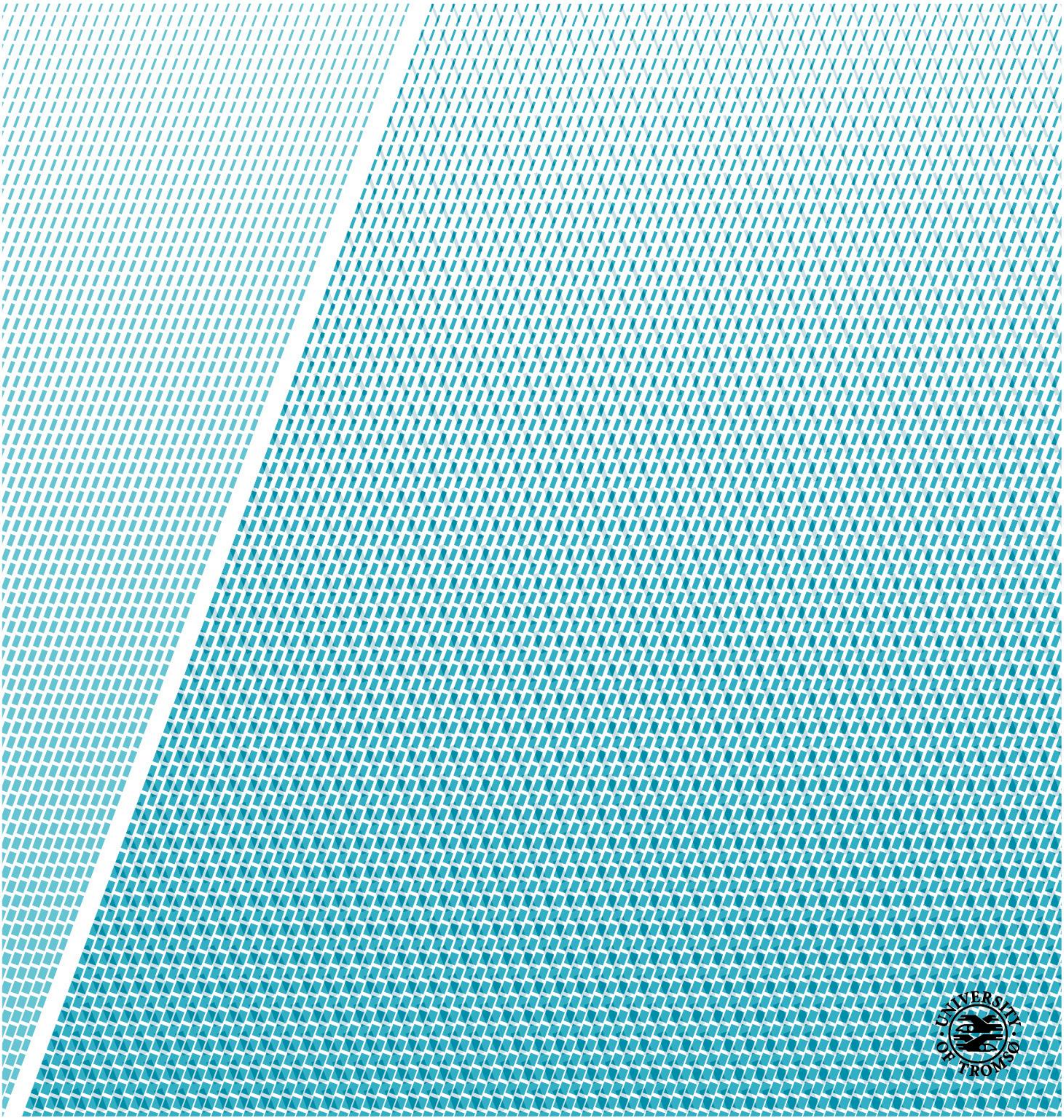
A cross-sectional study

—

Maria Carlander

Master's Thesis in Public Health, July 2019

Supervisors: Prof. Dr. Julia Dratva (ZHAW), Prof. Mette Bech Risør (UiT)



Acknowledgements

Writing a thesis is a longer process than one would expect. This process started in the fall of 2018 when I first met my supervisor Julia Dratva at a rather spontaneous meeting at the Zürich train station on a busy September afternoon. My biggest thank you goes to her for being open-minded and giving me the opportunity to write my thesis under her professional supervision.

A second thank you goes to the rest of the paediatric chronic pain project group, Helen Koechlin and Andreas Wörner, for giving their inputs throughout the process. Also, a thank you to everybody else who was somehow involved in the process of the questionnaire development, and especially Fabien Claude who kindly helped us with the Italian and French translation of the questionnaire, and Sibylle Juvalta who always supported me when I had any questions.

I would also like to thank my co-supervisor in Tromsø, Mette Bech Risør, for helping with the NSD approval, which turned out to be one of the most difficult tasks in the process. Thanks to her persistence we finally got the approval and could proceed with the study. Thank you for being patient and always being there when I had questions.

Thank you, Melanie Röthlisberger and Crista Grönroos, for correcting and reading my thesis critically.

I would also like to thank my friends from the MPH programme in Tromsø and Munich for the valuable support in “desperate” times. Without you this Master’s programme would only have been half as fun!

Finally, the last but not least thank you goes to my better half and Excel-wizard Andreas, for always being there for me with endless patience at midnight when I had some last-minute problems.

Maria Carlander

Helsinki, July 2019

Abstract

Background: Chronic pain (CP) prevalence in children and adolescents has been increasing over the past decades. The patient-reported prevalence is around 25% depending on the methodology and location of pain. Chronic pain is defined in this study as persisting or recurrent pain that has lasted longer than three months.

Objectives: To estimate the prevalence of chronic pain in children and adolescents in Switzerland based on reported number of patients with CP and patient visits in paediatrician practices in primary healthcare, and to investigate the CP care concepts, care provision for CP and professional experiences with chronic pain among paediatricians in Switzerland.

Methods: Cross-sectional online questionnaire study (languages German, French and Italian) to Swiss paediatricians. Questionnaire items: 1. Sociodemographic, work-related characteristics, number of children seen per 3 months in paediatrician practices; 2. Experience with CP, training in CP treatment, comfort with treating patients with CP, estimated prevalence of patients with CP seen, measurement of pain intensity, referral patterns of patients with CP. Descriptive analysis. Prevalence calculations based on number of children with CP seen in the past 7 days and number of total patient visits per 3 months (categorical answers with min., mean and max. values), multiplied to represent the annual total. Multivariate logistic regression analyses on predictors of confidence, experience and training with CP as well as referral.

Results: 337 participants (participation rate 21%). 20% of the paediatricians feel comfortable and have experience with patients suffering from CP. The same amount report to have training in treating patients with CP. More than two thirds of the paediatricians estimate that less than 5% of their paediatric patient population suffer from CP. The calculated estimated prevalence of CP in paediatric single and group practices in this study is 2.54–3.89%. Almost 80% have referred a patient to a pain ambulatory specialized in children and adolescents. Paediatricians working in hospitals had almost 4 times higher odds of referring a patient compared to those working in a practice. Estimating a higher prevalence of CP in the paediatric population was associated with being trained in CP treatment. Men have 3 times higher odds of feeling comfortable treating paediatric CP. Being experienced in CP gave 11 times higher odds off feeling comfortable with treating CP.

Conclusion: In this sample of paediatricians, on average 3.35% of patients are identified as patients with CP. The discrepancy to self-reported pain is high. Swiss paediatricians do not feel comfortable with treating CP. Correspondingly they rate their experiences and training low. More focus on educating Swiss paediatricians about CP and information on care options seem necessary.

Key words: chronic pain, children, adolescents, prevalence, experience, Switzerland

List of Abbreviations

CP:	Chronic Pain
FHM:	Swiss Medical Association
HBSC:	Health Behaviour in School-Aged Children
ICD:	International Classification of Disease
NRS:	Numeric Rating Scale
NSD:	Norwegian Center for Research Data
OR:	Odds Ratio
SSP:	Swiss Society of Paediatrics
UiT:	University of Tromsø
UKBB:	University Children’s Hospital Basel
VRS:	Visual Rating Scale
WHO:	World Health Organization
ZHAW:	Zürich University of Applied Sciences

Table of Contents

List of Figures

List of Tables

1 Introduction

Pain is the most prevalent reason for seeking medical services. Usually, pain is a necessary warning sign of distress or injury in the body. However, when pain becomes chronic, it loses its purpose as a warning sign and becomes a disease itself. The sensation of pain is always subjective and cannot be defined by others (1). Because pain is not always visible on the outside, it may also cause social stigmatisation.

Chronic pain (CP) in children and adolescents is a global health problem. The body of evidence of CP prevalence and related areas such as management has been growing in the past decades, especially in the Western countries. Although CP in children is common, it is one of the most ignored and under-treated conditions of today (2). Prevalence data are often inconclusive and not comparable because of methodological differences in assessing CP, due to the lack of international guidelines. The management of CP is complex and requires expertise from many different disciplines. As CP affect people both indirectly and directly, this makes it one of the most important public health problems today. Moreover, CP has not only direct and indirect consequences on the individual, but also on the family and the society (3).

In this thesis the areas of chronic pain prevalence in children and adolescents and paediatricians’ experiences with CP in Switzerland are addressed.

2 Background

2.1 Definition

Until now, there has not been any official definition of chronic pain, and the definitions most commonly used is “pain that has lasted from three to six months” (4). The new handbook of International Classification of Disease-11 (ICD-11) published by the World Health Organization (WHO) will be the first one to include chronic pain in its list of diagnoses. The ICD-11 will include seven different definitions of subgroups of chronic pain: 1) chronic primary pain, 2) chronic cancer pain, 3) chronic posttraumatic and postsurgical pain, 4) chronic neuropathic pain, 5) chronic headache and orofacial pain, 6) chronic visceral pain, and 7) chronic musculoskeletal pain (5).

The definition of chronic primary pain by ICD-11 is the following:
“Chronic primary pain is pain in 1 or more anatomic regions that persists or recurs for longer than 3 months and is associated with significant emotional distress or significant functional disability (interference with activities of daily life and participation in social roles) and that cannot be better explained by another chronic pain condition.” (5)

These diagnose codes will in the near future be implemented into the clinical practice after the ICD-11 handbook has properly been published. The fact that “chronic primary pain” finally will be recognized as an official disease has a major impact on the affected individual. The ICD is used by health insurers whose reimbursement also depend on the ICD coding. Having a recognized illness can help the individual to receive appropriate health services and reimbursement. The disease coding also enables diagnose-based healthcare research and the data-based allocation of health resources (6).

2.2 Prevalence of chronic pain in children and adolescents

Current studies suggest that the prevalence of paediatric chronic pain has been increasing over the last several decades (7, 8). Prevalence rates across studies vary widely, which makes it hard to draw general conclusions of the prevalence rate (7, 8). Many studies have also used inappropriate measurements of pain, and since no ICD-code was available for CP until 2018, the extraction of the CP diagnosis from different medical databases has not been possible. King et al. (7) wrote the last systematic review on the epidemiology of chronic pain in children and adolescents in 2011, and they found that the estimated median prevalence of headache is 23% and that median prevalence of other types of pain (abdominal, back, musculoskeletal and combinations) is between 11–38%. In a study by Roth-Isigkeit et al. 30.8% of the paediatric population reported pain that has lasted longer than 6 months. The most common types of reported pain were headache (60.5%), abdominal pain (43.3%), limb pain (33.6%) and back pain (30.2%) (9). Another cross-sectional study on school children reported a CP prevalence of 25.0% in all age groups, irrespective of pain location (8). A Norwegian survey on school children had similar results with a CP prevalence of 21% (10).

CP prevalence increases with age (8, 11-13) and is more common in girls than in boys (8, 11-16) especially in older age groups (13, 17). The majority of children and adolescents are not greatly disabled by CP, but approximately 3% of the CP patients require intensive rehabilitation (12, 14). In a study with Spanish school children by Huguet & Miró (12), the authors found a total CP prevalence of 37.7% of which 5.1% had moderate or severe CP problems. An American cohort study for adolescents showed a life-time prevalence of 25.9% in all types of CP (18).

Recently, the first data on any chronic pain in Swiss children and adolescents was reported in the Health-Related Behaviour of School-Aged Children (HBSC) study from 2014. 11-15-year-old Swiss school children reported a prevalence of 13–14% of weekly or monthly head and neck pain (19). The prevalence of CP in the Swiss adult population is 16%, which equals 1.5 million people (3).

2.3 Causes and risk factors of chronic pain

The cause and development of paediatric CP is not always clear, and there are only a few studies addressing this question. In 10–30% of cases CP has somatic aetiology, for example CP caused by rheumatism or cystic fibrosis (20). In a study on chronic musculoskeletal pain, Becker et al. found that the most common causes were injury, chronic disease, infection, illness and surgery (21). Other somatic diseases associated with chronic pain are hypermobility, chronic fatigue, postural orthostatic tachycardia syndrome and fibromyalgia (22). Multiple contributors are believed to cause CP, such as neurosensory, affective, sociocultural, behavioural, cognitive factors (11) and psychosocial factors (16), but we know only little about the exact relationship between these potential causes and CP. The impact of other risk factors is also not well-known, but earlier untreated pain, gender, parents with chronic pain (especially headache), low self-esteem, anxiety, depression, behavioural problems, stressful life-events, and other health problems could be some among them (13, 16, 23-25). A Finnish study found that low cardiorespiratory fitness and high levels of sedentary behaviour were associated with increased odds of various pain conditions (1). Low physical activity and high sedentary behaviour is associated with CP, especially in girls. In girls a higher BMI is associated with a higher prevalence of CP and in boys the prevalence is also higher among those who are overweight and obese. During adolescence, smoking and alcohol is associated with higher prevalence of CP and also single-parent households were associated with higher prevalence of CP in both sexes (26). Parental chronic pain is also associated with chronic pain in their children (27). Risk factors for extremely high pain-related impairment are associated with duration, frequency and intensity of pain. School absence and disability are associated with older age, multiple locations of pain, depression and previous hospital stays (28). The biobehavioural process involved in the development and persistence of chronic pain is still unexplored and needs to be further investigated (29). Many times the aetiology of CP is also unknown, which is the reason why the new “chronic primary pain of unknown origin” diagnosis is included in the ICD-11 handbook (5).

2.4 Consequences of chronic pain in childhood

There are several, possibly life-long, negative consequences of paediatric chronic pain. CP rarely comes alone, and it can affect the quality of life (11, 12) in different ways as well as influence the recovery time after an incidence (11). CP is associated with reduced physical functionality, sleeping problems, fatigue, and concentration difficulties (10, 11). Sleeping problems have a multidimensional impact on children’s lives and children with CP stay away from school more often (10, 12) and perform worse academically (10). In the study by Roth-Isigkeit et al. (9) 54.6% of children with chronic pain reported sleeping problems, 53.3% reported an inability to pursue hobbies, 51.1% reported eating problems, 48.8% reported school absence and 46.7% reported inability to meet friends. Cucchiaro et al. (30) investigated the characteristics of children who had been referred to a pain clinic and found that 32% of the patients had missed at least ten days of school in a calendar year and 47% had stopped playing sports.

Children and adolescents with chronic pain are more likely to use analgesics and seek medical care (12). More severe pain and pain in multiple locations are risk factors for bigger long-term impairments and decreased functioning (8). Young children with CP and depressive symptoms are found to have functional impairment and school functioning. The risk of depression rises with the frequency of pain, and depressive symptoms have been found to be a risk factor for pain frequency, pain persistence and the progress of further pain problems over time (10, 11).

Untreated CP in children may lead to development of pain and psychological disorders later in life, for example anxiety and depressive disorders (14). Anxiety and behavioural disorders are both risk factors and consequences of CP (18). Of children who were referred to a pain clinic 25% had an unnoticed anxiety-diagnosis and 13% had a missed depression-diagnosis (30). Another study on German pain clinic patients found that the prevalence of depression and anxiety was 24% and 19% respectively (28). Almost 20% of adult CP patients reported a history of CP in childhood or adolescence, and up to 80% reported that the CP persisted from their youth to adulthood (14, 31).

2.5 Treatment, management and care provision of chronic pain

CP is hard to diagnose and manage and it is therefore often undertreated. Recent evidence suggests an integrative biopsychological approach for CP treatment to be the most successful. An integrative multidisciplinary approach in either in-or outpatient settings including rehabilitation, complimentary therapies. psychological counselling and normalization of daily life activities (school, sleep, and physical activity) together with a cautious use of pharmacological products usually reduce or eliminate the patient’s pain (11, 14). An interdisciplinary treatment should at least include paediatricians, nurses, physiotherapists and psychotherapists, and other professionals can also be involved according to the patient’s individual needs (32).

Clinical anamnesis needs to be collected from multiple sources: from the patient, parents or caregivers, and teachers or other professionals who interact with the child in its daily environment (11). Haraldstad et al. (10) found that parents often are unaware of their child’s pain and that pain often is underestimated in the both sexes in younger age groups and in older girls. Children’s pain may be hard to recognize not only because of their coping strategies, which seem like normal behaviour to the caregiver (including play and sleep), but also because the children cannot always express their pain due to cognitive ability and vocabulary (23).

Medication is usually not a first-line therapy for CP treatment, and opioids are not indicated at all (14). Many paediatric CP patients have often seen several physicians without receiving successful treatment and they receive analgesics without adequate medical supervision (15). There are many psychological interventions that are useful in paediatric CP treatment. Examples of these include stress management, attention and distraction techniques, art and play therapies, guided imagery, hypnosis, counselling, psychotherapy, relaxation training, biofeedback, modelling, desensitization, and behavioural management. Ideally the treatment plan is set up individually for each child and adolescent. With these kinds of psychological interventions there are rarely any contraindications (33). Especially relaxation therapies and cognitive behavioural therapy have been shown to reduce the frequency and severity of CP in children and adolescents (34).

The severity and chronicity of chronic pain is associated with more use of healthcare services (35). On average, three physicians and five visits are needed for a referral to a specialized pain clinic in Canadian children (36), and in a German study more than 70% of the participants had consulted more than three physicians before referral (37). Another German study also shows that children consulted three physicians on average before being referred to a pain specialist, and that 13% of the children had visited more than six physicians before referral (28). Konijnenberg et al. (20) reported two physician visits before the patients received a referral to an paediatric specialist, and a median duration of pain related symptoms of one year. These long referral times to specialized pain clinics can cause significant social and psychological consequences (30).

A study from a German pain clinic showed that after children and adolescents are admitted to a specialized pain clinic, the use of analgesics decreased significantly after three months. More than half of the patients had a 50% reduction of pain intensity after three months, and almost 60% after a 12-month follow-up. Also, the quality of life could be improved due to a decrease in pain intensity, pain-related disability, school absence, and pain-related coping (15). A German study on children with chronic pain admitted to pain clinics showed that 43% of the children were taking analgesics without any indication of pharmacological treatment (28). More than two thirds of patients who were referred to a paediatric pain clinic could return to school and start playing sports again after four months from the initial consultation (30). Globally, approximately 3% of the children and adolescents suffering from CP exhibit significant disability caused by chronic pain that it is difficult to treat in an outpatient setting (35). Intensive inpatient treatment is recommended for highly affected children, as this has better health and social outcomes such as reduced pain levels and reduced school absence (38). Due to gender differences in the prevalence of chronic pain, specific pain management strategies should be added for girls (15). Hence, the two most important areas to be highlighted are the long delays in referral time to specialized pain clinics, and the failure to recognize underlying psychological conditions (30).

Assessing the intensity of pain is demanding, because the sensation of pain is a very subjective matter. One possibility would be to assess the pain intensity, pain related distress and functional impairment (5). According to new recommendations CP in paediatric clinical trials should be assessed with outcomes in pain intensity, physical functioning, emotional functioning, role functioning, symptoms and adverse events, global judgement of satisfaction with treatment, sleep, and economic factors. The preferred assessment should be chosen according to the patient’s age (39).

CP is a complicated disease which requires multi-professional treatment and involvement of the patient and their families. Many adolescent CP patients report pain dismissal by healthcare professionals, and this is also associated with feelings of isolation and self-directed negativity (40). Physicians often underestimate the prevalence of CP in children and adolescents. In a study from the United Kingdom, up to 63% of general practitioners (GPs) reported that the CP prevalence is <5%. 77% of pain clinicians and 95% of GPs in the same study reported that they have an inadequate training of CP management. They also noted, that the problem of CP has been increasing in the past five years (41).

In a Swiss study only 37% of anaesthesiologists and surgeons reported that they assessed therapeutic success of analgesics prescribed postoperatively (42), while 25% of children experiencing postoperative pain continued to experience clinically significant pain after returning home (43, 44). This means that follow-up of pain and effectiveness of pain-medication postoperatively is insufficient and may cause CP.

Current studies suggest that parents and paediatricians need further guidance on treatment options for CP (40). Often children with CP are left in a so-called “diagnostic vacuum”, where the GP is looking for serious underlying diseases before referring the patient to specialist treatment. During this vacuum the child usually does not receive treatment for their pain. This time period is, however, crucial for the further health outcomes of the patient (45). Adequate prevention and management of children’s pain is thus hindered by inadequate education of parents and health professionals in children’s pain management. There is also a lack of paediatricians with a specialisation in pain who can provide consultation and specialist treatment (23). When CP patients receive diagnoses such as “functional” or “psychosomatic” pain, the families often understand these as negative labels blaming them for their child’s pain. This apparent blame often causes parents to seek out multiple doctors in search of an appropriate diagnosis and treatment (45).

The socioeconomic status of the patient and their family also affects the access to tertiary pain clinics. Families with lower socioeconomic status usually live further away from the pain clinics and are more likely to miss appointments (46), while parents with a high occupational skill level are more likely to bring their children to the appointments from a long distance (47). According to a report by the OECD, one fifth of the Swiss population did not visit their doctor in 2016 due to the high medical costs. This might mean that children from less wealthy families see physicians less often due to costs (48).

One of the main problems in CP care management is the lack of education in pain and CP and the use of available materials and participation in the available courses (49, 50).

2.6 Economic consequences and burden of chronic pain

Chronic pain in adults creates a high economic burden, being one of the costliest conditions in Western society, but only a few studies have analysed the costs induced by children and adolescents (18, 51). There are both direct and indirect costs of CP. Parents and caregivers must often adjust their lives to be able to support the affected adolescent, which leads to economic costs to the families, institutions and the state due to loss of tax incomes. The most commonly used health services are those of the GPs, but families often have out-of-pocket costs caused by complementary treatments, i.e. chiropractors (51). CP that starts during childhood and adolescence can cause unemployment in adulthood and the thus lead to an even further increase of the economic burden over time (18). Due to the lack of adequate ICD coding for CP, the assessment of exact healthcare costs is difficult (5). A Swiss study on the adult population estimated the direct costs of low back pain, which is also the most prevalent health problem in the Swiss adult population, to be €2.6 billion which constitutes 6.1% of the total healthcare costs in Switzerland. The total burden of lower back pain on the Swiss society was 1.6–2.3% of the gross national product in 2005 (52). These numbers, albeit in adults, give an indication of how big the economic burden of CP is on the individual, the family and the society.

2.7 Child and adolescent healthcare in Switzerland

Switzerland had a total population of 8.5 million people in 2017. Of those, approximately 15% are 0–14 years old and 5% are 15–19 years old, making up a total of 20% of the population. Of these children and adolescents one in four have an immigration background (53). There are four national languages in Switzerland, German, French, Italian, and Romansh, and three main language regions, the German-, French- and Italian-speaking areas (54).

The Swiss healthcare system is mainly regulated by the legislation of the individual cantons, but it is also run by a mixed system built on federal regulations and private funding. A personal private health insurance is required by all Swiss residents to cover healthcare costs (this can be subsidized for people who fall under a minimum household income). Approximately 10% of the healthcare costs are met by the patients themselves and there are also additional out of pocket payments. However, the exact numbers for the latter are unknown. There is a freedom of choice for medical services depending on the type of health insurance, and the typical gatekeeper role of GPs is not applicable. Switzerland has currently 400 physicians per 100 000 people. This is considered relatively high on an international level, but in the next decades the number is expected to decrease, especially in regards to the number of primary care physicians (54).

Paediatric healthcare providers in Switzerland can be divided into the following groups (54):

1. primary care paediatricians and GPs in private practices
2. paediatric hospitals with primary, secondary and tertiary care
3. adult hospitals without formal paediatric services (caring for approximately 30–40% of the paediatric population)
4. mental healthcare providers in university- or cantonal-based psychiatric units and private practices, including specialists in adolescent and child psychology and psychiatrists
5. paediatric surgeons in public and private hospitals
6. non-medical providers such as nurses, physiotherapists, occupational therapists and others

Primary paediatric care was provided by 985 paediatricians and 5,945 GPs in 2016. Secondary and tertiary services were provided by 32 paediatric hospitals and departments. Paediatric primary care is mostly taken care of by paediatricians (almost 80% of all pre-schoolers consulting them) but as the child grows older the proportion of GPs caring for the paediatric population rises, and up to every second adolescent over 11 years consults a GP instead of a paediatrician. In 2014 there were approximately 740,000 patient visits (not including all Swiss cantons due to missing data) at primary care paediatricians. Any kind of pain was the reason for 5.6% of the sick child visits and 1.0% of the well child visits in a Zürich-based study on paediatric primary care provision (54). Regional variation in the health status of children and adolescents have been observed, i.e. the children and adolescents in the German-speaking parts of Switzerland are more physically active and less obese than those from the French-speaking part (55, 56). Currently, there are four specialized paediatric pain ambulatories in Switzerland, all of them in some of the biggest cities in the country, Zürich, Basel, Bern (German-speaking Switzerland) and Lausanne (French-speaking Switzerland), located at the children's university hospitals of each respective city.

2.8 Hypothesis

A recent German study found that the private and group paediatric practices do not follow any guidelines for chronic pain treatment in children and adolescents when it comes to diagnosis and treatment (57). There is lack of research and knowledge in the field of healthcare provision of chronic pain in children and adolescents, and often primary and secondary healthcare provision has been neglected in research (54, 58). Assuming that reports of CP from other Western countries, presented in the background section, also hold in Switzerland, where there are very few data currently available, the present thesis hypothesises that the number of chronic pain patients seen by paediatricians in the sample differ significantly by language region and workplace. Care provision is thereby assumed to be associated with previous experience of chronic pain, training in chronic pain, availability of interprofessional teams and vicinity of ambulatory pain clinics.

2.9 Objectives

Due to the lack of research in this area this thesis has two primary objectives:

1. to estimate the prevalence of chronic pain in children and adolescents in Switzerland based on reported number of patients with CP and patient visits in paediatrician practices in primary healthcare

2. to investigate the chronic pain care concepts, care provision for chronic pain and professional experiences with chronic pain, among paediatricians in Switzerland

Currently, there are little data on chronic pain in children and adolescents in Switzerland. Data are neither available on prevalence, nor on treatment, care management and care concepts. This study was conducted with the aim to fill this gap, to estimate the CP prevalence in paediatric patients in Switzerland and to gain a better understanding of the current state of care provision and professional experiences in Swiss paediatrics. Being a first of a kind study in Switzerland the results of this study can contribute with valuable information for further research and healthcare policies in Switzerland.

3 Methods

This master's thesis is part of a cross-sectional trilingual questionnaire study in Swiss paediatricians led by a Swiss chronic pain research consortium, namely the Zurich University of Applied Sciences (ZHAW), the University Children's Hospital Basel (UKBB) and the University of Basel in Switzerland, in collaboration with the University of Tromsø (UiT) in Norway. The affiliations of the research consortium can be found in Appendix 1.

3.1 Development of study design and questionnaire

The development of the study design and questionnaire started in October 2018. In meetings and e-mail exchanges among the whole research consortium the cross-sectional study-design was agreed on and soon after the development of the questionnaire started. The development of the questionnaire lasted from October 2018 until January 2019. External inputs from experts in the field of paediatric chronic pain were received during the process to support the work. The author of this thesis designed the questionnaire and programmed it in the online survey tool UniPark by Questback in January-February 2019. The questionnaire was originally made in German, which is the language used by the research consortium, and the French and Italian versions of the questionnaire were translated by professionals in February-March 2019. The questionnaire was verified by two paediatricians working at UKBB, one native in German and the other native in French and Italian, for comprehension of the questions. The online questionnaire was tested multiple times and changed accordingly for best possible results, and the questionnaire was finished for distribution by March 2019. An English version of the complete questionnaire, created solely for illustration purposes in this thesis by the thesis author, can be found in Appendix 2. The invitation letter to the study is in Appendix 3. There was no actual pilot study. Andreas Wörner, member of the research consortium, contacted the Swiss Society of Paediatrics (SSP) and organized the collaboration and contact information of the participants eligible for participation.

3.2 Important definitions

In our study, we used the following definition for chronic pain: *Pain, which can be of a lasting character, episodic or recurrent, that has been present for at least 3 months. The aetiology of pain may be known, somatic or psychological, but also of unknown origin.* We introduced it in the information letter and asked all participants to refer to it in their answers. We also defined the age of the children and adolescents referred to in the questions to be 0–18 years old. By care provision we refer to how patients with chronic pain are treated and referred by paediatricians. Chronic pain management includes treatment, different assessments and care patterns.

3.3 Data collection

The data collection took place over the course of seven weeks in March-April 2019 with the online questionnaire. The questionnaire was filled in by the participants online in UniPark. The participants received an invitation e-mail with the link to the questionnaire. The questionnaire could be accessed once through the link. The participants received two reminder e-mails to participate in the questionnaire.

3.3.1 Questionnaire

The questionnaire could be filled in using any of the Swiss official languages: German, French or Italian. The participant could choose their preferred language after opening the questionnaire link. Although Switzerland has four national languages, the fourth, Romansh, was not given as an option. The German version of the questionnaire was created by the research team and translated by professional translators into French and Italian.

The questionnaire consists of three parts, of which part one and two will be described more in detail in the next chapters. The third part is not part of this thesis, but because it is an important part of the research project it is mentioned here. The three parts in the questionnaire are the following:

1. Sociodemographic questions of the participant
2. Questions on chronic pain prevalence, approach and treatment of it
3. A case vignette about an adolescent with chronic pain; questions related to the case

The first part of the questionnaire includes questions about age, sex, reception year of the specialist title, professional and current workplace information as well as the workload of the participant. In cases where the participant worked in an individual or group practice, the participant was also asked to answer questions about how many children they see in their practice per three months and if there are other specialists working in the practice.

The second part of the questionnaire concentrates on chronic pain prevalence and the paediatrician’s experience with working with children suffering from chronic pain. The following questions are included: how much experience does the participant have working with children with chronic pain, if they have training in treatment of children with chronic pain, if they are comfortable with treating children with chronic pain, what their estimation about the total prevalence of children with chronic pain in their paediatric patient population is, how many children with chronic pain they have treated in the past seven days and if this number corresponds with the normal amount of children with CP that they see, how they measure the intensity of pain in their patients, if they have referred children with chronic pain to other specialists, if they have referred children to pain ambulatories specialized in children and adolescents. and if they would consider referring their patients to one of these specialized ambulatories. If the participant answered that they do not consider a referral to a pain ambulatory a therapeutic option, they were asked why it is not, and if they had referred patients with chronic pain to other professionals or other paediatricians with a different specialisation, they were asked to which ones.

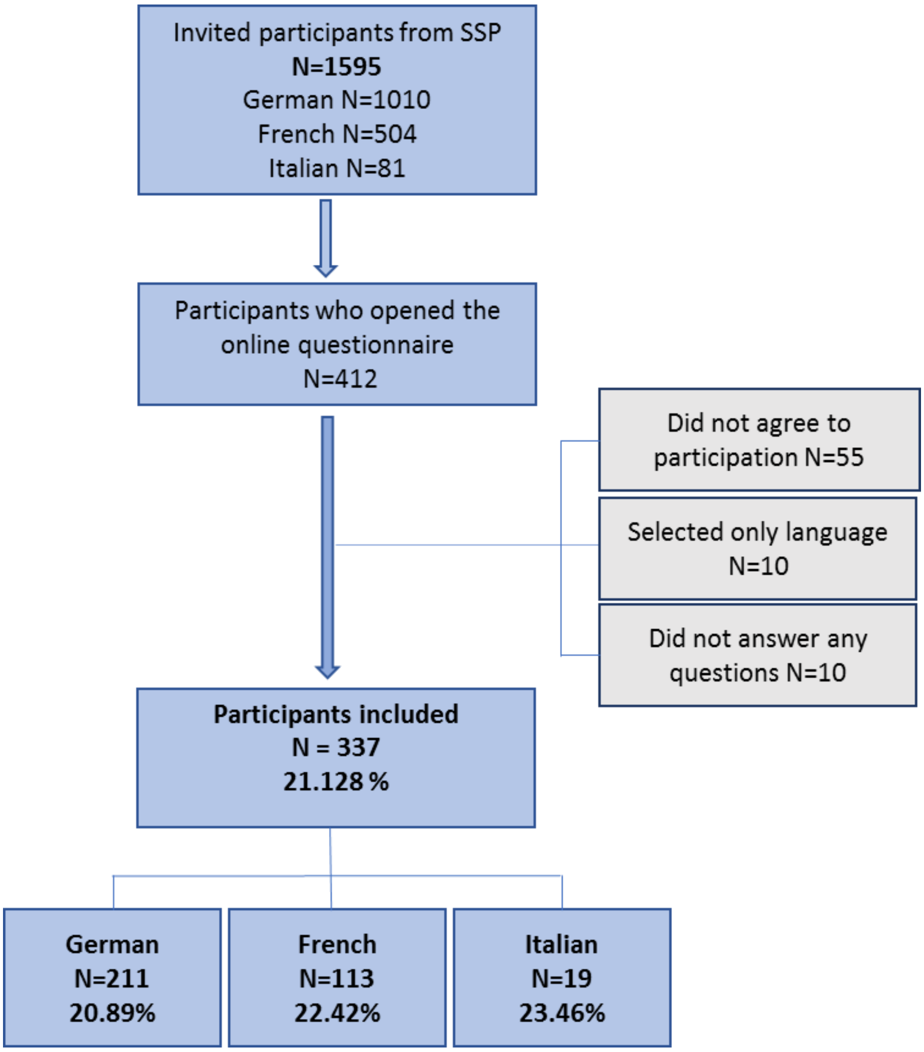
3.4 Study sample

The Swiss Society of Paediatricians (SSP) is the biggest national multilingual organization for paediatricians in Switzerland. They have approximately 2500 members from all Swiss language regions. SSP offers three types of memberships: 1) ordinary membership for paediatricians with a specialisation, 2) extraordinary membership for medical specialists in other fields or non-physician specialists interested in paediatrics, and 3) assistant members for paediatricians in training for their specialisation (59). According to the FMH Swiss Medical Association (60), there were 1304 paediatricians from all medical disciplines with a specialisation in paediatric medicine working in Switzerland in 2018.

The SSP was contacted by Andreas Wörner to establish a collaboration between the research team and the SSP. The study protocol was evaluated through the SSP board and they concluded that chronic pain in children and adolescents is an important topic and that they are willing to support the research project. They agreed to provide the research group with the e-mail addresses of their members for of contacting possible participants of this study.

Only participants who were working as paediatricians were invited. Paediatricians in training and those who are not clinically active anymore were not included, although some of them had not updated their information at SSP and received the invitation nonetheless (*N*=ca. 30). There was a total of 412 participants who opened the online questionnaire. 55 did not fill in the required “I agree to participation” question and 10 participants only looked at the first page of the questionnaire and were therefore deleted, leaving 337 actual participants in the final sample.

Figure 1: Participant flow



3.5 Ethical considerations

The online questionnaire used for data collection in this study is anonymized and participants are not identifiable in the results. Identification of participants is also not possible with the background information collected in the survey. Personal information of the participants was collected, which is why ethical approval was needed. This study was done as a co-operation between universities in Norway and Switzerland (ZHAW, UiT and University of Basel), and therefore ethical approval was needed from both countries, although data was only collected in Switzerland. The Norwegian Center for Research Data (NSD) evaluated and approved the questionnaire and the information letter and agreed that the study complies with the Norwegian privacy policy. The cantonal ethics committee in Zürich classified the study as ethically uncritical and exempt of ethical review. Only the research consortium has access to the survey data. Participants of the study had to give their consent that they were aware of the objectives and questions of the study and that they approved of the anonymous storage and the use of their data to address the research objectives. If the participants did not agree, they could not proceed with the study and were excluded from the statistical analysis. If a participant at any point in the future wishes to withdraw from the study, they can do so by providing a self-created identification code.

3.6 Statistical analysis

The statistical analysis was done with IBM SPSS, version 25 (61), exclusively by the author of this thesis. The raw data could be directly extracted from the online questionnaire programme UniPark to IBM SPSS. A codebook was created for the collection of the variable information. The data was cleaned, and new variables were created for statistical analysis. For example, year of receiving specialist title was originally a continuous variable, but for the analyses it was binned into 10-year time periods creating a categorical variable. Missing values were recoded and excluded from the analysis. If a participant had provided an answer that did not fit into any of the groups and which was not an actual option, the answer was either recoded as missing or included in the appropriate category. For example, if a participant answered that their workload was >100% they were recoded to be in the 100% group.

Descriptive statistics and frequencies were used to describe and analyse the answers (single or multiple choice) obtained from the questionnaire. There are only a few continuous variables and most of the variables are nominal or ordered, therefore it was not necessary to check for linear model assumptions. Some of the questions in the questionnaire allowed for open answers. $\chi 2$ tests and Fisher’s exact t-tests were conducted for testing the null hypothesis of no difference between variables.

Prevalence of paediatric chronic pain in Swiss private paediatric practices was calculated as follows. All participants who answered the question on workplace and answered either “single practice” or “group practice” were included in the analysis. Other criteria for inclusion was the answer to the questions “how many children do you see in your practice per three months” and “how many children with chronic pain have you treated in the past 7 days”. All in all, N=202 participants answered all three questions and were included in the calculation for prevalence. More detailed information on the calculation is available in the results section in Table 4.

Explorative logistic regression analyses were used for statistical analysis of the correlation between the dependent and independent variables. The dependent variables ‘comfort treating patients with chronic pain’ and ‘experience with treating chronic pain’ were dichotomized and recoded as binary variables. For the first variable, participants indicating that they feel comfortable or are more likely to feel comfortable with treating patients with chronic pain were coded as ‘comfortable’ and participants indicating that they felt this to be ‘partly true’, ‘rather not true’ or ‘does not apply’ were grouped together and recoded as ‘not comfortable’. The second variable which gauges experience with treating chronic pain was recoded into a binary variable with “very much experience” and “much experience” recoded as ‘experience’ and participants indicating “some experience”, “little experience” or “no experience” recoded as ‘no experience’. For the variable which assesses whether participants have received training in chronic pain while being a specialist, some participants answered, “I do not know” and their answer was subsequently excluded from the analysis. Different regressions models were tested, first including all possible predictors, then eliminating those with a *p*-value > 0.2. All models always include age, sex and language region. The predictors which had a significance of *p* = < 0.2 were included in the final model.

Statistical tests reported for the logistic regression models are the Omnibus test of Model coefficients, the pseudo R Squares Cox & Snell and Nagelkerke, the Hosmer and Lemeshow Test and the Wald statistic. Omnibus test of Model Coefficients is reported to check that the new model is an improvement over the baseline model. If the *p*-value is significant (<0.05) it confirms that the new model is significantly better than the old one, and the new model explains more of the variance. Pseudo R Squares (R^2) reported under each regression model are the ones from Cox & Snell and Nagelkerke. These values explain roughly how much variation the model explains in the outcome in percentage (%). The values of these two pseudo R^2 -test are only approximations and differ from each other. Hosmer and Lemeshow Test is used for goodness of fit, and if the *p*-value is >0.05 it means that the model is a good fit to the data. The Wald statistic is used to test if a regression coefficient for an independent variable is significantly different from zero. The independent variable with the highest Wald statistic is the most important predictor for the outcome variable and therefor contributes in predicting the outcome.

4 Results

4.1 Study population

In total 337 participants answered the questionnaire. This equals a 21.1% (337/1595) total participation rate. Because our address list of eligible participants provided by SSP also included participants who are retired or not clinically active, we assume that the actual participation rate is higher. The number of working paediatricians in 2018 was also lower than our study sample (60). Not all participants answered all questions, as shown by the number (*N*=) below each question in the tables. The denominator for calculating the overall percentage response to each question was the actual number of answers for that questions. The sociodemographic characteristics and work-related characteristics of the participants can be seen in Table 1 below.

Table 1: Sociodemographic and work-related characteristics

Demographic	Category	*N*	(% of total sample)
Sex ***N*= 337**	Female	238	(70.6%)
	Male	99	(29.4%)
Age ***N*=337**	≤ 35 years	21	(6.2%)
	36-45 years	144	(42.7%)
	46-55 years	109	(32.3%)
	56-65 years	59	(17.5%)
	> 65 years	4	(1.2%)
Year of specialisation ***N*=337**	1980-1989	22	(6.5%)
	1990-1999	78	(23.1%)
	2000-2009	119	(35.3%)
	2010-2019	118	(35.0%)
Language region of workplace ***N*=337**	German-speaking	211	(62.6%)
	French-speaking	113	(33.5%)
	Italian-speaking	19	(5.3%)
Workplace **(multiple choices possible)** ***N*=337**	Single practice	54	(16.0%)
	Group practice	171	(50.7%)
	University hospital	70	(20.8%)
	Cantonal hospital	64	(19.0%)
	Regional hospital	23	(6.8%)
	Other	19	(5.6%)
Workload 0-100% ***N*=335**	mean	75.21%	
	SD, range	± 20.99	10-100
Time worked in the past 7 days ***N*=335**	Days, mean	4.26	
	SD, range	± 1.41	0-7
	Hours, mean	36.52	
	SD, range	±17.89	0-120

More than two thirds of the participants are female. The most common age for participants is 36–45 years old. 70% of the participants received their specialist title in paediatrics after the year 2000. The majority of the participants work in the German-speaking area of Switzerland, followed by the French- and Italian-Speaking parts. Two thirds of the participants report that they work in single or group practices, 46.6% report that they work in hospitals. 5.6% report another working place, these are specified as administration or health authorities in the open answers. The mean workload is 75% and the participants have been working four days or 37 hours in the past seven days.

There were two questions on sociodemographic characteristics which were only answered by participants who selected single or group practice as their workplace (*N*=214), the results of which are presented in Table 2 below.

Table 2: Workplace characteristics of single and group practices

Question	Category	*N*	(% of total sample)
Number of children seen per 3 months *N*=209	< 250 children	27	(12.9%)
	250-500 children	51	(24.4%)
	500-750 children	48	(23.0%)
	750-1000 children	42	(10.1%)
	1000-1500 children	35	(16.7%)
	>1500 children	6	(2.9%)
Other professionals working in the same practice *N*=214	Specialist in paediatrics	145	(67.8%)
	Psychologist	33	(15.4%)
	Physiotherapist	15	(7.0%)
	Occupational therapist	5	(2.3%)
	Medical specialist (other area)	37	(17.3%)
	Not applicable	45	(21.0%)

The number of children seen in the group or individual practice every three months is reported to be 250–750 children by approximately half of the participants. Other professionals working in the practice are most commonly another specialist in paediatrics, other medical specialists and psychologists. Other professionals reported in the open answers were specialists in internal general medicine (*N*=17), orthopaedists and surgeons (*N*=10), different specialists in paediatrics, i.e. children’s psychiatrists and developmental paediatrics (*N*=19), other specialists in internal medicine, i.e. gastroenterology and rheumatology (*N*=26), and other specialists such as dieticians (*N*=23).

4.2 Descriptive statistics

Table 3 below summarizes the descriptive statistics of the questionnaire items from the second part of the questionnaire, where specific questions on chronic pain were asked.

Table 3: Descriptive statistics of chronic pain related questions

Question	Category	N	(% of total sample)
Experience with chronic pain	Very much experience	8	(2.5%)
***N*=317**	Much experience	52	(16.4%)
	Some experience	126	(39.7%)
	Little experience	110	(34.7%)
	No experience	21	(6.6%)
Training in treatment of children with chronic pain as a specialist in paediatrics	Yes	58	(18.3%)
	No	249	(78.5%)
***N*=317**	I don't know	10	(3.2%)
Rating of the sentence "I feel comfortable treating children who suffer from CP"	Applies	6	(1.9%)
	More likely to be true	59	(18.6%)
***N*=317**	Partly true	119	(37.5%)
	Rather not true	94	(29.7%)
	Does not apply	39	(12.3%)
Estimated prevalence of children with chronic pain of the total paediatric patient population	<1 %	112	(35.8%)
	1-5 %	113	(35.6%)
***N*=317**	5-10%	44	(13.9%)
	10-20%	15	(4.7%)
	>20%	10	(3.2%)
	No patients with CP	22	(6.9%)
Number of children with chronic pain treated in the past 7 days	mean per paediatrician	1.6	
***N*=316**	sum, SD	506	± 2.56
Does the number of children with CP treated in the past 7 days correspond with the average weekly number of CP patients	Yes	188	(59.7%)
	No, higher than the average	44	(14.0%)
***N*=315**	No, lower than the average	83	(26.3%)
Measuring intensity of pain (multiple answers)	Visual Analog Sale (VAS)	161	(50.8%)
***N*=317**	Smiley Scale (Wong-Baker Faces Pain Rating Sale)	128	(40.4%)
	Numerical rating scale (NRS)	134	(42.3%)
	Subjective assessment of the child's face or behaviour	198	(62.5%)
	Subjective assessment based on anamnesis and examination	229	(72.2%)
	Based on the parents' assessment	187	(59.0%)
	Other	23	(7.3%)
Ever referred a patient to another specialist because of chronic pain *N*=316	Yes	244	(77.0%)
	No	72	(23.0%)
***N*=227* for number last year**	Mean number last year*	5.3	
	sum, SD	1217	±7.117

Table 3: Descriptive statistics of chronic pain related questions continues

Question	Category	N	(% of total sample)
Ever referred a child to a pain ambulatory specialized in children and adolescents ***N*=316**	Yes	116	(36.7%)
	No	200	(63.3%)
***N*=111* for number last year**	Mean number last year	2.10	
	sum, SD	233	± 2.876
Is referral to a pain consultation specialized in children and adolescents a therapeutic option ***N*=316**	Yes	286	(90.2%)
	No	30	(9.8%)
Reasons why a referral to a pain ambulatory specialized in children and adolescents is not a therapeutic option **(*N*=30*)**	Doesn't know any pain ambulatory	14	(46.7%)
	Too far away for patients	5	(16.7%)
	Enough other therapeutic resources	10	(33.3%)
	Other reasons	10	(33.3%)
Referral of patients with CP to other professionals; to whom? **(*N*=243*)**	Specialist in paediatrics with a different focus	168	(69.1%)
	Psychologist	114	(46.9%)
	Psychotherapist or psychiatrist	114	(46.9%)
	Physiotherapist	110	(45.3%)
	Occupational therapist	25	(10.3%)
	Medical specialist from another specialist area	91	(37.4%)
	Other professionals	42	(17.3%)
	Not applicable	1	(0.4 %)
Referral of chronic pain patients to a paediatrician with a different focus **(*N*=243*)**	Endocrinology&Diabetology	4	(1.6%)
	Gastroenterology&Hepatology	119	(49.0%)
	Cardiology	13	(5.3%)
	Nephrology	1	(0.4%)
	Neuropaediatry	115	(47.3%)
	Oncology&Haematology	12	(4.9%)
	Orthopedy	99	(40.7%)
	Pneumology	2	(0.8%)
	Rheumatology	119	(49.0%)
	Developmental paediatrics	4	(1.6%)
	Other	24	(9.9%)

*Filter questions were only answered by participants who gave answers to previous specific questions
SD= Standrard Deviation

In total, 18.9% of the participants report to have very much or much experience in CP. A little less, 18.3%, report to have partaken in training in CP management and treatment after receiving their specialist title in paediatrics. 20.5% report to feel comfortable (answers 'applies' and 'more likely to be true') treating children who suffer from chronic pain. More than two thirds report a prevalence of children with chronic pain in their paediatric patient population to be <5%. There was no statistical significance when testing for difference between sexes and estimated prevalence of chronic pain in the paediatric patient population seen. 22% of women and 24% of men reported a prevalence of over 5%. In our sample, a total of 506 children with chronic pain had been seen by the paediatricians in the last week. 60% of the participants agree that this number corresponds with the average number of children with CP seen during a normal week.

About half of the paediatricians chose to measure the intensity of pain with different instruments (VAS, NRS, Smiley Scale). The majority rely on subjective assessments of the child’s pain based on the child’s face or behaviour or the clinical anamnesis and examination as well as the parents’ assessments. Other assessments of pain intensity reported in the open answers, were i.e. pain protocol (‘diary’) or other measurement tools. Some participants also answered that they measure the daily functioning and that instruments are better used for acute than chronic pain. Three quarters of the participants had referred a child with CP to other specialists, with an average of 5.3 children per participant. Almost two thirds of the participants had never referred a child to a pain ambulatory specialized in children and adolescents because of CP, and those who had referred, had referred on average 2.1 children in the past year. Nine out of ten participants find a pain ambulatory specialized in children and adolescents a therapeutic option for CP. Of those who answered that it is not a therapeutic option, almost half did not know about any, 16.7% found that it is too far away for the patients and a third reported that they have enough own therapeutic resources. Reasons for not referring, specified in the open answers, were that there is no such service in their working area, that they do not approve of the methods used by the ambulatory pain clinics and that the children with CP should be treated as normal paediatric patients. Participants had referred children and adolescents with CP to many different medical professionals, most commonly to other paediatric specialists, of which gastroenterology and hepatology, neuropaediatry and orthopedy were the most common. In addition to the professionals, and other paediatric specialist shown in Table 3, the participants had referred the patient to i.e. pain specialists, specialists in internal medicine, i.e. rheumatologists, neurologists and anaesthetists, or orthopaedists. Many had also referred patients to hypnotists, acupuncturists, alternative medicine and psychiatry.

4.3 Prevalence of chronic pain

This subchapter aims to estimate the prevalence of chronic pain in children and adolescents in Switzerland based on reported number of patients with CP and patient visits in paediatrician practices in primary healthcare, according to the first objective of this thesis.

Table 4: Prevalence calculation of patients with chronic pain in single and group practices

Children with CP treated in the past 7 days	Children with CP treated in a year	Sum of children treated per three months in the practice[c]		Sum of children treated per year in the practice[d]	Prevalence
∑ 322[a]	∑ 16 744[b]	Minimum	107 527	∑ 430 108	3.89 %
		Average	136 250	∑ 545 000	3.07 %
		Maximum	165 000	∑ 660 000	2.54 %

[a] Estimated number of children with CP treated in the past 7 days in individual and group practices;
[b] Number of children with CP per year is calculated by multiplying the total sum from 7 days by 52;
[c] Number of children seen per three months is calculated based on the categorical options (0–250, 250–500,500–750, 750–1000, 1000–1500, >1500) and taking either the minimum, average or maximum value of each category; For the lowest category (<250 children seen in three months) 1 is used in the calculation of minimum sum. In the highest category (>1500 children seen in three months) 1500 is always used for the calculation
[d] Sum of children per three months in the practice is multiplied by 4 to represent the annual number

Based on the study data, we estimated the range of CP prevalence seen by paediatricians in group or individual practices in Switzerland to be 2.54%–3.89% (average 3.35%). The total number of participants included in the calculations is N=202. The estimation is based on the number of patients with CP seen by the respective physicians in a year (nominator) and the number of patient visits in these practices, taking the minimum, the average and the maximum of the provided categories. Example values for category ‘500–750 children seen in the practice per three months’; min.: 500, average: 625, max.: 750; in the denominator.

The calculated average prevalence corresponds with the reported estimate of prevalence seen in the practice, as approximately 35% of the participants estimated that the prevalence of CP is between 1–5%. Paediatricians in private or group practices reported having treated 322 children or adolescents with CP in the last week. 60% agreed that the number of children seen in the past 7 days corresponds with a normal week (15% higher and 25% less than normal). There is no gender difference in estimated CP prevalence in the paediatric population (Pearson’s Chi-square p-value = 0.346).

4.4 Predictors of comfort, experience and training in CP

This and the next chapter of the results aims to answer the second objective of the thesis. Multivariate logistic regressions are used to assess the effect of various predictors on three outcome variables, namely level of comfort when treating chronic pain, level of experience in chronic pain treatment and management, and level of training received in chronic pain treatment as a paediatrician. The results from the regression modelling for these three outcome variables are presented separately in the following sections. Odds Ratio (OR) is presented as the main outcome.

4.4.1 Comfort treating patients with chronic pain

21.4% of the participating paediatricians are comfortable (N=63) and 78.6% (N=231) do not feel comfortable treating children and adolescents with chronic pain. 87.2% (N=294) of the total participants answered this question and were included in the analysis. Table 5 shows the predicting model estimates of being comfortable in chronic pain treatment.

Table 5: Explorative analyses of predictors for being comfortable

Independent variables	OR	95% CI for OR		Wald statistic	*p*-value
***N*=294**		Lower	Upper		
Female	1.00	-	-	-	-
Male	3.330	1.328	8.351	6.576	.010*
Age ≤35 (ref.)	1.00	-	-	-	-
Age 36-45	3.674	.334	40.453	1.131	.288
Age 46-55	4.862	.444	53.197	1.678	.195
Age 56-65	11.021	.954	127.298	3.696	.055
Age >65	11.940	.358	397.967	1.921	.166
Language German (ref.)	1.00	-	-	-	-
Language French	.822	.372	1.818	.234	.629
Language Italian	1.257	.248	6.366	.076	.782
Workload in % (continuous)	.989	.969	1.009	1.133	.287
Estimated prevalence of CP <1% (ref.)	1.00	-	-	-	-
Prevalence 1-5%	1.876	.763	4.613	1.877	.171
Prevalence 5-10%	1.838	.580	5.826	1.068	.301
Prevalence 10-20%	.918	.177	4.768	.010	.919
Prevalence >20%	1.173	.196	7.009	.031	.861
No training in CP	1.00	-	-	-	-
Training in CP	2.172	.955	4.942	3.422	.064
No experience in CP	1.00	-	-	-	-
Experience in CP	11.045	4.665	26.149	29.836	<.001*

*Significant at the conventional 0.05 level
Omnibus Test of Model Coefficients p= <0.001
Pseudo R Squares Cox and Snell =0.248 and Nagelkerke= 0.385
Hosmer and Lemeshow Test for goodness of fit p=0.071

Men have 3.3 times higher odds (OR 3.330, 95% CI 1.328–8.351, *p*-value 0.010) of being comfortable treating patients with chronic pain compared to women. Being experienced in CP was also a significant predictor of feeling comfortable with patients with chronic pain. The odds for feeling comfortable were 11 times higher when having experience in CP compared to those without any experience (OR 11.045, 95% CI 4.665–26.149, *p*-value <0.001). Experience was also the strongest predictor (Wald-statistic 29.836). All the other predictors in the final model had no statistical significance.

4.4.2 Experience with treating patients with chronic pain

N=294 participants reported to have either experience (*N*=59, 20.1%) or no experience (*N*=235, 79.9%) in CP and were included in the analysis. Model estimates are shown in Table 6 for being experienced in chronic pain treatment as the predicted outcome.

Table 6: Explorative analyses of predictors for being experienced in chronic pain

Independent variables	OR	95% CI for OR		Wald statistic	*p*-value
***N*=294**		Upper	Lower		
Female	1,00	-	-	-	-
Male	.959	.432	2.128	.011	.918
Age ≤35 (ref.)	1.00	-	-	-	-
Age 36-45	1.189	.200	7.089	.036	.849
Age 46-55	1.467	.202	10.632	.144	.704
Age 56-65	4.742	.485	46.406	1.788	.181
Age >65	30.934	.904	1058.320	3.625	.057
Language region German (ref.)	1.00	-	-	1.396	.497
Language region French	1.251	.568	2.756	.308	.579
Language region Italian	.314	.031	3.196	.957	.328
Estimated prevalence of CP <1% (ref.)	1.00	-	-	-	-
Prevalence 1-5%	10.306	2.742	38.744	11.921	.001
Prevalence 5-10%	36.297	8.942	147.341	25.247	<.001*
Prevalence 10-20%	50.710	9.212	279.158	20.354	<.001*
Prevalence >20%	181.138	22.328	1469.493	23.696	<.001*
Year of receiving specialist title 1980-1989 (ref.)	1.00	-	-	-	-
Specialist title 1990-1999	13.526	1.679	108.940	5.988	.014*
Specialist title 2000-2009	13.650	1.313	141.938	4.786	.029*
Specialist title 2010-2019	9.402	.754	117.227	3.030	.082

*Significant at the conventional 0.05 level
Omnibus Test of Model Coefficients *p*= <0.001
Pseudo R Squares Cox and Snell =0.251 and Nagelkerke= 0.396
Hosmer and Lemeshow Test for goodness of fit *p*=0.010

In this model, the estimated prevalence of chronic pain in the paediatric population was a significant predictor, and the most important predictor, of being experienced with treating patients with chronic pain. Estimated prevalence of 1–5% has 10 times higher odds (OR 10.3, 95% CI 2.742–38.744, *p*-value 0.001) 5–10% estimated prevalence has 36 times higher odds (OR 36.297, 95% CI 8.942–147.34, *p*-value <0.001), 10–20% estimated prevalence has 51 times higher odds (OR 50.710, 95% CI 9.212–279.158, *p*-value <0.001) and >20% estimated prevalence has 181 times higher odds (OR 181.138, 95% CI 22.328–1469.493, *p*-value <0.001) of being experienced in patients with CP compared with those who estimate a CP prevalence of <1% in their paediatric patient population. The year of receiving a specialist title was also associated with experience in CP. Paediatricians who had received their specialisation in 1990–1990 had 11 times higher odds of being experienced.

4.4.3 Training in treating patients with chronic pain

Of the participants included in this analysis,18.2% (*N*=52) had received training and 81.8% (*N*=233) had not received training in CP treatment as paediatricians. Participants who answered, “I don’t know” (*N*=9), were excluded from the analysis, thus leaving *N*=285 in the analysis. Results of the model are shown in Table 7; the predicted outcome is having training in CP treatment after specialization in paediatrics.

Table 7: Explorative analyses of predictors for having training in treating chronic pain

Independent variables	OR	95% CI for OR		Wald statistic	*p*-value
***N*=285**		Lower	Upper		
Female	1.00	-	-	-	-
Male	1.185	.576	2.438	.212	.645
Age ≤35 (ref.)	1.00	-	-	-	-
Age 36-45	.980	.281	3.415	.001	.974
Age 46-55	.637	.174	2.332	.464	.496
Age 56-65	.851	.213	3.398	.052	.819
Age >65	4.949	.474	51.680	1.785	.182
Language region German (ref.)	1.00	-	-	1.021	.600
Language region French	.892	.445	1.790	.103	.748
Language region Italian	.346	.042	2.851	.972	.324
Estimated prevalence of CP <1% (ref.)	1.00	-	-	-	-
Prevalence 1-5%	1.331	.611	2.897	.518	.472
Prevalence 5-10%	3.822	1.578	9.257	8.827	.003*
Prevalence 10-20%	1.232	.243	6.232	.063	.801
Prevalence >20%	5.932	1.371	25.665	5.674	.017*

*Significant at the conventional 0.05 level
Omnibus Test of Model Coefficients p=0.094
Pseudo R Squares Cox and Snell =0.06 and Nagelkerke= 0.097
Hosmer and Lemeshow Test for goodness of fit *p*=0.667

Estimated prevalence of 5–10% CP in the paediatric population seen in the practice results in 3.82 times higher odds (OR 3.822, 95% CI 1.578–9.257, *p*-value=0.003) of having training in CP treatment. Estimated prevalence of >20% gives 5.92 times the odds (OR 5.932, 95% CI

1.371–25.665, *p*-value=0.017) of having a training in CP treatment. Overall, the estimated prevalence was the highest predictor in this explanatory model for having been educated in treating CP (highest Wald-statistic at 13.099). All the other predictors were non-significant at the 0.05 level.

4.5 Referral of patients to paediatric pain ambulatories

In a final model the predictors for referring patients with chronic pain to paediatric pain ambulatories was tested and the three previous dependent variables were included as independent variables. In total *N*=280 participants met the inclusion criteria. Results of the final model are shown in Table 8; the predicted outcome is a referral of patients to paediatric pain ambulatories.

Table 8: Factors influencing referral to paediatric pain ambulatories

Independent variables	OR	95% CI for OR		Wald statistic	*p*-value
		Lower	Upper		
Female	1.00	-	-	-	-
Male	.812	.449	1.469	.475	.491
Age ≤35 (ref.)	1.00	-	-	-	-
Age 36-45	1.469	.521	4.138	.529	.467
Age 46-55	1.968	.665	5.826	1.494	.222
Age 56-65	1.279	.390	4.197	.165	.685
Age >65	3.670	.377	35.748	1.253	.263
Language region German (ref.)	1.00	-	-	-	-
Language region French	.873	.496	1.538	.220	.639
Language region Italian	.407	.104	1.589	1.675	.196
Workplace practice	1.00	-	-	-	-
Workplace hospital	3.572	2.043	6.243	19.964	<.001*
No comfort with CP	1.00	-	-	-	-
Comfort with CP	.955	.460	1.982	.015	.901
No experience with CP	1.00	-	-	-	-
Experience with CP	.897	.426	1.888	.083	.774
No training in CP	1.00	-	-	-	-
Training in CP	1.645	.839	3.226	2.096	.148

*Significant at the conventional 0.05 level
Omnibus Test of Model Coefficients p=0.003
Pseudo R Squares Cox and Snell =0.095 and Nagelkerke= 0.129
Hosmer and Lemeshow Test for goodness of fit *p*=0.461

The most important predictor for having referred a patient to a pain ambulatory was workplace. Those working in a hospital have 3.6 times higher odds (OR 3.572, 95% CI 2.043–6.243, *p*-value <0.001) of having referred a patient to a pain ambulatory specialised in children and adolescents compared to those working in a practice. All the other predictors were non-significant at the 0.05 level.

5 Discussion

This study was designed to explore the current situation of CP prevalence and management in Switzerland. The main results of the study suggest that most of the Swiss paediatricians do not feel comfortable treating children with chronic pain that there is a lack of training in CP treatment, and that very few of the paediatricians are experienced with treating children with chronic pain. In this study we calculated the prevalence of chronic pain in the paediatric single and group practice patient population to be around 3%. This corresponds with the prevalence estimated by the paediatricians, where over two thirds of the paediatricians estimated a chronic pain prevalence of less than five percent.

5.1 Prevalence

Currently, there is no diagnosis code for chronic pain, therefore the prevalence cannot be deduced from hospital data, nor form ambulatory data, since these are not aggregated for statistical purposes in Switzerland. This study is the first attempt to estimate the prevalence in the primary care setting, The results of this study correspond with a similar study for paediatricians in the UK where about two thirds of the participants, pain clinicians and GPs, estimated a CP prevalence of <5% (41). When comparing the healthcare provider reported estimate of CP with the self-reported CP in children and adolescents. the prevalence differs very much. The patient reported prevalence lies around 25% depending on location and methodology of data collection (7, 8, 10, 17, 18). In this study we did not investigate the cause of pain, only the prevalence reported by the paediatricians. According to the results the disagreement between provider-reported and self-reported chronic pain is high. Unpublished prevalence data from the Swiss Health Behaviour in School-Aged Children (HBSC) study shows that about 14% of the youth (11-15 years old) experience daily and weekly headache and that 13% experience daily and weekly neck pain (19). It is also well documented, that CP prevalence increases with age (8, 11-13). In the adult population the CP prevalence is 16% (3). In this study, we did not consider the age of the children and adolescents visiting the paediatricians. Possible reasons for this discrepancy is that only half the of patients seek medical help for their pain (9) or that half of over 11-year-old adolescents rather visit a family GP than a paediatrician (54). There are also six times more GPs caring for paediatric patients than paediatricians in the primary healthcare (54). While the 3% prevalence is already noteworthy, we can therefore assume that the actual prevalence for CP in the Swiss children and adolescents is higher than what this study suggests.

The most common criteria for diagnosis and treatment has been pain that has lasted for more than 3–6 months (5). There are no guidelines for diagnosing chronic pain, but pain assessment is clearly relevant. We were interested in the methods used by paediatricians. Measuring the intensity, duration and frequency of pain plays a crucial role in treatment of pain and estimating the prevalence of chronic pain, since pain is such a subjective experience (10). Half of the paediatricians in our study prefer to rely on patient reported measure instruments such as VAS, NRS and the Smiley-scale where patients report a specific level of pain based on a scale. Two thirds of the paediatricians preferred to assess the pain subjectively and more than half measured the intensity of pain based on the parents' assessment. However, studies show that chronic pain and the intensity of pain is often under-reported by caregivers and healthcare providers (10, 23, 43). This also supports the idea of a higher actual prevalence of CP in Swiss children and adolescents.

5.2 Chronic pain care concepts: comfort, experience and training in chronic pain

We find a high number of paediatricians with discomfort in treating paediatric pain. Interestingly, a gender difference was observed, as the results show that men are more likely to feel comfortable treating chronic pain in children. This difference cannot be explained by men having a higher prevalence of children with chronic pain in their paediatric population, as women and men estimated equally high prevalence. Having experience in CP is also strongly associated with feeling comfortable. Although not statistically significant, the comfort level increased with older age as well as having received training in CP treatment. The older age effect may be related to more working experience and experience with children with pain, which intuitively leads to more comfort with the patients. Okumura et al. shows that female paediatricians are less comfortable with treating young adults with chronic conditions and that comfort is highly associated with more experience (62).

Estimating a higher prevalence of patients with chronic pain in the paediatric patient population the likelihood for being experienced with CP increases. Similarly, working experience was associated with the self-reported experience with treating children with CP. Although age was not a predictor for experience, the year of receiving the paediatrician specialist title was. Those participants who have been working as specialists for at least ten years feel more experienced with children suffering from chronic pain.

Approximately one in five had received training in CP treatment during their medical training in paediatrics. This number is almost the same for Swiss pain clinic practitioners, where 22% had received training after specialization, half had not received any pain education (63). In the UK, nearly all paediatricians (77% of pain clinicians and 95% of GPs) participating in the study by Bhatia et al. had not received adequate training in CP management. More than half felt that they needed more CP education (41). We also know from previous studies that there is a lack of pain education for paediatricians (49, 50). Almost nine out of ten of practitioners working in Swiss pain clinics for adults find CP therapy difficult or very difficult and highlight a need for more training (63). Higher levels of training in CP is associated with increased comfort in treating patients with CP (64). Although we did not investigate the perceived need for more training in CP in our study, the result indicates that the current training situation for Swiss paediatricians should be improved.

5.3 Referral

Next to little prevalence data, care provision data are also missing with respect to children with chronic pain. A special aim of this study was to examine referral patterns of children and adolescents with chronic pain, especially referrals to ambulatory pain clinics. One third of all participating paediatricians had referred a child or adolescents suffering from chronic pain to a pain ambulatory. Almost all paediatricians also find that referring a child or and an adolescent to a paediatric pain ambulatory is a therapeutic option for them. Currently, there are only four pain ambulatories for children and adolescents in Switzerland, all located in big cities. Pain clinics specialized in children and adolescents have been shown to increase the quality of life and reduce the suffering caused by chronic pain in children and adolescents (15, 37, 58). The closer the pain ambulatory clinics are, the more patients and their families are willing to travel to them. Only a few paediatricians mentioned distance to the clinic being an access barrier. This points to a possibility of reducing socioeconomic differences caused by availability of pain clinics and willingness to travel to pain ambulatory clinics (47), since wealthier families are often more likely to travel farther distances than families with a lower income. Although the infrastructure in Switzerland is very good and travel distances are usually not too long, families living in the rural areas or far away from the four ambulatory pain clinics have a disadvantage compared to those living closer.

Four fifths of the participants had referred a patient to another specialist because of chronic pain before, in most cases to a paediatrician with a different specialization. Almost half had also referred chronic pain patients to psychotherapists, psychiatrists and physiotherapists, which is in line with the interdisciplinary approach recommended for chronic pain treatment (35). The most common paediatricians with a different specialisation that participants had referred patients to were gastroenterology and hepatology, neuropediatric, orthopedy and rheumatology. As the most common chronic pain locations in children and adolescents are head, stomach and in the musculoskeletal areas (7, 14), the results of this study indicate that patients have been referred to appropriate specialists. However, this also shows that the paediatricians might be looking for somatic reasons for chronic pain, which in most cases is not the best approach, as chronic pain less often has a somatic cause (20, 38). The time which the child spends in a diagnostic vacuum and is referred from one specialist to another could also be reduced by an earlier referral to pain ambulatories (30, 57). Literature shows that it is beneficial with regard to health outcomes and recovery, as well as the duration of health problem, when children and adolescents are referred to pain specialists, for example paediatric pain ambulatories, where they have the expertise to treat CP (65).

5.4 Strengths and limitations of the study

There are no current data on sociodemographic characteristics of Swiss paediatricians, and the data from the SSP was not available by the date of publication of this thesis. When comparing our study with the paper by Jenni & Sennhauser (54), the distribution of sociodemographic characteristics (i.e. sex, age, year of receiving specialist title) of the study population sample seem to agree with the estimated distribution of paediatricians in Switzerland. The study population is therefore representative to the real Swiss paediatricians' population. We also invited all members who were registered as clinically active by the SSP to participate in our study. A participation rate of 21% can be considered acceptable in a cross-sectional online-questionnaire study on physicians (66). Lack of time in the hectic clinical daily life and a rather short time for data collection (7 weeks) may have limited the participation rate. Missing data in the study was low, and participants who did not fulfil specific criteria were excluded from the analysis. The data we used to calculate the prevalence rate was validated through other questions in our questionnaire. We validated the number of children with chronic pain seen in the past seven days by asking if the number corresponds with the average weekly number. This was also a means to reduce recall bias which often are an issue in cross-sectional studies.

Some of the members of the SSP who received the invitation to the study did not (want to) participate, possibly because they do not see or treat children with chronic pain in their paediatric patient population. This may have led to participation bias and may have caused selection bias, leading to an overestimation of CP. On the other hand, we only included participants working in single and group practices in the calculations, which means that participants working in pain ambulatories were excluded. We chose to contact the biggest organization for Swiss paediatricians, however, we cannot fully dismiss the fact that we may have lost potential participants because of this, as not all Swiss paediatricians are members of the SSP. Because of practical reasons and accessibility of i.e. address information, this approach was appropriate. For future research the inclusion of GPs should be considered, as they treat a noteworthy number of adolescent patients. There is no national database in Switzerland on epidemiology of paediatric chronic pain, which means the results perceived in this study cannot be externally validated. The questionnaire created for this study has not been validated nor did a pilot study take place before the study.

6 Conclusion

Chronic pain in childhood is an important public health problem, with possible life-long consequences, affecting individuals, families and the society in a direct and indirect way. In our study, we found a 3% prevalence of CP in the paediatric patients visiting single- and group practices. This corresponds with the estimated prevalence by the paediatricians, but not with the prevalence of self-reported CP. The predictors of being comfortable treating CP are male sex and being experienced with CP. Having experience with CP is associated with higher estimated prevalence of CP in the practice, as is training in CP treatment. Referral to pain ambulatories was highly associated with working in a hospital. In this study, we also see that many paediatricians are still unaware of the different services offered by the cantons and hospitals, and that they therefore do not refer patients to pain clinics. Most of the participants have referred patients to different professionals. This is a good indicator that the interprofessional approach to chronic pain treatment has been rooted into the care concepts of chronic pain patients in Switzerland.

This study was conducted as a first attempt in filling the gap of lacking information on paediatric CP prevalence in Switzerland, and to gain a better understanding of the current state of care provision and professional experiences in the Swiss paediatrics. This being the first study in Switzerland looking into these questions, the results of this study can contribute with valuable information for development of adequate services, further research and healthcare policies in Switzerland. Suggestions for future research include longitudinal and cross-sectional studies on paediatric chronic pain which should be conducted to establish a Swiss national database for prevalence. When the IDC-diagnosis for chronic pain is established in the coming years, epidemiological data on CP can be analysed more easily and accurately. Some years after the ICD-diagnosis has been established, a follow-up study of the Swiss paediatricians, with similar questions to our study, would be interesting to investigate if there has been a positive change.

References

1. Vierola A. Prevalence and determinants of pain and tempotomandibular disorders in 6-8-year-old children [Doctoral Thesis]. Jyväskylä: University of Eastern Finland; 2017.

2. Palermo TM. Assessment of chronic pain in children:Current status and emerging topics. Pain Research & Management. 2009;14(1)(2009 Jan-Feb):21-6.

3. Breivik H, Collett B, Ventafridda V, Cohen R, Gallacher D. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. European journal of pain. 2006;10(4):287-.

4. Merskey N. Classificaiton of chronic pain; Description of chronic pain syndromes and definitions of pain Terms. Task force on taxonomy of the International Association for the study of pain. 1994:41-3.

5. Treede R-D, Rief W, Barke A, Aziz Q, Bennett MI, Benoliel R, et al. A classification of chronic pain for ICD-11. Pain. 2015;156(6):1003.

6. WHO. WHO releases new International Classification of Diseases (ICD 11) 2018 [updated 18.06.2018. Available from: https://www.who.int/news-room/detail/18-06-2018-who-releases-new-international-classification-of-diseases-(icd-11)

7. King S, Chambers CT, Huguet A, MacNevin RC, McGrath PJ, Parker L, et al. The epidemiology of chronic pain in children and adolescents revisited: a systematic review. PAIN. 2011;152(12):2729-38.

8. Perquin CW, Hazebroek-Kampschreur AA, Hunfeld JA, Bohnen AM, van Suijlekom-Smit LW, Passchier J, et al. Pain in children and adolescents: a common experience. Pain. 2000;87(1):51-8.

9. Roth-Isigkeit A, Thyen U, Stöven H, Schwarzenberger J, Schmucker P. Pain among children and adolescents: restrictions in daily living and triggering factors. Pediatrics. 2005;115(2):e152-e62.

10. Haraldstad K, Sørum R, Eide H, Natvig GK, Helseth S. Pain in children and adolescents: prevalence, impact on daily life, and parents’ perception, a school survey. Scandinavian journal of caring sciences. 2011;25(1):27-36.

11. Liossi C, Howard R. Pediatric chronic pain: biopsychosocial assessment and formulation. PEDIATRICS. 2016;138(5):e20160331.

12. Huguet A, Miró J. The severity of chronic pediatric pain: an epidemiological study. The Journal of Pain. 2008;9(3):226-36.

13. Kröner-Herwig B, Heinrich M, Morris L. Headache in German children and adolescents: a population-based epidemiological study. Cephalalgia. 2007;27(6):519-27.

14. Friedrichsdorf S, Giordano J, Desai Dakoji K, Warmuth A, Daughtry C, Schulz C. Chronic Pain in Children and Adolescents: Diagnosis and Treatment of Primary Pain Disorders in Head, Abdomen, Muscles and Joints. Children. 2016;3(4):42.

15. Hechler T, Blankenburg M, Dobe M, Kosfelder J, Hübner B, Zernikow B. Effectiveness of a multimodal inpatient treatment for pediatric chronic pain: a comparison between children and adolescents. European Journal of Pain. 2010;14(1):97. e1-. e9.

16. Stanford EA, Chambers CT, Biesanz JC, Chen E. The frequency, trajectories and predictors of adolescent recurrent pain: a population-based approach. Pain. 2008;138(1):11-21.

17. Roth‐Isigkeit A, Thyen U, Raspe H, Stöven H, Schmucker P. Reports of pain among German children and adolescents: an epidemiological study. Acta paediatrica. 2004;93(2):258-63.

18. Tegethoff M, Belardi A, Stalujanis E, Meinlschmidt G. Comorbidity of mental disorders and chronic pain: chronology of onset in adolescents of a national representative cohort. The Journal of Pain. 2015;16(10):1054-64.

19. HBSC. Study on Health Behaviour of School-Aged Children in Switzerland. 2019.

20. Konijnenberg A, Uiterwaal C, Kimpen J, van der Hoeven J, Buitelaar J, de Graeff-Meeder E. Children with unexplained chronic pain: substantial impairment in everyday life. Archives of disease in childhood. 2005;90(7):680-6.

21. Becker AJ, Heathcote LC, Timmers I, Simons LE. Precipitating events in child and adolescent chronic musculoskeletal pain. Pain reports. 2018;3(Suppl 1).

22. Landry BW, Fischer PR, Driscoll SW, Koch KM, Harbeck-Weber C, Mack KJ, et al. Managing chronic pain in children and adolescents: a clinical review. PM&R. 2015;7(11):S295-S315.

23. Finley GA FL, Grunau RE, von Baeyer CL. Why Children's Pain Matters - International Association for the study of Pain PAIN. 2005;8:6.

24. Aromaa M, Sillanpaa M, Rautava P, Helenius H. Pain experience of children with headache and their families: a controlled study. Pediatrics-Springfield. 2000;106(2; PART 1):270-5.

25. Knook LM, Konijnenberg AY, van der Hoeven J, Kimpen JL, Buitelaar JK, van Engeland H, et al. Psychiatric disorders in children and adolescents presenting with unexplained chronic pain: what is the prevalence and clinical relevancy? European child & adolescent psychiatry. 2011;20(1):39-48.

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. The Journal of Pain. 2012;13(9):874-83.

27. Jamison RN, Walker LS. Illness behavior in children of chronic pain patients. The International Journal of Psychiatry in Medicine. 1992;22(4):329-42.

28. Zernikow B, Wager J, Hechler T, Hasan C, Rohr U, Dobe M, et al. Characteristics of highly impaired children with severe chronic pain: a 5-year retrospective study on 2249 pediatric pain patients. BMC pediatrics. 2012;12(1):54.

29. Yazdani S, Zeltzer L. Treatment of chronic pain in children and adolescents. Pain management. 2013;3(4):303-14.

30. Cucchiaro G, Schwartz J, Hutchason A, Ornelas B. Chronic pain in children: a look at the referral process to a pediatric pain clinic. International journal of pediatrics. 2017;2017.

31. Brattberg G. Do pain problems in young school children persist into early adulthood? A 13 ‐ year follow ‐ up. European Journal of Pain. 2004;8(3):187-99.

32. Wörner A. Den Schmerz den Weg weisen - Interdiziplinäre stationäre Schmerztherapie UKBB. Pädiatrie und Pädiatrische Rheumatologie. Universitäts-Kinderspital bei der Basel UKBB: Wörner, Andreas; 2017.

33. McGrath PA, Holahan A-L, editors. Psychological interventions with children and adolescents: Evidence for their effectiveness in treating chronic pain. Seminars in Pain Medicine; 2003: Elsevier.

34. Eccleston C, Morley S, Williams A, Yorke L, Mastroyannopoulou K. Systematic review of randomised controlled trials of psychological therapy for chronic pain in children and adolescents, with a subset meta-analysis of pain relief. Pain. 2002;99(1-2):157-65.

35. Hechler T, Dobe M, Zernikow B. Commentary: a worldwide call for multimodal inpatient treatment for children and adolescents suffering from chronic pain and pain-related disability. Journal of pediatric psychology. 2009;35(2):138-40.

36. Shiff NJ, Abdwani R, Cabral DA, Houghton KM, Malleson PN, Petty RE, et al. Access to pediatric rheumatology subspecialty care in British Columbia, Canada. The Journal of rheumatology. 2009;36(2):410-5.

37. Hechler T, Dobe M, Kosfelder J, Damschen U, Hübner B, Blankenburg M, et al. Effectiveness of a 3-week multimodal inpatient pain treatment for adolescents suffering from chronic pain: statistical and clinical significance. The Clinical journal of pain. 2009;25(2):156-66.

38. Hechler T, Wager J, Zernikow B. Chronic pain treatment in children and adolescents: less is good, more is sometimes better. BMC Pediatr. 2014;14:262.

39. McGrath PJ, Walco GA, Turk DC, Dworkin RH, Brown MT, Davidson K, et al. Core outcome domains and measures for pediatric acute and chronic/recurrent pain clinical trials: PedIMMPACT recommendations. The Journal of Pain. 2008;9(9):771-83.

40. Defenderfer EK, Bauer K, Igler E, Uihlein JA, Davies W. The Experience of Pain Dismissal in Adolescence. The Clinical journal of pain. 2018;34(2):162-7.

41. Bhatia A, Brennan L, Abrahams M, Gilder F. Chronic pain in children in the UK: a survey of pain clinicians and general practitioners. Pediatric Anesthesia. 2008;18(10):957-66.

42. Wilder-Smith OH, Möhrle JJ, Martin NC. Acute pain management after surgery or in the emergency room in Switzerland: a comparative survey of Swiss anaesthesiologists and surgeons. European Journal of Pain. 2002;6(3):189-201.

43. Finley GA, McGrath PJ, Forward SP, McNeill G, Fitzgerald P. Parents' management of children's pain following 'minor'surgery. Pain. 1996;64(1):83-7.

44. Huth MM, Broome ME. A snapshot of children's postoperative tonsillectomy outcomes at home. Journal for Specialists in Pediatric Nursing. 2007;12(3):186-95.

45. Eccleston C, Malleson P. Managing chronic pain in children and adolescents. British Medical Journal Publishing Group; 2003.

46. Jay MA, Howard RF. Inequalities in access to a tertiary children's chronic pain service: a cross-sectional study. Archives of disease in childhood. 2016;101(7):657-61.

47. Wager J, Ruhe A, Hirschfeld G, Wamsler C, Dobe M, Hechler T, et al. Influence of parental occupation on access to specialised treatment for paediatric chronic pain. Der Schmerz. 2013;27(3):305-11.

48. OECD. Health at a Glance 2017: OECD indicators. Report. OECD; 2018.

49. Liossi C, Failo A, Schoth DE, Williams G, Howard RF. The effectiveness of online pain resources for health professionals: a systematic review with subset meta-analysis of educational intervention studies. Pain. 2018;159(4):631-43.

50. Hurley-Wallace A, Wood C, Franck LS, Howard RF, Liossi C. Paediatric pain education for health care professionals. Pain reports. 2019;4(1).

51. Sleed M, Eccleston C, Beecham J, Knapp M, Jordan A. The economic impact of chronic pain in adolescence: methodological considerations and a preliminary costs-of-illness study. Pain. 2005;119(1-3):183-90.

52. Wieser S, Horisberger B, Schmidhauser S, Eisenring C, Brügger U, Ruckstuhl A, et al. Cost of low back pain in Switzerland in 2005. The European Journal of Health Economics. 2011;12(5):455-67.

53. BFS. Die Bevölkerung der Schweiz 2017: Bundesamt für Statistik; 2018 [Available from: https://www.bfs.admin.ch/bfs/de/home/statistiken/bevoelkerung/stand-entwicklung/bevoelkerung.html.

54. Jenni OG, Sennhauser FH. Child health care in Switzerland. The Journal of pediatrics. 2016;177:S203-S12.

55. Bringolf-Isler B, Mäder U, Dössegger A, Hofmann H, Puder JJ, Braun-Fahrländer C, et al. Regional differences of physical activity and sedentary behaviour in Swiss children are not explained by socio-demographics or the built environment. International journal of public health. 2015;60(3):291-300.

56. Bürgi F, Meyer U, Niederer I, Ebenegger V, Marques-Vidal P, Granacher U, et al. Socio-cultural determinants of adiposity and physical activity in preschool children: a cross-sectional study. BMC Public Health. 2010;10(1):733.

57. Schmidt P, Wager J, Frosch M, Zernikow B. Niedergelassene Pädiater und tertiäre Versorgungsstrukturen der Schmerztherapie. Der Schmerz. 2014;28(4):398-404.

58. Zernikow B, Hermann C. Chronische primäre Schmerzen bei Kindern und Jugendlichen. Der Schmerz. 2015;29(5):516-21.

59. SSP. Swiss Society of Paediatrics 2019 [Available from: https://www.swiss-paediatrics.org/de.

60. FMH. Berufstätige Ärzte FMH-Schwerpunkte und Ausweise 2018. Statistics. Swiss Medical Association; 2019.

61. Corp. I. IBM SPSS Statistics for Windows Version 25. Armonk, NY: IBM Corp.; 2017.

62. Okumura MJ, Heisler M, Davis MM, Cabana MD, Demonner S, Kerr EA. Comfort of general internists and general pediatricians in providing care for young adults with chronic illnesses of childhood. Journal of general internal medicine. 2008;23(10):1621.

63. Wilder-Smith OH, Möhrle JJ, Dolin PJ, Martin NC. The management of chronic pain in Switzerland: a comparative survey of Swiss medical specialists treating chronic pain. European Journal of Pain. 2001;5(3):285-98.

64. Vargovich AM, Schumann ME, Xiang J, Ginsberg AD, Palmer BA, Sperry JA. Difficult Conversations: Training Medical Students to Assess, Educate, and Treat the Patient with Chronic Pain. Academic Psychiatry. 2019:1-5.

65. Scascighini L, Toma V, Dober-Spielmann S, Sprott H. Multidisciplinary treatment for chronic pain: a systematic review of interventions and outcomes. Rheumatology. 2008;47(5):670-8.

66. Cunningham CT, Quan H, Hemmelgarn B, Noseworthy T, Beck CA, Dixon E, et al. Exploring physician specialist response rates to web-based surveys. BMC medical research methodology. 2015;15(1):32.

Appendix

Appendix 1: Affiliations of the paediatric chronic pain research group involved in this study

Maria Carlander[1, 6], Helen Koechlin[2, 3], Cosima Locher[2, 4], Andreas Wörner [5], Julia Dratva[6, 7]

[1] UiT the Arctic University of Norway, Tromsø, Norway

[2] Faculty of Psychology, University of Basel, Switzerland

[3] Department of Anesthesiology, Critical Care and Pain Medicine, Boston Children's Hospital, Harvard Medical School, Boston, USA

[4] School of Psychology, University of Plymouth, UK

[5] University Children`s Hospital Basel, Switzerland

[6] University of Applied Sciences, Institute of Health Sciences, Winterthur, Switzerland

[7] Medical faculty, University of Basel, Switzerland

Appendix 2: Online questionnaire

Dear colleague,
Thank you for your interest in our study!
The following questionnaire deals with the occurrence of chronic pain in children and adolescents and paediatricians professional experience with it. For this study, chronic pain is defined as follows:
Pain that has existed for at least 3 months, that is both of a persistent character and episodic or can be recurring. The aetiology of pain may be known, somatic or psychological, but also of unknown origin.

Data protection
Your data will be collected and evaluated anonymously. We have taken this into account when collecting personal and professional data, that the data does not allow participants to be identified.
The personal code we ask you to create on your own is based on information that is not public. This code does not allow any member of the study team to identify participants, but they can be identified and reconducted by the participants themselves at any time.

The code is used for two purposes:

1. for any subsequent withdrawal of the data, for which the participants have the option at any time to
2. to be able to link data in the case of a second survey.

Creation of the personal code:
Please create a personal code according to the following instructions:
The first two letters of your father's first name (example: Andreas= AN)
The last two letters of your mother's first name (example Susanne = NE)
Your mother's month of birth (example March = 03)
The example code would be ANNE03.
Your code: ______

Approval
Please confirm that you are aware of the objectives and questions of the study (see participant information) and with the anonymous storage and use of the data to answer these questions.
Yes, I agree ☐

E-mail

If you would like to be informed about the most important results at the end of the study, you can send us an e-mail address here
to specify. Your e-mail will be separated from your answers and stored separately.
E-mail: ________________________________

PART 1

Age
☐ ≤ 35 years
☐ 36 - 45 years
☐ 46 - 55 years
☐ 56 - 65 years
☐ >65

Sex

☐ Female ☐ Male ☐ Not specified

What year did you receive your specialist title? e.g. 1980 _________

Where do you work?

☐ individual practice
☐ group practice
☐ university hospital
☐ cantonal hospital
☐ regional hospital
☐ other: ____________________

In which language region do you work?

☐ German speaking
☐ French speaking
☐ Italian speaking

How large is the catchment area of your place of work? _________________

Please indicate the (estimated) number of inhabitants in the catchment area: ________________

What is your workload? Please indicate your current workload in percent (from 0-100% e.g. 70%): ______

How many days and about how many hours have you worked in the past 7 days of the week?

____ Days _____Hours

FILTER PART 1

How many children do you see in your practice on average per quarter (3 months)?

☐ *< 250*
☐ *250-500*
☐ *500-750*
☐ *750-100*
☐ *1000-1500*
☐ *>1500*

Are there other specialists employed in your practice who are active as consultants or therapists?

☐ Specialist in paediatrics
☐ Psychologist
☐ Physiotherapist
☐ Occupational therapist
☐ Medical specialist from another speciality area; which
☐ Other professionals
☐ No, not applicable

PART 2

How much clinical experience do you have with children with chronic pain?

☐ No experience
☐ Little experience
☐ Some experience
☐ Much experience
☐ Very much experience

As a specialist, have you been trained in the treatment of children with chronic pain?

☐ Yes ☐ No ☐ I don't know

How would you rate the following sentence? "I feel comfortable treating children who suffer from chronic pain."

☐ applies
☐ is more likely to be true
☐ partly true
☐ rather not true
☐ does not apply

What percentage of the total population of your patients are children with chronic pain?

☐ < 1 %
☐ 1-5 %
☐ 5-10 %
☐ 10-20 %
☐ > 20 %
☐ I have no patients with chronic pain in my practice/ ward/ consulting hour

How many children with chronic pain have you treated or seen in the last 7 days of the week?

____ Children

Does this number correspond with the average number of children per week with chronic pain?

☐ Yes ☐ No, higher than average ☐ No, lower than average

How do you measure the intensity of pain?

☐ Using the Visual Analog Scale (VAS)
☐ Using the Smiley Scale (Wong-Baker Faces Pain Rating Scale)
☐ Using the numerical rating scale (NRS)
☐ Subjective assessment of the child's face or behaviour
☐ Subjective assessment based on anamnesis and examination
☐ Based on the parents' assessment
☐ Other; what ____________________

Have you ever referred a child to another specialist because of chronic pain?

☐ Yes; number last year __ ☐ No

Have you ever referred a child to a pain ambulatory specialized in children and adolescents?

☐ Yes; number last year __ ☐ No

Is referral to a pain ambulatory specialized in children and adolescents a therapeutic option for you?

☐ Yes ☐ No

FILTER PART 2

If you said no, why is the referral to a pain ambulatory specialised in children and adolescents not a therapeutic option?

☐ *I don't know any specialized pain consultation hour*
☐ *The specialized pain consultation is too far away (unreasonable for patients).*
☐ *I have enough other therapeutic resources*
☐ *Other reasons:* _______________

If you have referred patients with chronic pain to other professionals, to whom?

☐ *Specialist in paediatrics with a different focus*
☐ *Psychologist*
☐ *Psychotherapist, Psychiatrist*
☐ *Physiotherapist*
☐ *Occupational therapist*
☐ *Medical specialist from another specialist area; which*
☐ *Other professionals; who*
☐ *No, not applicable*

If you have referred a patient to a paediatrician with a different focus, please indicate it here:

☐ *Endocrinology- Diabetology*
☐ *Gastroenterology and Hepatology*
☐ *Cardiology*
☐ *Nephrology*
☐ *Neuropaediatrics*
☐ *Oncology haematology*
☐ *Orthopedy*
☐ *Pneumology*
☐ *Rheumatology*
☐ *Developmental paediatrics*
☐ *Other:*

PART 3

In the last part of the questionnaire we ask you to read the following case vignette.
The following questions and answers refer to it.

Current problems:
AG is a 14-year-old girl who comes to your office again. She reports about changing musculoskeletal pain in the lower and upper extremities. These occur symmetrically with movement, are spread over the day with a duration of a few seconds to a few hours and improve at rest. Special triggers of the complaints cannot be determined. Swelling, redness or overheating of joint have not occurred. There is no morning stiffness, no muscle weakness and no pain at night. At the first presentation of the girl 3 months ago at your office, these symptoms had been present for 3 months. According to your assessment in the consultation hour, the girl was admitted to an orthopaedist and to a paediatric rheumatologist, both of whom found no evidence for a cause from their specialty. Extensive laboratory testing for inflammatory, haematological or metabolic causes was inconspicuous. The pain has led to four absences from school of several days each in the previous 6 weeks.

Personal anamnesis:
Until 5 months ago Hip-Hop dancing 1x/week for 1 hour each; then suspended. About 7 months ago, AG suffered a distortion trauma to the left upper ankle joint. At that time there was a local haematoma, a lesion of the ligamentous apparatus or a fracture had been excluded. The further personal anamnesis is as follows inconspicuous. Vaccinations à jour according to BAG recommendations, no allergies, no further traumas.

Family history:
12-year-old brother, healthy. Parents without known illnesses.

Clinical findings:
14-year-old girl in good AZ and EZ. Weight 51 kg (P50), body length 160.1 cm (P 50). Walking pattern symmetrical, muscular trophic inconspicuous. Unobtrusive integument and normal muscular strength on all sides. All joints are free, movable without redness, swelling or overheating. During passive movement of the wrist left, shoulder elevation left and knee joint right Indication of pain, during the examination, however, are alternating with distraction. Further paediatric status is inconspicuous.

How do you assess the intensity of pain in this patient?

☐ Using the Visual Analog Scale (VAS)
☐ Using the Smiley Scale (Wong-Baker Faces Pain Rating Scale)
☐ Use of the numerical rating scale (NRS)
☐ Subjective assessment of the child's face or behaviour
☐ Subjective assessment based on anamnesis and examination
☐ Based on the parents' assessment
☐ Other; what

What are your next steps?

☐ Arrangement of a further appointment in practice
☐ Prescription of painkillers (e.g. paracetamol, ibuprofen)
☐ Prescription of stronger painkillers (e.g. opiates)
☐ Referral to another specialist

☐ Referral to a pain consultation specialised in children and adolescents
☐ Hospitalization
☐ Other steps

In your opinion, to what extent is the quality of life of this adolescent impaired?
☐ extremely much
☐ much
☐ little
☐ not at all

What do you think is the aetiology of the pain?

Please describe how you explain the cause of the pain to the parent/adolescent.

Please describe how you explain to the parents/adolescent how to deal with the pain?

Filter PART 3

If you would like to refer the patient to a paediatrician with a different focus, please indicate this here:

☐ *Endocrinology- Diabetology*
☐ *Gastroenterology and Hepatology*
☐ *Cardiology*
☐ *Nephrology*
☐ *Neuropaediatrics*
☐ *Oncology haematology*
☐ *Orthopedy*
☐ *Pneumology*
☐ *Rheumatology*
☐ *Developmental paediatrics*
☐ *Other:*

Final Page

The questionnaire is finished.

Thank you very much for your participation!

Appendix 3: Invitation to the study (E-mail and Letter/PDF versions)

E-mail invitation text:

Dear colleague,

With this letter we invite you to participate in our research project "Chronic pain in paediatrics". In Switzerland, we lack basic data on the incidence and handling of chronic pain in children and adolescents, as well as physician experience with chronic pain. The aim of this research project is to close some of these gaps.

Chronic paediatric pain is defined as follows in this study: a pain that has existed for at least 3 months, which can be of a lasting character, episodic or recurrent. The aetiology of pain may be known, somatic or psychological, but also unknown.

All paediatricians registered with the Swiss Society of Paediatrics in Switzerland are eligible to participate and will be contacted. Your participation is, of course, voluntary and your details will be managed confidentially. Answering the study takes about 15 minutes.

This link will take you to the questionnaire: xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

Thank you very much for your participation!

Yours sincerely, on behalf of the Research Consortium

Dr. med. Andreas Wörner, University Children's Hospital Basel

Prof. Dr. med. med. Julia Dratva, ZHAW, Institute for Health Sciences, Head of Research in the Field of Health Sciences

Dr. phil Cosima Locher and Dr. phil Helen Koechlin, University of Basel, Department of Psychology

Maria Carlander, University of Tromsø, Norway, Master of Public Health student

---

Letter/PDF together with the E-Mail: ____

Chronic Pain in Paediatrics

Dear colleague,

With this letter we invite you to participate in our research project on paediatric pain. In Switzerland, we lack basic data on the incidence and handling of chronic pain in children and adolescents, as well as experience in practice. The aim of this research project is to close some of these gaps.

Chronic paediatric pain is defined as follows in this study: a pain that has existed for at least 3 months, which can be of a lasting character, episodic or recurrent. The aetiology of pain may be known, somatic or psychological, but also unknown.

Study questions: The concrete questions of the study are:

1. to provide an estimate of the number of children with chronic pain who are seen and treated in the paediatric practice or hospital.
2. to assess the experience of paediatricians in dealing with children with chronic pain in the practice and hospital.

The research project is carried out with the support of the Swiss Society of Paediatrics (SGP) by the research consortium:

Prof. Dr. med. med. Julia Dratva, ZHAW, Institute for Health Sciences, Head of Research in the Field of Health Sciences

Dr. med. Andreas Wörner, University Children's Hospital Basel

Dr. phil Cosima Locher and Dr. phil Helen Koechlin, University of Basel, Department of Psychology

Maria Carlander, University of Tromsø, Norway, Master of Public Health student

Participation in the study: All paediatricians registered with the Swiss Society of Pediatrics (SGP) are eligible to participate and will be contacted. Your participation is, of course, voluntary.

Questionnaire: The questionnaire includes general questions on children with chronic pain, and in addition also contains a case vignette. Answering the study takes about 15 minutes.

This link will take you to the questionnaire: xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

Data protection: The Cantonal Ethics Commission Zurich has classified the study as ethically uncritical and exempt of ethical review. Great care has been taken to ensure full data protection, even though the personal information (age bracket, gender, year of specialization and work environment, such as hospital or practice) leaves a slight risk of identification. However, only the research consortium mentioned above will have access to the data as collected by the survey service Unipark/Questback and then stored on a password-protected server. Participants will certainly not be identifiable in publications.

We will ask you to generate a personal code that does not allow direct identification of you, but in the case of a second survey allows us to link data and to withdraw the data if necessary. Generating the code is voluntary.

Study timetable: Data collection should be completed by the end of March and analysis by September 2019. End of project will be 01.09.2019 and data will be completely anonymized after this date. Unipark/Questback will delete all data not later than at the end of project.

The results of the study will be published in peer-reviewed journals and at national and international congresses. If you wish to be informed about the results, you have the possibility to read them on the homepage xxxxx from October 2019 or to send us your e-mail in the questionnaire to receive a summary.

If you have any questions about the study, please do not hesitate to contact the Primary Investigator:

Julia Dratva: julia.dratva@zhaw.ch, +41 589346372

We would be very happy if you participated in the study.

Prof. Dr. Julia Dratva	Dr. med. Andreas Wörner	Maria Carlander*
ZHAW/ Primary Investigator	UKBB/ Senior Physician Co-Investigator	UiT/ MPH Student

* Maria Carlander is writing her master thesis at UiT The Arctic University of Norway. For this reason, the study also has to comply with the Norwegian Privacy Policy: The research consortium (ZHAW, University of Basel, UiT) are joint data controllers and have access to the data. The data will be managed confidentially. Rights of participants include access, correction, deletion, restriction and transferability of data, as well as the right to complain to the Data Inspectorate UiT: Contact address: Privacy Ombudsman at UiT, Joakim Bakkevold, personvernombud@uit.no