Chronic pain in children and adolescents: Observational studies

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Chronische pijn bij kinderen en adolescenten: Observationele studies

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Contents

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General introduction

In adults, chronic pain is by most people involved considered to be a serious disorder. Although chronic pain in adults is in general not life-threatening, a considerable amount of literature elucidates the large number of sufferers, the high cost to the person in question and to the society as a whole, and the often crushing effects it has on personal and family life.[1] Both in children and adolescents however, there is only little objective information available about the prevalence and prognosis of different types of pain, and the related consequences. Pain in children and adolescents probably does not create the same economic burden of illness as does pain in adults.[2] However, a better understanding of pain in children and adolescents is warranted to gain more insight in the etiology of pain, to relieve the associated burden for children and their families, and for the adequate allocation of health care resources. Does a subset of the children and adolescents with chronic pain become adults with debilitating chronic pains that are often resistant to effective treatment? If so, it might be possible to reduce the proportion of adults with chronic pain if these syndromes were identified and managed in childhood.

The International Association for the study of Pain (IASP) agreed on a common definition of pain: Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Note: Pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life.[3] The IASP definition highlights the fact that learning about pain and how to respond to painful situations occurs during childhood. Like for adults, pain is an unpleasant sensory and emotional experience for children. Their pain perceptions are subjective. Like their other perceptions, it is impossible to know exactly what a child's pain experience is like, even though there are methods available to measure different aspects of pain. Children describe their pains according to the unpleasantness or aversive dimension, the sensory attributes, the intensity, quality (such as aching, sharp), location, and duration. They understand the concept of pain and the multidimensional nature of pain; even very young children describe the emotional and suffering aspects of pain as well as the physical aspects.[4] Obviously, their concepts of pain differ according to their age, sex, cognitive level, and pain experience. From this perspective, studies on pain in children have to include not only measures on the sensory aspects of pain, but also measures of disability and handicap.

Prevalence of pain in children and adolescents

Many children in Western societies suffer from relatively unpredictable episodes of severe headaches, abdominal pains, or limb pains. Up to about one-third of children and adolescents may experience recurrent headaches or abdominal pains.[5-14]

Most epidemiological studies investigating pediatric pain have addressed specific pain conditions (e.g. headache, recurrent abdominal pain) rather than providing a comprehensive analysis of pain problems in childhood and adolescence.[15] Moreover, because of limitations in their design and methodology, as well as differences in the defining criteria for pain, the data they provide are often conflicting. For instance, Deubner (1977)[8] reported the prevalence of headache in adolescent females to be 82%, whereas in a similar study Passchier and Orlebeke (1985)[16] reported the prevalence to be approximately 11% for the same age group, even though both studies used the same questionnaire developed by Waters (1970).[17] The differences in the reported prevalence rates between these two studies can be attributed to differences in the definition of headache used and the time frame about which the children were questioned. Many studies on pediatric pain used very restricted age groups, which does not allow for investigation of developmental changes in pain problems over time. Especially studies of pain in pre-schoolchildren are scarce. The majority of epidemiological studies on pediatric pain simply registered presence or absence of pain. This approach has of course serious shortcomings because a minor pain occurring once a week may be regarded the same as a severe persistent pain. Use of measures of frequency, intensity and duration can solve this problem.

Of all chronic pain conditions in children, headache has received most attention, resulting in supposedly valid estimates of the prevalence.[15] Prevalence estimates for migraine start with the study of Bille (1962)[18], reporting figures of 2.5%, 4.6% and 5.3% for age groups 7-9, 10-12 and 13-15 years, respectively. The prevalence of headache increased with age in many studies.[16,18-20] Most studies on headache indicate a higher prevalence among girls.[8,13,16,19-23] Recurrent abdominal pain was assessed in the early study of Apley and Naish (1958) by directly questioning schoolchildren aged 5-15 years; one-year prevalence rates were 9.5% for boys and 12.3% for girls.[24] Faull and Nicol (1985) noted a much higher prevalence rate of approximately 25% for recurrent abdominal pain in children aged 5-6 years; however, a 6-9 month follow-up of a subsample showed that almost all children became substantially pain free.[25,26] The reported prevalence rates of recurrent limb pain in children range from 2.6% to 33.6%, reflecting the diversity in methods and diagnostic criteria used.[13,27-29] Back pain was reported almost exclusively in older children.[23,30-33] Other pain conditions have not yet been widely investigated.

Data on the co-occurrence of different pain conditions in the same child are important in understanding whether some children are pain prone.[15] Only a few studies have addressed the prevalence of pain combinations.[13,34-36] Øster (1972) indicated that 37% of the children in his study had two or three of the following symptoms: abdominal pain, headache and growing pains, simultaneously.[13] In Iceland, approximately 5% of 11-12 and 15-16 year old schoolchildren reported at least three weekly pains (back pain, headache and abdominal pain) and 25% had one of these pains weekly.[36]

Considering the high prevalence of some pain conditions, it is also important to elucidate the prevalence of overall pain and of pain combinations, and how demographic characteristics influence their distribution. It would be preferable to measure the prevalence of different pain conditions simultaneously in the same sample, because of the comparability of these prevalence rates.

Health care use

In many studies, it is common to measure the use of health care services as an indicator of 'illness behavior' or 'pain behavior'. In adults, chronic benign pain is related to frequent and costly utilization of health services, and use of medical services itself may interfere with quality of life.[1] Frølund and Frølund (1986) reported that pain, for children as well as for adults, is a major reason for medical consultations.[37] They found that in 22% of all contacts (all ages) with the general practitioner pain was the cause of the patient-doctor contact, from which 39% was due to chronic pain. Regarding medical consumption of children with chronic pain very little is known, primarily because most of the studies in medical settings have been hospital-based, taking children with (chronic) pain as point of departure for investigations. Because this approach does not allow for a direct comparison of medical consumption with children without pain nor is it informative for primary care settings, it is important to investigate the health care use in children with chronic pain in the open population. Tasche et al. (1993) found that excessively crying infants, which is generally supposed to be related to pain, have more than twice as many GP consultations compared to children of the same age without this problem (3.2 versus 1.4 contacts in 3 months).[38] About one-fifth of adolescents with recurrent headaches reported a 'daily or almost daily' use of analgesic medication for their headaches.[39]

Because extremely low or high use of medical care may not adequately protect and cure children's health, it is important to investigate the factors related to the amount of health care used for chronic benign pain in children.[40] Pain is a symptom that prompts many, but not all, to seek medical attention and there may be substantial differences between those who seek medical attention and those who do not.[41] Except for headache, studies addressing the use of health care services in children in relation to chronic pain are scarce. A Finnish population study on the use of health care services in childhood migraine revealed that consultation of a physician, which was mostly a medical specialist, was related to the severity of complaints, school absence, and co-morbidity.[42] More insight in the relationship between pain problems in childhood and adolescence and use of health care services may improve the overall care for children and adolescents. This might for instance be achieved when it appears that less care or a different kind of care is needed.

Referral

Crook et al. (1985) compared adult persistent pain sufferers in the general population with those referred to a specialty pain clinic.[43] Although the population sample, which was drawn randomly from a family medical group practice, resembled the pain clinic patients in demographics, pain location, and pain duration, the family practice pain patients endorsed significantly less pain, less continuous pain, less psychological distress, less pain on activity, fewer psychosocial complications, and less use of health care services. Examination and comparison of a hospital sample and a population sample of chronic pain sufferers may help to clarify the referral process and thereby contribute useful information for treatment strategies.

Prognosis of chronic benign pain

The natural course and prognosis of chronic pain in children and adolescents are largely unknown. The majority of epidemiological studies of pain in children and adolescents have been retrospective and had a cross-sectional design. Retrospective assessment of pain means that the respondents are asked to recall their pain experienced within a certain time frame in the past. Long time frames are likely to be unreliable, whereas a too short time frame may yield less meaningful data. An alternative strategy is to use a pain diary which requires prospective recording of pain.[44] In addition, longitudinal studies of chronic pain sufferers have drawn merely from hospital samples and have ignored the question of how representative this selected group is for the general population who suffer chronic pain and are not referred. Crook et al. compared adult persistent pain sufferers in the general population with those referred to a specialty clinic, and found not only more severe pain for the referred patients at baseline, but also a worse prognosis at two-year follow-up.[43,45]

Many studies in children reported that headache characteristics change over time.[19,46-54] These studies, mostly hospital-based studies on migraine in childhood, reported spontaneous remission in 30-40% and improvement in about 50% at 5-10 year follow-up. Studies from clinical samples on recurrent abdominal pain suggest that 25-50% continue to experience symptoms even into adulthood.[7,55,56] A Finnish population-based study reported that of the schoolchildren with weekly musculoskeletal pain 52% persisted at 1-year follow-up.[57] None of these studies however included measures of disability in order to determine the course of pain, or its impact on daily functioning.

Also little is known about the factors that predispose to persisting chronic pain. One hospital-based study aimed to determine the predictors of persisting chronic idiopathic musculoskeletal pain in children and found an unfavorable outcome in children with generalized pain and a low parental educational level.[58] For the prevention of pain becoming persistent, it is crucial to identify predictive and prognostic factors. The first step in the control of the pain syndrome is an objective and comprehensive assessment of the relevant bio-psycho-social factors related to the syndrome, as well as an assessment of the sensory aspects of the pain.

This thesis

Headache, limb pain, and abdominal pain may occur in many serious diseases, but it is generally recognized that, in the majority of children with these symptoms, no organic cause can be found. It is with this benign pain group that this thesis is concerned. Subjects with pain resulting from specific chronic diseases (e.g. rheumatoid arthritis, malignancies) were excluded, because the rareness of these conditions would require a different design and the treatment of the disease and of the pain would be difficult to separate.

Chronic benign pain was defined as continuous or recurrent pain with unknown organic etiology existing for three months or longer. In order to obtain a comprehensive picture on chronic pain, no restrictions were made to subgroups based on severity of pain or disability.

This thesis aims to establish the extent of the problem of chronic benign pain in Dutch children and adolescents by clarifying several of the uncertainties described above. These are:

- What is the prevalence of (chronic) pain in children and adolescents in the general population?
- What is the extent of utilization of health care services in children and adolescents with chronic benign pain?
- Do children and adolescents with chronic benign pain using health care services for this condition and those not using medical services differ in background factors, pain perception, behavior, and its impact on the child and the family?
- What is the course and prognosis of chronic benign pain in children and adolescents in the general population over a two-year period?
- Do children and adolescents with chronic benign pain who were referred to a specialist for this condition and those not referred differ in background factors, pain perception, behavior, and its impact on the child and the family?
- Do children and adolescents with chronic benign pain consult their general practitioner more often than those without chronic benign pain, and do pain characteristics predict a higher consultation rate?

The research questions are addressed in the following chapters. Chapter 2 and 3 present a population-based study with a cross-sectional design among 6,636 children and adolescents from 0 to 18 years of age to identify subjects with chronic pain. Chapter 2 describes the prevalence of (chronic) pain in children and adolescents and chapter 3 focuses on the health care use. The cohort of 987 children and adolescents with chronic pain, who were identified in the above-mentioned study, participated in a two-year follow-up study. Chapter 4 presents the results of the baseline assessment of this follow-up study and further explores the utilization of health care services. Chapter 5 describes the natural course and prognosis of chronic benign pain in childhood and adolescence over a two-year period. Additionally, a sample of children and adolescents referred for chronic pain was obtained, and assessed during a follow-up period of two years in the same way. In chapter 6 this hospital sample is compared with the population sample on background factors, pain perception, behavior, and its impact on the child and the family. A third sample of children and adolescents was drawn from general practitioner records, and consultation rates between children and adolescents with and without chronic benign pain were compared. The results are described in chapter 7. The main findings of these studies are discussed in chapter 8, along with conclusions and suggestions for future research.

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2

Pain in children and adolescents: a common experience

Pain 2000;87:51-58.

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Abstract

Little is known about the epidemiology of pain in children. We studied the prevalence of pain in Dutch children aged from 0 to 18 years in the open population, and the relationship with age, gender and pain parameters.

A random sample of 1,300 children aged 0-3 years was taken from the register of population in Rotterdam, the Netherlands. In the Rotterdam area, 27 primary schools and 14 secondary schools were selected to obtain a representative sample of 5,336 children aged 4-18 years. Depending on the age of the child, a questionnaire was either mailed to the parents (0-3 years) or distributed at school (4-18 years).

Of 6,636 children surveyed, 5,424 (82%) responded; response rates ranged from 64% to 92%, depending on the subject age and who completed the questionnaire. Of the respondents, 54% had experienced pain within the previous 3 months. Overall, a quarter of the respondents reported chronic pain (recurrent or continuous pain for more than 3 months). The prevalence of chronic pain increased with age, and was significantly higher for girls ($p<0.001$). In girls, a marked increase occurred in reporting chronic pain between 12 and 14 years of age. The most common types of pain in children were limb pain, headache and abdominal pain. Half of the respondents who had experienced pain reported to have multiple pain, and one-third of the chronic pain sufferers experienced frequent and intense pain. These multiple pains and severe pains were more often reported by girls ($p<0.001$). The intensity of pain was higher in case of chronic pain ($p<0.001$) and multiple pains ($p<0.001$), and for chronic pain the intensity was higher for girls ($p<0.001$).

These findings indicate that chronic pain is a common complaint in childhood and adolescence. In particular, the high prevalence of severe chronic pain and multiple pain in girls aged 12 years and over calls for follow-up investigations documenting the various bio-psycho-social factors related to this pain.

Introduction

In children and adolescents, little is known at present about the prevalence of pain. This contrasts sharply with the extensive knowledge on the epidemiology of pain in adults. It has been reported that pain in adults is a common experience, interferes with quality of life, and is costly both for the individual and for health services.[1] A better understanding of pain in children is needed to gain insight in the etiology of pain in children, to relieve the associated burden for children and their families, and for the adequate allocation of health care resources.

Most epidemiological studies investigating paediatric pain have addressed a specific pain condition (e.g. headache, recurrent abdominal pain) rather than providing a comprehensive analysis of pain problems.[2] Only a few studies have addressed the prevalence of pain combinations.[3-6] The majority of studies on paediatric pain used restricted age groups and simply registered presence or absence of pain, not addressing pain parameters, such as frequency, duration and intensity. Especially studies of pain in pre-schoolchildren are scarce. Of all chronic pain conditions in children, headache is the most extensively investigated, resulting in precise estimates of prevalence.[2] The overall prevalence of migraine in children aged 7 to 18 years, as assessed by Dalsgaard-Nielsen et al., was 7%.[7] The prevalence of headache increased with age in many studies.[8-10] Most studies on headache indicated a higher prevalence among girls.[3,8-14] In their classical study, Apley and Naish investigated the prevalence of recurrent abdominal pain by directly questioning schoolchildren aged 5-15 years. They found a prevalence of 9.5% in boys and 12.3% in girls.[15] Faull and Nicol noted a much higher prevalence rate of 25% for abdominal pain in children aged 5-6 years;[16] a follow-up study showed that almost all children became substantially pain free.[17] The reported prevalence rates of recurrent limb pain in children range from 2.6% to 33.6%, reflecting the diversity in methods and diagnostic criteria used.[3,18-20] Back pain was reported almost exclusively in older children.[14,21-24] Other pain conditions have not been widely investigated.

Considering the high prevalence of some pain conditions, it is also important to elucidate the prevalence of overall pain and of pain combinations, and how demographic characteristics influence their distribution, in order to generate new etiologic hypotheses regarding the origin of (chronic) pain. Further, it would be preferable to measure the prevalence of different pain conditions simultaneously in the same sample, because of the comparability of these prevalence rates. Therefore, we investigated prevalence of pain in a community sample of Dutch children aged 0 to 18 years, and the relationship with age, gender and pain parameters including location, frequency, duration and intensity of pain. Because of the burden of pain for the child and the family, we were particularly interested in the prevalence of chronic pain.

Methods

Design

Since little is known about the occurrence, the natural history, and the determinants of chronic pain in children we conducted a descriptive study. At the end of 1996, this study was carried out as a cross-sectional population survey with approval of the local ethics committee. This type of survey is useful for studying relatively frequent conditions that have a long duration, such as chronic pain in children, and for generating more specific etiologic hypotheses.[25]

Subjects

A questionnaire was sent to a sample of 6,636 children aged from 0 to 18 years in Rotterdam and adjacent municipalities through the Municipal Health Service Rotterdam Area. Children were selected in two ways depending on age. For pre-school age (0-3 years) a random sample of 1,300 children was taken from the register of population in Rotterdam, and their parents were sent a questionnaire with a cover letter by mail. To increase the response rate in this sample two reminders were sent to the non-responders. For the age group 4-18 years, 5,336 children were selected through school. To obtain a representative sample of Dutch children in this age group, schools were included on the following criteria: 1. 70% of the children had to be of Dutch origin, matching the general distribution in the Netherlands. 2. Schools should be geographically spread over the region. 3. Distribution of secondary school students over school year and education level should reflect the general distribution in the Netherlands. Schools which refused to participate were replaced by schools selected according to the same criteria ($n = 9$). In total, 27 primary schools and 14 secondary schools in Greater Rotterdam participated in this study. Parents were informed by letter about the study two weeks before assessment and were given the opportunity to refuse participation. Only two parents refused to participate in our survey. Through the school health services we approached 3,137 primary schoolchildren and 2,199 secondary schoolchildren. In the first four school years of primary school (ages approximately 4-7 years), questionnaires were taken home, filled out by one of the parents, and subsequently collected at school. The older children (from about 8 years of age onward) filled out the questionnaire in the classroom, supervised by a school nurse. Because the absence rate in this sample was only 3%, and since it has been reported that only a small proportion of school absence is related to headache and that headache scores between absent and present students are similar, we did not attempt to include any absent children.[10,26]

Questionnaire

The structured pain questionnaire designed especially for this study (because no validated instrument was available) was adapted for three age groups (0-4, 5-11, and 12-18 years) and took less than ten minutes to complete. Children were instructed to fill out the form on their own. Only if they did not understand a question, a specially trained school nurse engaged for this survey helped them. Because the questionnaire was self-explanatory, a minority had to be helped.

The questionnaire first recorded demographic details such as the child's date of birth, gender, nationality, education level and school year. If the answer to the first question, "Did you/your child experience pain in the previous three months?" was no, no further questions were asked. When the answer was yes, additional information about the pain was requested concerning location, frequency, duration, and intensity. From a list of possible locations (head, abdomen, limb, ear, throat, back, unknown and elsewhere) subjects were asked to tick all locations where they had experienced pain in the previous three months. Children were asked to fill out the questions about the frequency, duration and intensity of pain for the pain that troubled them most. Pre-coded categories were used to assess the frequency of occurrence ('< 1x/month', '1x/month', '2-3x/month', '1x/week', '2-6x/week', 'each day'), and the duration of pain ('< 4 weeks', 'between 4 weeks and 3 months', '> 3 months'). The intensity of pain was assessed with a Visual Analogue Scale (a 100-millimetre long line with the verbal anchors 'no pain' versus 'the worst pain you can imagine' on both ends), and by asking: "How worse is the pain usually?"

Data analysis

Chronic pain was defined as pain, existing recurrently or continuously for more than three months; non-chronic pain as pain, lasting less than three months.

Data were evaluated in five age groups (0-3, 4-7, 8-11, 12-15 and 16-18 years) and by gender.

Data were analysed by frequencies and cross-tabulations. Differences were tested for categorical variables by chi-square tests, for ordinal variables by Mann Whitney U tests, Kolmogorov-Smirnov (K-S) or Kruskall-Wallis (K-W) tests, and means by Student's t-tests and analysis of variance. Since we conducted about fifty exploratory analyses, we adapted the threshold for statistical significance to a *p*-value of less than 0.001 (0.05/50).

Results

Response

From the 6,636 distributed questionnaires, 5,423 completed questionnaires were returned, giving an overall response rate of 82%. Table 1 shows the response rates for groups that were approached by the previously described methods. The response rate for the different age groups ranged from 64% to 92%.

Table 1
Methods of approach and response rates by age group

Age (years)	Method of approach	Questionnaire filled in by	No. of approached children	Response rate
0 - 3	Mail	Parent	1,300	77%
4 - 7	School	Parent	1,567	64%
8 - 18	School	Child	3,769	92%
Overall			6,636	82%

Table 2
Three-month prevalence rates of pain (percentages) for different duration of pain, by age groups and gender. Percentages given in parentheses

Age (years) and gender	Number of respondents	Experienced pain past 3 months	Duration of pain		
			Non-chronic pain		**Chronic pain**
			< 1 month	1 - 3 months	> 3 months
0 - 3	964	292 (30.3)	72 (7.5)	51 (5.3)	114 (11.8)
boys	500	149 (29.8)	31 (6.2)	24 (4.8)	68 (13.6)
girls	464	143 (30.8)	41 (8.8)	27 (5.8)	46 (9.9)
4 - 7	982	335 (34.1)	56 (5.7)	45 (4.6)	190 (19.3)
boys	475	145 (30.5)	30 (6.3)	21 (4.4)	75 (15.8)*
girls	507	190 (37.5)	26 (5.1)	24 (4.7)	115 (22.7)
8 - 11	1,369	910 (66.5)	371 (27.1)	165 (12.1)	324 (23.7)
boys	695	406 (58.4)*	168 (24.2)	79 (11.4)	137 (19.7)*
girls	674	504 (74.8)	203 (30.1)	86 (12.8)	187 (27.7)
12 - 15	1,618	1,114 (68.9)	296 (18.3)	167 (10.3)	577 (35.7)
boys	734	438 (59.7)*	150 (20.4)	67 (9.1)	188 (25.6)*
girls	884	674 (76.2)	145 (16.4)	99 (11.2)	389 (44.0)
16 - 18	490	260 (53.1)	53 (10.8)	37 (7.6)	153 (31.2)
boys	249	106 (42.6)*	25 (10.0)	18 (7.2)	49 (19.7)*
girls	241	154 (63.9)	28 (11.6)	19 (7.9)	104 (43.2)
Total	5,423	2,911 (53.7)	848 (15.6)	465 (8.6)	1,358 (25.0)
boys	2,653	1,244 (46.9)*	404 (15.2)	209 (7.9)	517 (19.5)*
girls	2,770	1,665 (60.1)	443 (16.0)	255 (9.2)	841 (30.4)

Data were based on one pain report per child. In 4.5% of the cases (*n* = 240) the duration of pain was missing, which was equally distributed over age group and gender. The first number in a subgroup is the prevalence rate for that age group, and the second two rates those by gender.
*Significant difference between gender: $p < .001$.

Age- and gender-related prevalence rates

Table 2 presents the age and gender distribution of the respondents and prevalence rates for pain. Pain was reported frequently; 53.7% of the respondents reported a pain experience in the previous three months, ranging from 29.9% in boys younger than 4 years old to 76.4% in girls aged 12-15 years. Of all respondents, 25.0% reported chronic pain and 24.2% reported non-chronic pain; in 4.5% data on the duration of pain were missing. Chronic pain was most frequently reported in the age group 12-15 years; more than one-third of this age group reported to have chronic pain. Except for the youngest age group (0-3 years), girls reported significantly more often chronic pain than boys. Especially in the age groups 12-15 and 16-18 years gender differences were significant.

Figure 1a and b show prevalence rates of pain related to age for a different duration of pain in boys and girls. The occurrence of chronic pain increased with age in both boys and girls (boys: χ^2 for trend=26.41, df=1, p<0.001; girls: χ^2 for trend=206.04, df=1, p<0.001). In girls, a considerable increase in the occurrence of chronic pain was seen between 12 and 14 years of age.

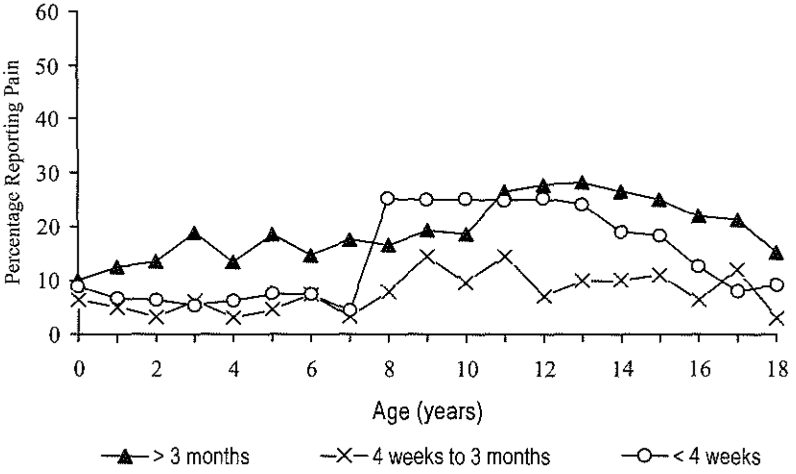
Characteristics of pain

Duration of pain was categorised into three groups; 32% of the reported pain lasted less than four weeks, 18% between four weeks and three months, and half of the reported pain lasted longer than three months (not shown in table). Girls more often reported chronic pain than boys (table 2).

We asked how often children experienced the pain they reported. Of the chronic pain sufferers, 49% indicated a frequency of occurrence of at least once a week, 21% less than once a month and 30% somewhere in between. Significantly higher frequencies of occurrence (weekly pain) were reported in case of chronic pain (49% versus 39% in non-chronic pain), in girls (48% versus 37% in boys), and in older children; the mean age for children reporting weekly pain was 11.0 (SD=3.8) compared to 10.0 (SD=4.6) for children who reported pain less than once a month.

Table 3 shows the mean pain intensity for chronic pain versus non-chronic pain, by age groups, gender, location of pain and single/multiple pain. The intensity of chronic pain was significantly higher than for non-chronic pain, and significantly higher for girls than for boys. Significant relations were also found between the intensity of pain and age of the child and location of pain; children aged 4-7 years reported lower intensities than the other age groups. Furthermore, the mean intensity of multiple pain was significantly higher than for single pain. The more locations of pain were reported, the higher the intensity of pain (not shown).

(a) Age Specific Prevalence Rates of Pain in Boys



(b) Age specific prevalence rates of pain in girls

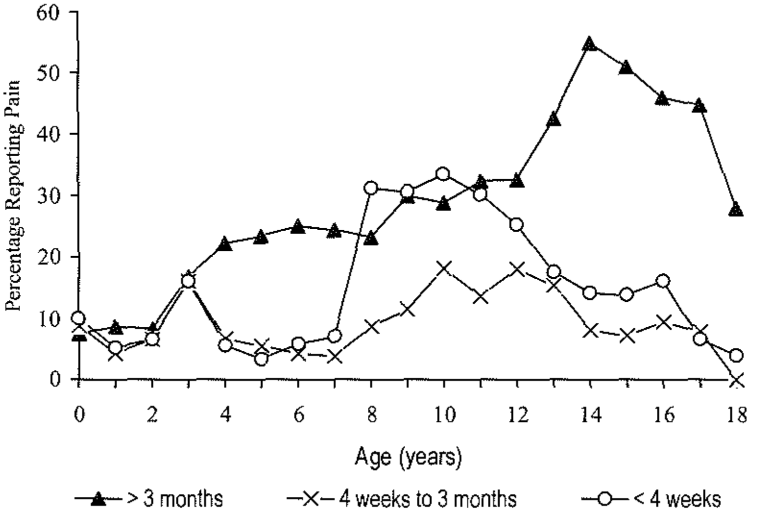


Figure 1a and b
Three-month prevalence rates of pain in boys and girls for the 18 separate years. Lines represent pain of different duration. Data were based on one pain report per child.

Table 3
Mean pain intensities for children with chronic pain versus non-chronic pain, by gender, age groups, location of pain and single/multiple pain

	Chronic pain			Non-chronic pain		
	Mean intensity	SD	P	Mean intensity	SD	P
Total	54.4	24.2		41.2	24.4	
Gender			< .001			NS
Boys	50.7	25.0		40.2	24.5	
Girls	56.6	23.5		42.1	24.4	
Age (years)			< .001			< .001
0 – 3	54.7	27.7		36.6	27.7	
4 – 7	45.9	23.5		32.7	24.1	
8 – 11	58.3	24.7		43.7	25.6	
12 – 15	54.9	23.5		42.1	22.4	
16 - 18	54.4	21.8		37.5	20.8	
Location of pain			< .001			< .001
Head	53.1	22.1		34.7	22.7	
Abdomen	49.5	24.7		39.0	24.0	
Limb	51.2	24.1		42.0	24.0	
Back	57.6	23.5		40.5	22.3	
Ear	58.9	23.8		42.4	25.1	
Throat	57.1	24.4		40.4	24.2	
Unknown	59.1	23.9		67.3	24.8	
Other site	59.5	24.2		45.3	26.5	
Single/multiple pain			< .001			< .001
Single pain	51.0	24.5		38.0	23.7	
Multiple pain	57.6	23.4		44.2	24.7	

The intensity of pain, measured with the Visual Analogue Scale, ranged from 0 (no pain) to 100 millimetres (worst pain). Data were based on one pain report per child.
Differences were tested by Student's t-tests or analysis of variance.

Single pain

The prevalence rates for headache, abdominal pain and limb pain, which were overall most frequently reported, were 23%, 22% and 22%, respectively. Figure 2 shows the prevalence rates of chronic pain for different locations of pain in children who reported one pain location (single pain), by age. For children aged up to 8 years chronic abdominal pain was the most prevalent pain type. The limbs, head and abdomen, in this order, were the most frequently reported locations of chronic pain in children aged 8 years and over. Girls were significantly more likely to report chronic abdominal pain ($\chi^2=19.58$, df=1, p<0.001), boys were more likely to report chronic limb pain ($\chi^2=11.48$, df=1, p<0.001) and chronic pain at other sites ($\chi^2=12.93$, df=1, p<0.001).

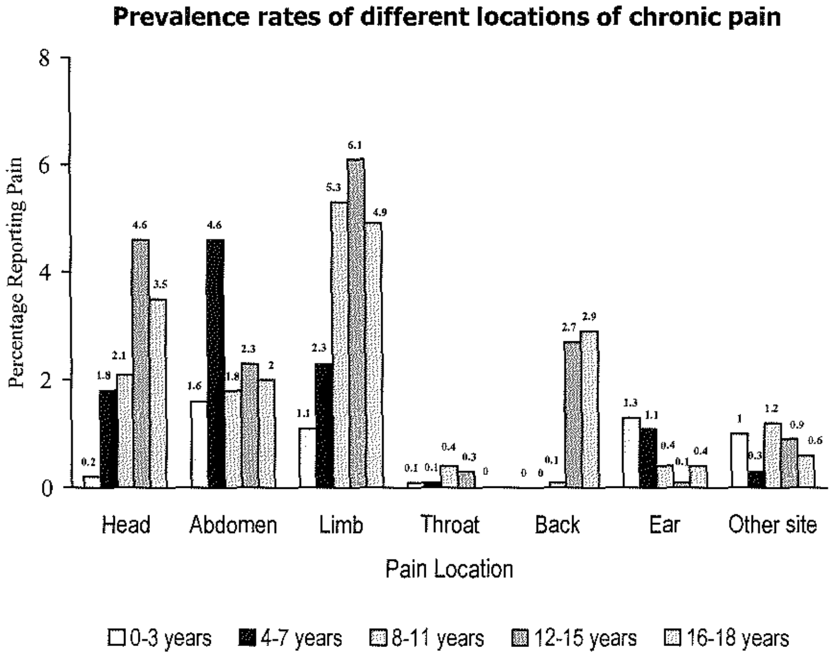


Figure 2
Three-month prevalence rates of chronic pain according to location for children who reported one pain location by different age groups.

Multiple pain

About half of the children who reported pain indicated one location of pain (*n* = 1,450 (overall) and *n* = 659 (chronic pain), the remainder reported more than one location of pain (*n* = 1,456 (overall) and *n* = 699 (chronic pain)). The mean number of reported locations was 1.87 (SD = 1.11, range = 7). Children who reported more than one pain location (multiple pain) reported most frequently headache (68%), abdominal pain (63%), limb pain (47%) and back pain (25%). The prevalence of multiple pain increased with age; girls indicated multiple pain twice as much as boys (K-S, Z=4.71, p<0.001). The combination of headache and abdominal pain was the most prevalent, occurring in 25% of all cases with two sites of pain. The prevalence of this combination was in case of chronic pain and non-chronic pain 5% and 6%, respectively; prevalence increased significantly with age (M-W, Z=3.37, p<0.001) and was higher for girls than for boys (χ^2=88.89, df=1, p<0.001).

Severe chronic pain

Figure 3 shows the prevalence of severe chronic pain (occurring weekly for more than three months with intensities above 50 mm on the VAS) by age groups and gender. Overall (not shown), one-third of the chronic pain sufferers (*n* = 431) experienced very frequent and more intense pain.

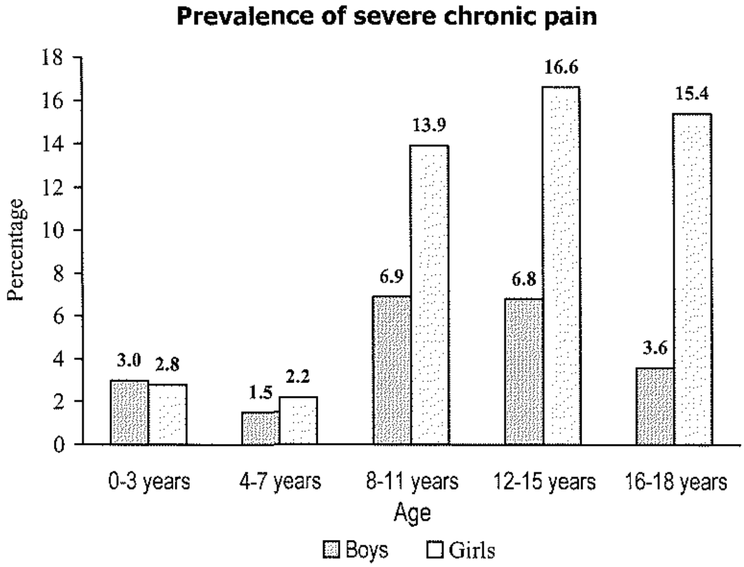


Figure 3

Three-month prevalence rates of severe chronic pain (chronic pain with intensities of more than 50 mm on the VAS and occurring weekly) by age groups and gender. Data were based on one pain report per child.

Discussion

This study provides a comprehensive picture of the prevalence of pain in Dutch children and adolescents. An important advantage of our study in comparison to earlier studies is that we did not restrict our analysis to a particular age or a specific pain condition, but investigated all types of pain in children up to 18 years of age. Pain was quantified in terms of presence and localisation, as well as in terms of characteristics (frequency, duration and intensity).

We obtained a high overall response rate of 82%, ranging from 64% to 92% in the different age groups. The lower response in pre-schoolchildren, and in the first four classes of primary school, can be explained by the method of approaching participants.

The results of this study show that pain is prevalent among Dutch children and adolescents; more, however, among girls and older children. More than half of the children reported pain in the previous three months, which is not surprising because these data also include everyday 'bumps and hurts'. Fearon et al. determined a much higher prevalence of incidents of everyday pain in 3-7-year-olds by using direct observation.[27] The high prevalence of chronic pain (25%) in our study is more disturbing because of the associated emotional, social, and financial burden for children and their families. We cannot compare this finding with other studies because no literature is available on the prevalence of chronic pain irrespective of site. Nevertheless, previous studies have found high prevalence rates for some types of pain.[7-10,15,24,28] In addition, it should be noted that our definition of chronic pain differs from that used by many others in that it is broader. Unlike others, we did not impose restrictions regarding frequency or severity of pain to obtain a comprehensive picture on long-term pain. Nevertheless, even severe chronic pain is quite prevalent, especially among older girls.

In our study, a marked increase in the prevalence of pain, lasting less than four weeks, occurred at the age of 8 years, which was probably due to the change in method of obtaining data (from parent rating to self-reporting). Because parents may not always be aware of their children's minor pains, pain problems could have been underestimated by their parents. However, this effect can also be related to age, since other studies investigating paediatric pain also found that prevalence rates increase with age.[6,8-10,14,21-24,28] Furthermore, it should be noted that parent ratings may be the best proxy measure available in very young children, particularly in longer lasting pain.[29,30] The marked increase in the prevalence of chronic pain in girls aged 12 to 14 years could be due to the onset of menstruation. The prevalence of non-chronic pain and chronic pain declined after the age of 14 years, especially in girls, which may be due to participation in higher levels of education; educational attainment has been shown to be negatively associated with the prevalence of pain.[31,32] However, our previous work showed that the relation between education level and the prevalence of chronic pain was dependent of age.[33]

In the present study, headache, abdominal pain and limb pain were the most frequently reported types of pain; this is not unexpected since many previous studies reported high prevalence rates for these pain conditions. Unfortunately, comparison between studies is difficult because of methodological differences (e.g., data collection process and period for recall). Another restriction to comparison between studies is that we assessed the prevalence of chronic pain for children who reported only one pain location. To reduce the possible bias due to the experience of having more than one pain, and to increase the compliance, our instrument was designed to obtain data on pain parameters for one pain location, which was the pain that troubled them most.

More than a quarter of the children reported more than one location of pain. The combination of headache and abdominal pain was reported most frequently (prevalence rate 3.5%), especially in older girls. Øster assessed the prevalence of headache, abdominal pain and limb pain in children aged 6-19 years and found an even higher prevalence rate (9.2%) for multiple pains (combination of two or three sorts of pain);[19] however, the period for recall was unspecified.

In summary, our findings suggest that pain, particularly chronic pain, is a common problem in children and adolescents. Especially the high occurrence of severe chronic pain and multiple pain among adolescents and girls should be a concern for health care services. The high prevalence of chronic pain found in this study calls for follow-up investigations focussing on the course of pain over the years, the quality of life, and other bio-psycho-social factors related to the experience and extent of this pain in children, which may be potential starting points for intervention.

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Chronic pain among children and adolescents: physician consultation and medication use

Clin J Pain 2000;16:229-235.

Perquin CW, Hazebroek-Kampschreur AAJM,
Hunfeld JAM, van Suijlekom-Smit LWA,
Passchier J, van der Wouden JC.

Abstract

The aim of this study was to assess physician consultation and use of medication in Dutch children (0-18 years) having chronic pain, in relation to sociodemographic factors and pain characteristics. A random sample of 1,300 children aged 0-3 years was taken from the register of population, and 41 schools were selected to obtain a representative sample of 5,336 children aged 4-18 years in the Rotterdam area. A questionnaire was either mailed to the parents or distributed at school, and was filled out by the parents (0-7 years) or by the child (8-18 years).

Of 6,636 children surveyed, 5,424 (82%) responded. Thirteen hundred and fifty-eight respondents (26%) reported chronic pain. Of these, 57% consulted a physician and 39% had used medication for the pain. Children with earache, more intense pain, more frequent pain, and children attending lower vocational training were more likely to consult a physician for the pain than the average of respondents. Children with earache, sore throat, headache, more intense pain, multiple pain, children aged 0-3 years, and girls were more likely to use medication for the pain. Logistic regression analyses showed that for physician consultation the most significant predictive factors were the intensity of pain, age, and earache, and for children aged 12-16 years the education level. The use of medication was merely predicted by earache, headache, limb pain, intensity of pain, and age.

Our data suggest that chronic pain is a common complaint in children and adolescents, frequently resulting in consultation of a physician and medication use. Concerning physician consultation, children with lower education level seem to be a group at risk.

Introduction

Chronic pain is a frequent complaint in childhood and adolescense.[1,2] Our work showed that 26% of a population sample of children aged 0 to 18 years (*n* = 5,424) had chronic pain (defined as recurrent or continuous pain for more than three months); headache, abdominal pain and limb pain were the most frequently reported, particularly in older children and in girls.[2] Furthermore, chronic pain is often associated with a heavy burden for children and their families.[3-5]

Considering the high prevalence of chronic pain in children and its impact on the quality of life, it is also important to elucidate the relationship between pain and physician consultation, and medication use. From now on, we will use the term 'medical consumption' in stead of 'physician consultation and medication use'. In adults, chronic pain is related to a high medical consumption, with financial implications for the individual and for health care services, and medical consumption itself may interfere with the quality of life.[6] In children, however, little is known about the extent of medical consumption due to chronic pain, and the factors related to it. Studies addressing medical consumption in children are scarce. In particular the physician consultation rate was studied, but few of these studies focused on a specific reason, such as pain, for consulting a physician.[7] Headache in relation to medical consumption is the most extensively investigated pain condition in children. Linet et al. assessed physician consultation for headache, and reported that 11% of girls and 6% of boys aged 12-17 years who had a headache in the previous 12 months consulted a physician for this reason.[8]

As part of a larger investigation on chronic pain in Dutch children, the present study addressed this topic by assessing to what extent children with chronic pain consult a physician and use medication for pain, and the relationship between medical consumption and sociodemographic factors, and pain characteristics.

Methods

Study population

At the end of 1996, this study was carried out as a cross-sectional population survey with approval of the ethics committee of the Erasmus University Rotterdam. We distributed questionnaires to 6,636 children aged 0 to 18 years in Greater Rotterdam through the Municipal Health Service.

Children were recruited in two ways depending on age. For pre-school age (0-3 years), a random sample of 1,300 children was taken from the register of population in Rotterdam, and their parents were sent a questionnaire with a cover letter by mail, and were asked to return the completed questionnaire in a pre-stamped addressed envelope. To increase the response rate in this sample two reminders were sent to the non-responders. For the age group 4-18 years, 5,336 children were selected through school. To obtain a representative sample of Dutch children in this age group, schools were included on the following criteria: 1. 70% of the children had to be of Dutch origin, reflecting the general distribution of the Netherlands. 2. Schools should be geographically spread over the region. 3. Distribution of secondary school students over school year and education level should match with the general distribution in the Netherlands. Schools which refused to participate (*n* = 9) were replaced by schools selected according to the same criteria. In total 27 primary schools (3,137 children) and 14 secondary schools (2,199 children) in Greater Rotterdam participated in this study. Parents of children who were recruited by school were informed by letter about the study two weeks before assessment and given the opportunity to refuse participation. Only two parents refused participation in our survey. In the first four school years of primary school (ages approximately 4-7 years) questionnaires and informed consents forms were taken home, filled out by one of the parents, and subsequently collected at school. The older children (from about 8 years onward) filled out the questionnaire in the classroom, supervised by a school nurse. Because the absence rate in this sample was only 3%, and since it has been reported that only a small proportion of school absence is related to headache and that headache scores between absent and present students are similar, we did not attempt to include any absent children.[9,10]

Written informed consent of participants aged up to 8 years was obtained from their parents, and passive parental consent (or negative consent) was used for older children who were tested in the school.

We defined chronic pain as pain existing for more than three months, recurrently or continuously. Our definition did not impose any demands regarding frequency or severity of pain, nor did we attempt to relate chronic pain to a clinical diagnosis.

Questionnaire

The structured pain questionnaire designed for this study (because no validated instrument was available) was adapted for three age groups (0-4, 5-11, 12-18 years) and took less than ten minutes to complete. Children were instructed to fill out the form on their own. Only if they did not understand a question, a specially trained school nurse engaged for this survey helped them. Because the questionnaire was self-explanatory, a minority had to be helped.

The questionnaire first recorded demographic details such as the child's date of birth, gender, nationality, education level and school year. If the answer to the first question, "Did you/your child experience pain in the previous three months?" was no, no further questions were asked. When the answer was yes, additional information about the pain was requested concerning location, frequency, duration, and intensity. From a list of possible locations (head, abdomen, limb, ear, throat, back, unknown and elsewhere) subjects were asked to tick all locations where they had experienced pain in the previous three months. Children were asked to fill out the questions about the frequency, duration and intensity of pain for the pain that troubled them most. Pre-coded categories were used to assess the frequency of occurrence ('< 1x/month', '1x/month', '2-3x/month', '1x/week', '2-6x/week', 'each day') and the duration of pain ('<4 weeks', 'between 4 weeks and 3 months', '>3 months'). The intensity of pain was assessed with a Visual Analogue Scale (a 100-millimetre long line with the verbal anchors 'no pain' versus 'the worst pain you can imagine' on both ends), and by asking: "How worse is the pain usually?"

Finally, we asked: "Did you/your child ever go to the doctor because of this pain?" and "Did you/your child ever use medication because of this pain?" These questions could simply be answered by 'yes' or 'no'.

Data analysis

Data were evaluated in five age categories (0-3, 4-7, 8-11, 12-15, and 16-18 years). Education levels of the children were categorised into four groups: 1. lower vocational training; 2. lower secondary school, which is a four-year program; 3. middle secondary school, which is a five-year program and allows students to attend professional training; 4. higher secondary school, a six-year program and the prerequisite for admittance to university. The intensity of pain was divided into two groups: 1. less intense pain, which means less than fifty millimetres on the VAS, and 2. more intense pain, with fifty millimetres or more on the VAS.

Chi-square tests and Mann-Whitney U tests were used to compare sociodemographic variables and characteristics of pain between consulters and non-consulters, and between children using medication or not. The Student's t-test was used to compare means of age between gender, and the Kruskall-Wallis test for analysing categorical variables.

Univariate and multivariate logistic regression analyses with 95% confidence intervals were carried out in order to find out which factors were most strongly associated with consultation and use of medication in children with chronic pain. These analyses used age (as categorical variable), gender, and pain characteristics as independent variables, and consultation and medication use as dependent variables. In addition, the age group 12-16 years was also analysed separately in order to include the education level in the regression analysis. To avoid a selection bias, we excluded children aged 17 and 18 years from this analysis because only a small percentage of Dutch adolescents of these ages attend school, and this age group is confined to higher levels of education only. In these additional regression analyses age was used as a continuous variable. The most frequently reported categories in these regression analyses were chosen as reference categories for categorical independent variables, except for location of pain. The reference category for location of pain was the sum of the other locations. The odds ratios indicate the chance that a physician was consulted or medication was used by e.g. children with more intense pain (reference category, odds ratio = 1) compared to children with less intense pain (see table 3).

Results

Response

From the 6,636 distributed questionnaires, 5,423 completed questionnaires were returned, giving an overall response rate of 82%. The response rate ranged from 64% for children in the first four school years of primary school (4-7 years) to 77% for pre-schoolchildren (0-3 years) and 92% for children in the last four school years of primary school or secondary school (8-18 years).

Table 1

Sociodemographic factors in children with chronic pain related to physician consultation and use of medication

Sociodemographic factors	No of children	**Consultation** N = 1,343		**Medication** N = 1,346	
		N (%)	P	N (%)	P
Total	1,358	774 (57)		528 (39)	
Age group			NS		<0.05
0-3 years	114	81 (71)		62 (56)	
4-7 years	190	101 (54)		72 (38)	
8-11 years	324	157 (49)		119 (37)	
12-15 years	577	344 (60)		218 (38)	
16-18 years	153	91 (61)		56 (37)	
Gender			NS		<0.05
Boys	509	283 (56)		179 (35)	
Girls	834	491 (59)		348 (42)	
Education level			<0.05		NS
Lower vocational training	275	181		113 (41)	
Lower secondary school	167	88 (53)		58 (35)	
Middle secondary school	97	50 (53)		29 (30)	
Higher secondary school	88	47 (53)		31 (35)	

Age and education level was analysed by Mann-Whitney U tests; gender by chi-square tests. P-values were given in case of a significant deviation within the factors. NS = not significant

Respondents

The respondents were 2,653 boys and 2,770 girls, with an average age of 9.1 years (SD = 5.0) for boys and 9.4 years (SD = 4.9) for girls. Of the respondents, 26% reported chronic pain and 28% reported non-chronic pain (i.e. pain existing less than three months). The group of children with chronic pain consisted of 517 boys and 841 girls, with an over-representation of older children. The average age of girls (11.4 years, SD = 4.1) was significantly higher than that of boys (10.1 years, SD = 4.6) (t-test, t=5.57, df=1,356, p<0.001).
Considering education level, of all respondents aged 12-16 years (*n* = 1,892), 42% attended lower vocational training, 27% lower secondary school, 18% middle secondary school, and 13% higher secondary school. Logistic regression analysis showed that, after adjusting for age, education level was not associated with the prevalence of chronic pain.

Medical consumption

Of all children who reported chronic pain, 57% had consulted a physician and 39% had used medication for their pain. About 30% of the chronic pain sufferers had indicated both physician consultation and use of medication, 27% indicated only consultation of a physician, 9% only use of medication, and 34% of them indicated neither of these.
Table 1 shows the sociodemographic factors of children with chronic pain, in relation to consultation of a physician and use of medication. (Parents of) children aged 0-3 years were the most likely to consult a physician and to use medication. Overall, (parents of) girls reported significantly more often than (parents of) boys that they had used medication. No gender difference was found for physician consultation, with the exception for children aged 0-3 years (not shown in table). In this latter age group, (parents of) boys consulted a physician more often than (parents of) girls (χ^2=5.44, df=1, p=0.02). Table 1 also shows a significant negative association between education level and physician consultation.
Table 2 shows the characteristics of pain in relation to physician consultation and use of medication. Particularly children having earache and sore throat consulted a physician and used medication. More than half of the children reported more than one location of pain (multiple pain) and these children had used medication significantly more often than children with a single pain location, whereas no difference was found for physician consultation. Frequency of pain was positively associated only with consultation, and intensity of pain was positively associated with both physician consultation and medication use.

Table 2

Pain characteristics in children with chronic pain related to physician consultation and use of medication

Pain characteristics	No of children	**Consultation** N = 1,343		**Medication** N=1,346	
		N (%)	P	N (%)	P
Total	1,358	774 (57)		528 (39)	
Location of pain					
Head	600	337 (56)		288 (48)	<0.001
Abdomen	558	315 (57))		243 (44)	<0.05
Limb	562	324 (58)		173 (31)	<0.001
Back	248	136 (55)		86 (35)	
Ear	188	137 (73)	<0.001	120 (64)	<0.001
Throat	185	118 (64)		105 (57)	<0.001
Unknown	31	23 (74)		13 (42)	
Elsewhere	176	107 (62)		74 (42)	
Single/multiple pain			NS		<0.001
Single pain	651	371 (57)		216 (33)	
Multiple pain	689	401 (58)		310 (45)	
Frequency of pain			<0.001		NS
≤ once a month	280	150 (54)		130 (47)	
> once a month	392	210 (54)		141 (36)	
> once a week	650	400 (62)		249 (38)	
Intensity of pain			<0.001		<0.001
< 50 mm	558	270 (49)		167 (30)	
≥ 50 mm	788	504 (64)		360 (46)	

Location of pain was analysed by chi-square tests; single/multiple pain, frequency, and intensity by Mann-Whitney U tests. P-values were given in case of significant deviation within the factors or in case of location, significant deviation from reference category, i.e. the sum of all other locations. NS = not significant

Table 3

Predictors for physician consultation and use of medication in children with chronic pain and adjusted for effects of all other variables in table

Predictors	**Consultation**		**Medication**	
	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Age group				
0-3 years	1.59 (0.94,2.68)	1.08 (0.61,1.95)	2.19 (1.33,3.62)*	2.12 (1.18,3.83)*
4-7 years	0.75 (0.49,1.16)	0.62 (0.38,0.99)*	1.05 (0.68,1.64)	0.85 (0.50,1.37)
8-11 years	0.62 (0.42,0.93)*	0.47 (0.31,0.73)*	0.99 (0.67,1.49)	0.91 (0.59,1.42)
12-15 years	0.98 (0.68,1.42)	0.92 (0.63,1.34)	1.03 (0.71,1.50)	1.11 (0.75,1.65)
16-18 years†	1	1	1	1
Gender				
Boys	0.87 (0.70,1.09)	0.88 (0.69,1.12)	0.75 (0.60,0.95)*	0.87 (0.67,1.12)
Girls†	1	1	1	1
Location of pain‡				
Head	0.91 (0.73,1.13)	0.93 (0.69,1.25)	1.96 (1.57,2.45)$	2.07 (1.54,2.80)$
Abdomen	0.92 (0.74,1.15)	0.95 (0.71,1.27)	1.38 (1.10,1.72)*	1.03 (0.77,1.38)
Limb	1.02 (0.82,1.27)	1.01 (0.77,1.34)	0.54 (0.43,0.67)$	0.63 (0.48,0.84)$
Back	0.87 (0.66,1.15)	0.70 (0.50,0.98)*	0.78 (0.59,1.05)	0.72 (0.51,1.01)
Ear	2.18 (1.55,3.07)$	2.21 (1.49,3.28)$	3.31(2.40,4.57)$	2.61 (1.78,3.82)$
Throat	1.35 (0.98,1.86)	1.37 (0.95,1.96)	2.27 (1.66,3.10)$	1.71 (1.20,2.45)*
Unknown	2.14 (0.95,4.83)	2.09 (0.89,4.89)	1.13 (0.55,2.32)	0.98 (0.45,2.13)
Elsewhere	1.20 (0.87,1.67)	1.20 (0.83,1.75)	1.15 (0.83,1.58)	1.04 (0.72,1.52)
Single/multiple pain				
Single pain†	0.95 (0.77,1.18)	1.20 (0.83,1.75)	0.60 (0.49,0.76)$	1.06 (0.72,1.55
Multiple pain	1	1	1	1
Frequency of pain				
≤ once a month	0.72 (0.54,0.96)*	0.71 (0.52,0.96)*	1.41 (1.06,1.87)*	1.56 (1.13,2.15)*
> once a month	0.72 (0.56,0.93)*	0.73 (0.56,0.93)*	0.90 (0.70,1.17)	0.86 (0.65,1.15)
> once a week†	1	1	1	1
Intensity of pain				
< 50 mm†	0.53 (0.42,0.66)$	0.56 (0.44,0.71)$	0.52 (0.40,0.67)$	0.52 (0.40,0.67)$
≥ 50 mm	1	1	1	1
Education level #				
Lower vocational†	1	1	1	1
Lower secondary	0.56 (0.38,0.83)*	0.48 (0.32,0.73)$	0.75 (0.51,1.12)	0.87 (0.56,1.35)
Middle secondary	0.57 (0.35,0.91)*	0.57 (0.35,0.98)*	0.61 (0.37,1.01)*	0.62 (0.36,1.06)
Higher secondary	0.57 (0.35,0.93)*	0.54 (0.33,0.89)*	0.77 (0.47,1.27)	0.76 (0.44,1.31)

† Reference category; ‡ Reference category is the sum of the other locations. # Education level was analysed only for children aged 12-16 years. * Significant deviation from reference category: p<0.05; $ significant deviation from reference category: p<0.001

Predictors for medical consumption

Table 3 shows that for chronic pain univariate analyses yielded differences in consultation and particularly in the use of medication for most factors. In multivariate analyses, the predictive values of age for consultation were modified, and the association between having single or multiple pain locations and use of medication disappeared. For consultation the most significant predictive factors were intensity of pain, earache, and age, in this order; use of medication was mainly predicted by earache, headache, limb pain and intensity of pain. However, limb pain was negatively associated with use of medication. Children aged 12-16 years were also analysed separately, in order to add the education level to the regression analysis. In this group the most significant predictor for consultation was the education level, followed by intensity of pain, headache and gender. Children attending lower vocational training, children with more intense pain, and girls were more likely to consult a physician; children with headache were less likely to consult a physician. The multivariate model for use of medication in the 12-16 year age group did not differ from the model in the entire study group.

Discussion

As far as we know, this is the first study that explores the relationship between chronic pain in different locations in children and adolescents (0-18 years old) in an open population and medical consumption. The results show that chronic pain in children and adolescents involves a large amount of medical consumption (i.e., physician consultation in 57% of respondents and use of medication in 39% of respondents) with differences found for sociodemographic factors and pain characteristics.

A comparison of the results of our study with those of previous studies is difficult, because only a few studies (using different methods) report on consultation (rates) for a specific (usually nonchronic) pain condition in children, whereas the extent of medication use in children with pain was generally not investigated at all. In addition, our definition of chronic pain differs from that used by many others in that it is broader. Unlike others, we did not impose restrictions regarding frequency or severity of pain so as to obtain a comprehensive picture on long-term pain.

About 15% of our sample consulted a physician for chronic pain, which is slightly higher than the overall consultation rate of 11% in children aged up to fourteen years (regardless of symptoms) reported by Bruijnzeels et al.[11] The consultation rate of 56% for chronic headache in our sample is similar to the reported 58% for headache in long-term migraine sufferers aged 11-13 years in a Finnish population-based study.[12] Because that study included only children who suffered from migraine for at least four years, whereas the participants in our study may have had pain for only three months, one would expect a lower consultation rate in our sample.

Age of the child or adolescent influences the decision to consult a physician and to use medication. Children aged 0-3 years were taken more often to the physician and used medication more often than children in the other age groups, as found in other studies.[11,13] Anxiety and inexperience of parents with young children could be an explanation for this. However, multivariate logistic regression analysis showed that for consultation the effect of age was modified compared to univariate analysis. This can probably be attributed to the large proportion of young children taken to the physician because of earache, as also reported by Bruijnzeels et al.[11] In our study children with earache consulted a physician twice as often as children with other chronic pain conditions. Parents may perceive earache as a more severe problem (fear of deafness), and it is often combined with fever and lack of sleep, which is an additional burden. Respondents with earache, headache or sore throat used medication more often, whereas those with limb pain used medication less often. This may be explained by the frequent occurrence of co-existing symptoms (as mentioned previously) in these pain conditions. The medication used for these pain conditions may have been antibiotics in some cases. Furthermore, we assume that in our study, earache and sore throat were not always chronic pain conditions, but in fact recurrent acute episodes of pain due to infection.

The intensity of pain is a strong predictor for consultation and medication use. Respondents who reported VAS intensities above 50 mm were almost twice as likely to consult a physician and to use medication. As expected, there was a positive association between frequency of pain and consultation, but we had not expected respondents with less frequent pain to use medication more often than those with more frequent pain. Perhaps children with more frequent pain found other strategies to cope with their pain or they got used to the pain and therefore needed less medication.

In children aged 12-16 years, the strongest predictor for consultation was educational level. Respondents attending lower vocational training programs consulted a physician almost twice as often as those pursuing higher levels of education, which corresponds with the findings of Bruijnzeels et al., who studied the influence of socio-economic status on children's general practitioner consultation patterns.[14] They found that children of lower and middle socio-economic status families (which is, of course, related to the educational level of children) consult their general practitioner more often than children of higher socio-economic status families. This finding might have implications for both the children and the health care system in different areas. Education on pain focused on health services in socio-economically deprived areas would benefit both patients and the society. The decision to use medication was not affected by educational level.

Based on reports addressing physician consultation patterns in adults, we expected to find girls predisposed to consult a physician.[15-17] Our study indicated such a predisposition in boys in the youngest age group (0-3 years old), whereas for the other age groups, no gender difference was found. Reports that this gender difference in adults is more related to behavioral than biological factors might explain our findings.[18] In children and adolescents, behavioral factors may play a minor role. Reports on physician consultation rates in children are inconsistent about whether or not a gender difference exists.[8,11,12,16,19] The gender difference demonstrated by Linet et al.[8] and Frølund et al.[16] might be due to the inclusion of older participants (12-29 years old) in the first study and the nonpopulation based study design in the latter.

We have to keep in mind that our data were obtained in two ways. In young children, data were obtained from the parents, and in children from the age of 8 years onward, data were self-reported. Self-reported data on pain are preferable. Conversely, parent ratings are the best proxy measure available in very young children, particularly in longer lasting pain.[20,21] Our previous work showed a sudden increase in the prevalence of acute pain at the age of 8 years.[2] The occurrence of chronic pain increased gradually with age, indicating that for chronic pain, our method of obtaining data may not have led to selection bias. Another limitation of our study is the way in which consent for participation was gained: written informed consent (in children aged 0-7 years) versus passive consent (in children and adolescents aged 8-18 years). Because the response rates in the younger age groups were still high, bias is unlikely. Furthermore, in participants aged 8 years or older, the effect of the classroom setting on response is unknown.

In conclusion, more than a quarter of the children and adolescents in our study population experienced chronic pain: 57% of these participants consulted a physician, and 39% used medication for this pain. Our results suggest that those with a lower educational level are more likely to seek medical attention for their pain. Nearly every practising physician is involved with children and adolescents and should be aware of this frequently occurring problem. Obviously, the decision to consult a physician, and perhaps also the decision to use medication, is not simply based on sociodemographic factors and characteristics of pain. Other social and psychological factors may also play a role.[15] Future studies should aim to elucidate these factors and should survey the different aspects of medical consumption such as the number of consultations, the amount and names of prescribed and over-the-counter medications, referral rates, and distribution between different specialties, diagnostic procedures, and causal factors related to the pain.

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4

Insights in the use of health care services in chronic benign pain in childhood and adolescence

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Abstract

The utilization of health care services in children and adolescents with chronic benign pain was studied in a Dutch population sample of 254 chronic pain sufferers aged 0-18 years. Children and adolescents who had reported chronic pain (continuous or recurrent pain >3 months) in our previous prevalence study were asked to keep a 3-week diary on their pain and to fill out questionnaires on background factors, health care use and the impact of pain. Parent ratings were used for children aged 0-11 years, self-report was used in adolescents (12-18 years).

In a three-month period, in 53.4% of the cases medication was used for pain, and general practitioners and specialists were consulted for pain in 31.1% and 13.9% of subjects, respectively. Physiotherapists, psychologists and alternative health providers were visited by 11.5%, 2.8%, and 4.0%, respectively. In the preceding year, 6.4% had been hospitalized due to pain. The most important factors linked to utilizing medical services were gender, various pain characteristics, school absenteeism and disability. Although consulters reported to be less physically fit and less satisfied with health, their parents were better adapted to the pain, by talking and sharing, mutual support, normalization of the child and heightened self-esteem, than non-consulters. Prospective studies are needed to test causality of coping on care-seeking behavior.

Introduction

Chronic pain is a frequent complaint in childhood and adolescence.[1] In a representative Dutch population sample of children aged 0 to 18 years (*n* = 5,424), we recently reported the three-month prevalence rate of chronic pain (> 3 months) to be 25%. Headache, abdominal pain and limb pain were the most frequently reported, particularly in older children and in girls.[2] Furthermore, chronic pain is often associated with a burden for children and their families.[3-5]

Considering the high prevalence of chronic pain in children and its impact on quality of life, it is important to elucidate the relationship between pain and use of health services. In adults, chronic pain is related to frequent and costly utilization of health services, and use of medical services itself may interfere with quality of life.[6] Frølund and Frølund (1986) reported that pain is a major reason for medical consultations.[7] They found that in 22% of all contacts (all ages) pain was the cause of the patient-doctor contact; the proportion of acute pain and chronic pain was 61 and 39 respectively. In children, however, little is known about the extent and type of health care use due to chronic pain, or the factors that determine the consultation rate for chronic benign pain. Except for headache, studies addressing use of health care services in children in relation to chronic pain are scarce. In a British community study, 11.3% of 3-to-11-year-olds with migraine had consulted a physician because of headache.[8] A Finnish community study reported that 51.8% of migraine sufferers aged 11-13 years consulted a physician; factors linked to the consultation rate were aura symptoms, frequency of attacks, degree of urbanization and school absence.[9] As far as we know, our previous study was the first to focus on chronic pain (irrespective of site) in relation to use of health services, and showed that 57% of the chronic pain sufferers aged 0-18 years ever had consulted a physician and 39% ever had used medication for the pain.[10]

The purpose of the present study was to examine health care utilization and medication use in children with chronic pain more comprehensively, by using a prospective study design. More insight in the relationship between pain problems and use of health care services may improve the overall care for children and adolescents. We defined chronic benign pain as continuous or recurrent pain with unknown organic etiology existing for three months or longer.

The organization of the Dutch health system is such that everybody is registered with a general practitioner, who is usually the first link in the chain of all health care services. Outpatient hospital care, hospital admission and consultation of a physiotherapist all require referral by the general practitioner. As a rule medical specialists work exclusively hospital based. For publicly insured (those below a certain income level, 60% of the population) as well as privately insured patients (the other 40%) they receive fees for items of service. Treatment of publicly insured patients by a physical therapist is only paid after authorization by the Sick

Fund; privately insured also pay fees for service. Mental health care is directly accessible for the whole population by the so-called General Act on Exceptional Medical Expenses (AWBZ), and is financed from tax revenues. Regarding alternative health care, patients usually have to pay for it themselves.

Because of the limited knowledge in this field the following study questions were addressed: (1) What is the extent and type of health service utilization in children and adolescents aged 0-18 years suffering from chronic pain? (2) Are there differences in sociodemographic factors, pain characteristics, school absenteeism, co-occurrence of chronic diseases, and occurrence of chronic pain in their parent(s), among subjects using health care services (consulters) versus those not using medical services for this condition (non-consulters)? (3) Do consulters and non-consulters differ in health status, quality of life and the impact of chronic pain on the family?

Methods

Subjects

This study was approved by the ethics committee of the Erasmus University. In a previous study that assessed the prevalence of chronic pain,[2] we obtained a representative sample of 6,636 children and adolescents aged 0 to 18 years in the Rotterdam area. Additionally, a second random sample was obtained from the records of 11 general practitioners (*n* = 1,456, 0-18 years). Overall, 6,282 questionnaires (response 78%) were filled out. If the answer to the first question, "Did you/your child experience pain in the previous three months?" was "yes" and subjects indicated on a three-point scale that the pain lasted longer than 3 months they were approached for the present study. Written informed consents were obtained from one of the parents and from subjects aged 12 years and over (*n* = 988).

Procedure

For subjects aged 0-11 years (*n* = 513) a pain booklet and a self-addressed envelope were sent by mail to parents or primary caregivers. They were first invited to answer the questionnaires and then to keep the diary to report their child's pain characteristics and behavioral consequences of the pain for three successive weeks. Subjects aged 12-18 years (*n* = 475) and their parents were each sent a pain booklet. The adolescents were first invited to answer the questionnaires and then to keep the diary to register pain intensities on their own. Their parents were also asked to fill out some questionnaires.

In case the child did not experience pain during the previous three months, only demographic data and a possible reason for the disappearance of the pain were requested. Subjects who had previously reported more than one location of pain were asked to report only on the pain that troubled them most. Subjects also received a calendar chart as an aide-mémoire.

Outcome measures and instruments

The following questionnaires were used: (1) Lists concerning demographic data of the child[a], the mother and father[b]. (2) The self-administered Pain List[a] was partly based on the questionnaire used in our previous study and comprised questions on location, frequency, intensity and history of the pain.[2] Additional questions concerned disability due to pain and comorbidity of chronic diseases. To confirm that the pain did not have an organic etiology we asked whether a physician had made a medical diagnosis for the pain. Subjects with pain resulting from specific chronic diseases (e.g. rheumatic arthritis, malignancies) were excluded. (3) The self-administered Health Care Use Questionnaire[a] recorded different types of health care utilization because of pain in the previous three months. Except for hospital admission, the period of recall was one year. (4) The Dutch version of the Functional Status II (R) (FSII)[b] was used to assess the child's health status.[11,12] The conditional part, asking whether the child's behavior could be attributed to the pain, was omitted because a pilot study revealed that in the written form this part caused comprehension problems. (5) The Dartmouth COOP Functional Health Assessment Charts/WONCA were used in a Dutch translation to measure the functional status of the parent[b] or child[a,c].[13] (6) To assess the impact of the child's pain on the family we used the Dutch version of the 24-item Impact on Family Scale (IFS)[b].[14,15] (7) The quality of life in four domains was assessed in adolescents with the Quality of Life Headache-Youth (QLH-Y) questionnaire[a,c], adapted for chronic pain irrespective of site.[16] The questionnaire also contained two visual analogue scales to measure satisfaction with life in general and health during the previous week. The questionnaires used have shown acceptable reliability and validity.

The diary consisted of Visual Analogue Scales (VAS) and the Postoperative Pain Measure for Parents (PPMP)[d] adapted for chronic pain, to obtain the intensity and frequency of pain.[17] Pain intensity was recorded three times daily, at breakfast, dinnertime and bedtime, during three successive weeks. In addition, mothers of subjects aged 0-11 years completed the PPMP at the end of each day; the list was adapted for chronic pain and therefore shortened from 29 to 10 items.[18]

[1a] Questionnaires filled out by children in age group 12-18 years, and parents in age group 0-11 years

[b] Questionnaires filled out by the parent

[c] Questionnaires only distributed to subjects aged 12-18 years

[d] Questionnaire only distributed to parents of subjects aged 0-11 years

Non-response

To detect whether non-response bias occurred we conducted a telephone survey among all subjects who did not respond to the diary study (*n* = 481). One research fellow carried out all interviews, using a structured questionnaire. The participants or their parents were first questioned about the reason for not responding. Then we asked: "Do you/does your child still experience pain?" If the answer was "yes", additional information was requested concerning the course, location, duration, frequency and intensity of the pain. Questions were also asked about interference with daily activities, school absence due to pain, utilization of health care services, medication use, a medical diagnosis for pain and comorbidity of chronic diseases. Most questions were open-ended, except for those about the intensity of pain and interference with daily activities. The subjects or their parents could give scores ranging from 0 to 10; the higher the score the less favorable. The period of recall used was the same as in the diary study.

Data reduction and analysis

To obtain intensity scores, the VAS markings were first converted into scores from 0 to 100 by reading off each mark against a millimeter ruler. Subsequently, VAS scores $\leq$ 5 millimeters were recoded to zero, because in a pilot study on the measurement of pain intensity in children interviews about the recording showed that those scores turned out to be 'no pain at all'.[18] To score the child's behavior due to pain the positively answered items of the PPMP were summated. To obtain an average pain intensity score, the VAS scores (and for participants aged 0-11 years also the PPMP scores) were divided by the number of VAS recordings or days in pain, respectively. Subjects with more than 25% missing values on VAS or PPMP in the diary were excluded from the analyses. The frequency of occurrence of pain was defined as the percentage of the number of recordings indicating the presence of pain divided by the total number of recordings (VAS and PPMP). For example, a pain frequency of 33% means that the pain was present in 21 (score > 5 mm) of the 63 VAS recordings, or in 7 (score > 0) of the 21 PPMP recordings.

Subjects were categorized into consulters and non-consulters. Consulters were those reporting use of some form of health care services; non-consulters did not report any use of health service. In this classification medication use was left out of consideration, because we could not differentiate whether medication was prescribed or over-the-counter medication.

Data were analyzed by frequencies and cross-tabulations. Differences were tested for categorical variables by chi-square tests, for ordinal variables by Mann-Whitney U (M-W) tests or Kruskall-Wallis (K-W) tests, and for continuous variables by Student's t-tests. Bivariate logistic regression analysis was carried out to test the effect of the person who filled out the booklet, with adjustment for age, on the use of medical services. A *P* value of less than 0.05 was considered significant.

Results

Response

Five hundred seven participants (51.3%) returned the pain booklet; of these, 248 reported that the pain had ceased during the previous three months, and 259 still suffered from chronic pain. Five subjects who reported chronic pain as the result of a diagnosed chronic disease were excluded, leaving a study sample of 254 participants.

Non-response

Of the 481 non-responders, 213 subjects were interviewed. The remainder was not contacted due to relocation or lack of a telephone number. One-third of the interviewed non-responders stated that the pain had ceased and about a quarter had not responded for lack of motivation; the remainder had not responded for various reasons including moving house, etc. In total, 85 of the interviewed non-responders (40%) still suffered from the same pain, which was mostly located in the limbs (37%), head (27%), abdomen (23%) or back (10%). In 65% of them pain was experienced weekly, and in 10% the pain was continuous. The mean intensity of pain and the mean of interference with daily activities was 6.8 (SD = 2.9) and 5.3 (SD = 2.9), respectively. Because of pain, 13 non-responders missed one or two schooldays monthly, another 13 consulted their general practitioner, 6 consulted a specialist, 3 went to a physiotherapist, and one used alternative medicine. None consulted a psychologist or social worker, and none used medication for the pain. No medical diagnosis for the pain or comorbidity was reported.

Compared with the total sample of 988 children and adolescents who reported chronic pain in the previous prevalence study[2] and were willing to participate in the present study, the present sample (responders, *n* = 254) had somewhat higher frequencies of pain (68% had weekly pain versus 60% in the non-responders; M-W, Z=2.28, p=0.023), consulted a physician more often (70% versus 58% in the non-responders; M-W, Z=3.40, p=0.001) and used medication more often (48% versus 40% in the non-responders; M-W, Z=2.16, p=0.030) than non-responders (*n* = 734). There were no significant differences for age, gender and pain intensity between responders and non-responders.

Study sample

The main characteristics of these 254 children and their parents are reported in table 1. The study sample comprised twice as many girls as boys.

Table 2 gives the characteristics of pain of our study sample. Questioned about the pain in the previous month, 70.1% of the subjects reported to have pain weekly and the mean pain intensity was 50.2 mm. The percentage and mean intensity of the pain in three successive weeks assessed by VAS was 49.5 and 30.6 mm, respectively. For subjects aged 0-11 years,

Table 1

Background factors in children suffering from chronic pain in relation to health care utilization

	Total N = 254	Consulters N = 109	Non-consulters N = 145	P
Person who completed the booklet				
Parent (for children aged 0-11 yrs)	123 (48.4)	45 (40.9)	78 (54.2)	.036
Adolescent (aged 12-18 yrs)	131 (51.6)	65 (59.1)	66 (45.8)	
Gender (N, %)				
Boys	80 (31.6)	28 (25.5)	52 (36.4)	NS
Girls	173 (68.4)	82 (74.5)	91 (63.6)	
Age of child				
Mean in years (SD)	11.1 (4.3)	10.7 (4.2)	11.7 (4.4)	NS
Ethnicity child (N, %)				
Dutch	244 (97.2)	107 (99.1)	137 (95.8)	NS
Non-Dutch	7 (2.8)	1 (0.9)	6 (4.2)	
Ethnicity mother (N, %)				
Dutch	214 (93.9)	91 (95.8)	123 (92.5)	NS
Non-Dutch	14 (6.1)	4 (4.2)	10 (7.5)	
Ethnicity father (N, %)				
Dutch	191 (94.6)	78 (96.3)	113 (93.4)	NS
Non-Dutch	11 (5.4)	3 (3.7)	8 (6.6)	
Birth-order position of child (N, %)				
First-born	118 (47.4)	45 (40.9)	73 (52.5)	NS
Later-born	131 (52.6)	65 (59.1)	66 (47.5)	
Family size				
Mean of number of children (SD)	2.4 (1.0)	2.4 (0.9)	2.4 (1.1)	NS
Age mother				
Mean in years (SD)	39.7 (5.5)	39.8 (5.6)	39.6 (5.4)	NS
Age father				
Mean in years (SD)	42.0 (7.3)	42.8 (5.8)	41.4 (8.1)	NS
Marital status of parents (N, %)				
Married or cohabitant	204 (85.4)	88 (84.6)	116 (85.9)	NS
Divorced or separated	35 (14.6)	16 (15.4)	19 (14.1)	
Education level mother (N, %)				
Low	91 (40.3)	39 (39.4)	52 (40.9)	NS
Middle	82 (36.3)	41 (41.4)	41 (32.3)	
High	53 (23.5)	19 (19.2)	34 (26.8)	
Education level father (N, %)				
Low	49 (25.9)	22 (28.6)	27 (24.1)	NS
Middle	79 (41.8)	31 (40.3)	48 (42.9)	
High	61 (32.3)	24 (31.2)	37 (33.0)	
Occupational level mother (N, %)				
Manual	8 (3.4)	3 (2.9)	5 (3.8)	NS
Non-manual	105 (44.5)	45 (43.7)	60 (45.1)	
Unemployed*	123 (52.1)	55 (53.4)	68 (51.1)	
Occupational level father (N, %)				
Manual	50 (24.4)	22 (26.2)	25 (21.7)	NS
Non-manual	144 (70.2)	58 (69.0)	86 (71.1)	
Unemployed*	11 (5.4)	4 (4.8)	7 (5.8)	
Chronic pain in mother (N, %)	106 (44.5)	46 (44.7)	60 (44.4)	NS
Chronic pain in father (N, %)	77 (37.6)	37 (43.0)	40 (33.6)	NS
Comorbidity (N, %)	20 (7.9)	13 (11.9)	7 (4.8)	.038

Education level was classified based on the highest completed school level: low (primary school or lower vocational training), middle (secondary school) and high (higher vocational training and university).
For occupational level the reported professions were coded according to the EGP code and classified into three socio-economic groups: non-manual, manual and unemployed.[19] The category 'unemployed' comprised: housewife/houseman, disabled, jobless or retired.

Table 2

Pain characteristics and school absenteeism in children suffering from chronic pain in relation to health care utilization

	Total N = 254	Consulters N = 109	Non-consulters N = 145	P
Course of pain (N, %)[a]				
Continuous	41 (16.1)	25 (22.7)	16 (11.1)	.013
Recurrent	213 (83.9)	85 (77.3)	128 (88.9)	
Location of pain (N, %)[a,c]				
Limb	71 (29.2)	31 (29.2)	40 (29.2)	NS
Head	65 (26.7)	32 (30.2)	33 (24.1)	
Abdomen	61 (25.1)	21 (19.8)	40 (29.2)	
Back	20 (8.2)	6 (5.7)	14 (10.2)	
Other	26 (10.7)	16 (15.1)	10 (7.3)	
History of pain[a]				
Mean in years (SD)	3.1 (2.7)	2.8 (2.8)	3.3 (2.6)	NS
Pain frequency (estimated)[a]				
Less than once a week	69 (29.9)	19 (19.2)	50 (37.9)	.002
At least once a week	162 (70.1)	80 (80.8)	82 (62.1)	
Pain frequency (diary)				
Mean of % in pain on VAS (SD)	49.5 (34.2)	62.6 (35.1)	39.0 (29.6)	< .001
Mean of % in pain on PPMP (SD)	22.5 (22.1)	28.6(28.5)	19.0(16.6)	.021
Pain intensity (estimated)[a,b]				
Mean in millimeters on VAS (SD)	50.2 (20.3)	53.5 (19.5)	47.7 (20.6)	.026
Pain intensity (diary)[b]				
Mean in millimeters on VAS (SD)	30.6 (15.0)	31.6 (14.4)	29.9 (15.4)	NS
Mean of PPMP score (SD)	3.1(1.6)	3.0 (1.7)	3.1 (1.5)	NS
Interference with daily activities[a,b]				
Mean in millimeters on VAS (SD)	32.6 (28.0)	42.0 (30.8)	25.3 (23.2)	< .001
School absenteeism (N, %)[a]	60 (25.2)	33 (31.4)	27 (20.4)	.050
Mean in days per month (SD)	4.1 (5.1)	4.3 (4.6)	3.8 (5.7)	NS

[a] Items of the Pain List. The time frame used was one month.

[b] Intensity of the pain and interference with daily activities were assessed by using the Visual Analogue Scale, a hundred millimeters long line with the verbal anchors 'no pain' (0 mm) versus 'the worst pain you can imagine' (100 mm) or 'no nuisance' (0 mm) versus 'unable to do daily activities' (100 mm), respectively, at both sides. Additionally, for children aged 0-11 years, the pain intensity was assessed by using the adapted version of the Postoperative Pain Measure for Parents (Chambers et al., 1996); the score ranges from 0 (no behavioral changes) to 10 (maximum number of behavioral changes).

[c] The analyses for the location of pain used the sum of all other locations as reference category.

the intensity and frequency of the pain were assessed by VAS and PPMP, which showed significant associations ($r = 0.22$, $p = 0.04$ and $r = 0.53$, $p < 0.001$, respectively).

Use of health services

Table 3 shows the extent and type of health care utilization among children and adolescents with chronic pain in a three-month period. The general practitioner was consulted by 31.1% of the participants, and a specialist (mainly a pediatrician) by 13.9%. More than half of the chronic pain sufferers used medication for the pain, mainly paracetamol. Most subjects indicated to use analgesics if necessary (data not shown).

Table 3

Extent and type of health care utilization due to pain among 254 children and adolescents with chronic pain in a three-month period

Consultation with (N, %)	
General practitioner	78 (31.1)
Specialist	35 (13.9)
Physiotherapist	29 (11.5)
Psychologist or social worker	7 (2.8)
Alternative health provider	10 (4.0)
Number of consultations (mean, SD)	
General practitioner	2.0 (1.6)
Specialist	2.1 (2.3)
Physiotherapist	8.7 (6.3)
Psychologist or social worker	3.9 (3.7)
Hospital admission (N, %)*	16 (6.4)
Mean hospital stay in days (SD)	4.9 (4.0)
Diagnostic tests (N, %)	40 (15.9)
Laboratory investigations	16 (6.3)
Imaging techniques	23 (9.1)
Function investigations	7 (2.8)
Medication use (N, %)	134 (53.4)
Paracetamol	72 (28.3)
Non-steroidal anti-inflammatory drugs	29 (11.4)
Others (e.g., spasmolytics)	47 (18.5)
Mean number of different medications used (SD)	1.3 (0.6)

*For hospital admission the period of recall was one year.

Differences between consulters and non-consulters

Tables 1 and 2 further also show differences in background factors and pain characteristics between consulters and non-consulters. Concerning background factors, no significant differences were found, but after excluding pre-school ages (0-4 years) girls were found to be more likely to use health care services for chronic pain than boys (48% versus 33%; χ^2=4.29, df=1, p=0.038). For pre-school age, although not significant, the opposite effect was found for gender. Furthermore, we found a significant difference for the person who completed the pain booklet (parent versus self-report), but after adjustment for age by logistic regression analysis this effect disappeared. Although not significant, considerable differences in utilization of medical services were found for ethnicity of the child and parents; subjects of Dutch origin were more likely to use health services than subjects of ethnic minorities. Comorbidity of chronic diseases was reported significantly more frequent in consulters, with asthmatic complaints as the most frequently reported (9.2% of consulters and 3.4% of non-consulters; data not shown).

Most characteristics of pain were strongly associated with the use of health services. Consulters had significantly more often continuous pain, more frequent and more intense pain. Interference with daily activities was reported more often in consulters, as was school absenteeism.

Table 4 shows the impact of chronic pain on the child and family in relation to the use of health care services. Among the adolescent consulters the physical fitness and the satisfaction with health were less than in non-consulters. The family of consulters could better master the stress of pain than non-consulters, but reported a higher financial burden due to pain.

Discussion

This study is the first to attempt to give a comprehensive picture of the use of medical services due to chronic pain in children and adolescents, and a broad range of related factors. An important advantage of our study compared with earlier studies on this topic is that we did not restrict our analysis to a particular age group, a specific pain condition or health care service, but investigated all types of pain and medical services in children up to 18 years of age. Unlike many others, our definition of chronic pain (continuous or recurrent pain > 3 months) is broader since we did not restrict ourselves to subgroups based on pain severity or disability in order to obtain a comprehensive picture on chronic pain.[20] In a high number of subjects (about half of the responders and one-third of the non-responders) the pain had ceased during the preceding 3 months. This is possibly a consequence of our definition of chronic pain including both continuous and recurrent pain, and chronicity for pain duration of only three months. Nevertheless, other studies on migraine[9,21] and idiopathic musculoskeletal

Table 4

Impact of chronic pain on the child and family in children suffering from chronic pain in relation to health care utilization. Mean scores (SD) of the different measures are presented.

	Total	Consulters	Non-consulters	P
Functional Status II[1,a]	80.4 (12.3)	79.8 (12.0)	80.9 (12.6)	NS
Impact on Family Scale[1,b]				
Financial burden	5.4 (2.2)	5.7 (2.2)	5.1 (2.1)	0.025
Social impact	12.2 (4.0)	12.7 (3.8)	11.9 (4.1)	NS
Personal strain	8.8 (3.4)	9.2 (3.3)	8.5 (3.4)	NS
Mastery	13.3 (3.7)	12.2 (3.5)	14.0 (3.6)	<0.001
Total	39.8 (7.3)	39.9 (6.9)	39.6 (7.7)	NS
Coop Wonca parents[1,c]				
Physical fitness	2.3 (1.0)	2.3 (0.9)	2.3 (1.0)	NS
Emotional feelings	2.1 (1.0)	2.0 (1.0)	2.1 (1.1)	NS
Daily activities	1.8 (1.0)	1.8 (1.0)	1.8 (1.0)	NS
Social activities	1.4 (0.9)	1.4 (0.8)	1.5 (0.9)	NS
Overall health	2.5 (1.0)	2.5 (1.0)	2.5 (1.1)	NS
Pain	2.4 (1.0)	2.3 (1.0)	2.4 (1.1)	NS
Coop Wonca adolescents[2,c]				
Physical fitness	2.2 (1.0)	2.4 (1.1)	2.0 (0.9)	0.054
Emotional feelings	2.4 (1.0)	2.4 (1.1)	2.4 (1.0)	NS
School work	2.2 (1.0)	2.1 (0.9)	2.2 (1.1)	NS
Social support	1.7 (0.9)	1.7 (0.8)	1.8 (1.0)	NS
Family	3.2 (1.1)	3.0 (1.0)	3.3 (1.2)	NS
Quality of Life – Youth[2,d]				
Psychological functioning	1.5 (0.2)	1.5 (0.2)	1.6 (0.5)	NS
Social functioning	1.6 (0.4)	1.7 (0.4)	1.6 (0.4)	NS
Somatic functioning	2.2 (0.5)	2.2 (0.5)	2.2 (0.5)	NS
Functional status	2.4 (0.5)	2.3 (0.4)	2.4 (0.5)	NS
Satisfaction with life in general	62.2 (24.2)	60.9 (23.0)	63.5 (25.5)	NS
Satisfaction with health	56.5 (24.8)	50.7 (24.5)	62.3 (23.9)	0.007

[1] Measures used in all subjects (109 consulters and 145 non-consulters).
[2] Measures only used in adolescents aged 12-18 years (65 consulters and 66 non-consulters).
[a] The score ranges from 0 (total impairment) to 100 (no impairment).
[b] Score ranges differ for the four subscales and the total score on the IFS ('financial impact' 4-16; 'social impact' 9-36; 'personal strain' 6-24; 'mastery' 5-20; total score 24-96). The higher the scores of the first three subscales, the higher the psychosocial impact, and the higher the score of the fourth subscale 'mastery', the less coping strategies were employed by their families to master the stress of pain, implying that a high total score represents a high impact of pain on the family.
[c] The higher the scores (range 1-5), the less favorable the level of functional status.
[d] The higher the scores of the four domains (range 0-3), the better the self-reported quality of life. The scores for satisfaction with life in general/health range from 0 (extremely dissatisfied) to 100 (completely satisfied).

pain syndromes[22] also reported high 'remission' rates for pain. To learn more about the prognosis of chronic benign pain in children we plan to follow up all children, whether they had pain or not at the first assessment, across a two-year period.

We found a relatively high use of medical services; 43% of the sample had used some form of health care services, and 53% had used medication for the pain in the previous 3 months. Since these pains were benign and already existed for a long period (about 3 years), we expected less use of health care services and probably other coping procedures than medication use. Our figures on hospital admission (6.4%) are astonishingly high compared with the data from the Central Bureau of Statistics, which indicated that 4% of the pediatric population was admitted to hospital over the years 1997/1998.[23] On the other hand, we had not expected to find such a low utilization of psychosocial care (2.8%) and alternative health care (4.0%). Krauss et al. (1998) reported that 33.9% of adult chronic pain patients listed at an outpatient vocational rehabilitation facility in New York consulted an alternative health provider in the past year.[24]

Many indicators of pain severity are associated with the use of medical services. Children and adolescents with continuous pain or more frequent and intense pain, with disability or school absenteeism due to the pain were more likely to use health care services for pain. These findings correspond with other reports on the utilization of health care services (Metsähonkala et al., 1996; Linet et al., 1991; Lipton et al., 1998).[9,21,25] Over 4 years of age, girls reported more use of health services than boys, in agreement with earlier reports.[7,25,26] Except for gender, background factors appeared to be similar for consulters and non-consulters, suggesting that pain severity plays a more important role in health care utilization. Based on previous reports we expected to find higher utilization among lower social class children,[10,27-29] first-born children and children with high parental morbidity.[27] Noteworthy is the high occurrence of chronic pain among parents of children and adolescents with chronic pain. Apley (1975) reported that abdominal pain was six times more likely to occur in siblings and parents of abdominal pain patients than in controls, suggesting that those pain sufferers come from 'pain-prone' families.[30] Another explanation could be that our respondents were modeled by the pain behavior of their parents.

Regarding the impact of chronic pain on the child and the family (table 4) only a few significant differences were found between consulters and non-consulters. Since we conducted multiple analyses we have to adapt the threshold for statistical significance to a *P* value of 0.002 (0.05/23); the difference for mastery remained significant. In the present study, parents of consulters reported better adaptation (by talking and sharing, mutual support, normalization of the child and heightened self-esteem) to the pain than non-consulters, in disagreement with Campbell and Roland who reported that inadequate coping strategies are associated with more consultation of a physician.[31] However, according to the criteria of Cohen only a moderate effect (Cohen's d = 0.5) was found for this relationship between health care use and mastery, implying the clinical relevance to be limited.[32] Further, there is the problem of causality. Prospective studies on the determinants of health care-seeking behavior for chronic pain are therefore needed.

Several limitations of our study have to be discussed. First, selection bias introduced by non-participation is a potential limitation, which must be considered. Our telephone survey among 213 non-responders showed a number of differences between these non-responders and our sample, especially towards the use of medical services. This could imply that our findings are biased due to selection. However, we argue that these differences are mainly the consequence of methodological differences, such as the instruments used and the time that expired between the diary study and the non-response survey. Moreover, the relatively small differences in demographics, pain characteristics, physician consultation and medication use, as assessed in the previous prevalence study,[2] between the responders and the non-responders, suggest the selection bias to be small.

Another drawback is the fact that we used parent ratings versus self-report. Because pain is subjective, self-report should be the 'gold standard' for pain assessment.[33] We used parent ratings for subjects aged 0-11 years because this is the best proxy measure available in young children, particularly in longer lasting pain.[34,35] Bias due to the different way of obtaining data is unlikely, since after adjustment for age no significant differences in use of health care services were found between parent and self-report.

The high referral behavior of physicians and the high application for diagnostic tests could promote somatization through which these children and adolescents stay in the medical circuit. Therefore, physicians should take into account the psychosocial background of chronic pain patients.

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5

The natural course of chronic benign pain in childhood and adolescence: a two-year population-based follow-up study

Abstract

Previous data on chronic pain in childhood and adolescence have derived mainly from cross-sectional studies using differing definitions for chronic pain and including different age groups. A longitudinal study design allows detailed description of different aspects of the natural history of chronic pain. A cohort of 987 children and adolescents aged 0-18 years with chronic pain (continuous or recurrent pain > 3 months), who were identified in a previous population-based prevalence study, were approached for a two-year follow-up study. Subjects were asked to keep a three-week diary on their pain and to fill out questionnaires about background factors, pain and pain-related consequences. This assessment was repeated annually for two years. At baseline, 254 subjects reported chronic benign pain; of these, 124 (48%) and 77 (30%) subjects still experienced chronic benign pain at 1-year and 2-year follow-up, respectively. Except for the estimated pain intensity, which decreased marginally, pain remained stable over the follow-up period. Minor changes occurred in the consequences of pain; the main changes were a decrease of the impact of pain on the child's behavior, social functioning and use of health care. Subjects with persistent pain (9.4%) differed from those with non-persistent pain in frequency, history and location of the pain, emotional problems and their mother's health. The implications are that chronic benign pain in childhood and adolescence is common, and seems to persist in a considerable proportion (30%-45%), although pain generally does not deteriorate over time.

Introduction

Chronic or recurrent pain is common in children and adolescents and is usually located in the head, limbs, or abdomen,[1,2] affecting one-third of unselected schoolchildren.[3] Headache, limb pain, and abdominal pain may occur in many serious diseases, but it is generally recognized that, in the majority of children with these symptoms, no organic cause can be found. It is with this benign pain group that this paper is concerned. Recent studies on chronic pain in children and adolescents indicate that pain is positively associated with psychological distress, somatic complaints, functional disability, and health care utilization.[4-7]

Data on the clinical course of children and adolescents with chronic pain are scarce. The majority of studies on pediatric chronic pain had a cross-sectional design using differing definitions for chronic pain and using restricted age groups, and little is known about the factors which predispose to persisting chronic pain. In addition, longitudinal studies on chronic pain sufferers have drawn merely from hospital samples only. Chronic pain sufferers seen in hospital clinics may not be representative of sufferers in the general population who are not referred. Moreover, Crook et al., comparing the course of adult persistent pain sufferers in the general population with those referred to a specialty clinic, found a worse prognosis for the referred patients.[8]

It has been reported that headache characteristics change over time.[9-18] These studies, mostly hospital-based studies on migraine in childhood, recorded spontaneous remission in 30-40% and improvement in about 50% at 5-10 year follow-up. Studies from clinical samples on recurrent abdominal pain suggest that 25-50% continue to experience symptoms into adulthood.[19-21] A Finnish population-based study reported that of the schoolchildren with weekly musculoskeletal pain in 52% the pain persisted at 1-year follow-up.[22] None of these studies, however, included measures of disability in order to determine the course of pain, or its impact on daily functioning.

The present study provides an overview of the course and prognosis of chronic benign pain in children and adolescents aged 0-18 years in the general population over a two-year period. The purpose was to determine what proportion of children do not "grow out of their pains", whether there were any changes in the clinical variables over time, and to identify predictive factors for the persistence of pain. The variables studied were pain parameters, pain-related consequences (functional status, quality of life, impact on the family, school absence, health care use and medication use), and some background factors (co-morbidity and chronic illness in the family). The identification of predictive and prognostic factors could provide new diagnostic and therapeutic insights, and more appropriate patient counseling.

Methods

Study sample

This longitudinal study was approved by the ethics committee of the Erasmus University Rotterdam. In a previous study that assessed the prevalence of chronic pain,[3] we obtained a representative community sample of 6,636 children and adolescents aged 0 to 18 years in the Rotterdam area. Additionally, a second random sample of 1,456 children and adolescents aged 0 to 18 years was obtained from the records of 11 general practitioners. In December 1996, both samples were screened on chronic pain (CP) by means of a self-administered questionnaire; 6,284 questionnaires (response 78%) were filled out. If the answer to the first question, "Did you/your child experience pain in the previous three months?" was "yes" and subjects indicated on a three-point scale that the pain lasted longer than 3 months they were approached for participation in a two-year follow-up survey. Written informed consent was obtained from one of the parents and from subjects aged 12 years and over.

Follow-up study

Subjects with chronic pain who gave their consent for follow-up (*n* = 987) were studied by means of a mailed pain booklet consisting of questionnaires and a three-week diary, and followed-up annually for two successive years. This follow-up survey started about 6 months after the screening on chronic pain. The sampling results are shown in Figure 1.

Parents of subjects aged 0-11 years (*n* = 512) were first invited to answer the questionnaires and then to keep the diary to report their child's pain characteristics and behavioral expression of the pain for three successive weeks. Subjects aged 12-18 years (*n* = 475) and their parents were each sent a pain booklet. The adolescents were first invited to answer the questionnaires and then to keep the diary to register pain intensities on their own. Their parents were also asked to fill out some questionnaires.

In case the child no longer experienced chronic pain in the previous three months, only demographic data and a possible reason for the remission of the pain were requested. Subjects who had previously reported more than one location of pain were asked to report only on the pain that troubled them most. Subjects received a calendar chart as an aide-mémoire. Subjects with pain resulting from specific chronic diseases (e.g. rheumatoid arthritis, malignancies) were excluded. We defined chronic benign pain (CBP) as continuous or recurrent pain with unknown organic etiology existing for three months or longer. In order to obtain a comprehensive picture on chronic pain we did not restrict ourselves to subgroups based on severity of pain or disability, as was the case in other studies on chronic pain.[23]

In this paper, for convenience, the baseline assessment (June 1997) will be denoted 'T_0', halfway through the follow-up period (June 1998) will be denoted 'T_1', and the end of the follow-up period (June 1999) will be denoted 'T_2'.

Outcome measures and instruments

Table 1 gives an overview of the outcome measures and instruments used in this study. The structured pain list was partly based on the questionnaire used in our previous prevalence study and comprised questions on location, frequency, intensity and duration of the pain.[3] Additional questions concerned functional disability due to pain and co-morbidity of chronic diseases. To confirm that the pain did not have an organic etiology we asked whether a physician had made a medical diagnosis for the pain. The conditional part of the Functional Status II (R) (FSII),[24,25] asking whether the child's behavior could be attributed to the pain, was omitted because a pilot study revealed that in the written form this part caused comprehension problems when it was self-administered. The questionnaires used have shown acceptable reliability and validity.

The diary consisted of Visual Analogue Scales (VAS)[30,31] and, for subjects aged 0-11 years also the Pain Behavioral Change Measure (PBCM), to obtain the intensity and frequency of pain. All subjects were asked to record pain intensity by VAS three times daily, during three successive weeks. In addition, parents of subjects aged 0-11 years completed the PBCM, a modified version of the Postoperative Pain Measure for Parents,[32] at the end of each day; the list was adapted for chronic pain and therefore shortened from 29 to 10 items. For subjects aged 0-11 years, the intensity and frequency of the pain, assessed by VAS and PBCM, showed significant associations ($r = 0.22$, $p = 0.04$ and $r = 0.53$, $p < .001$, respectively).

Data reduction and analysis

To obtain intensity scores, the VAS markings were first converted into scores from 0 to 100 by reading off each mark against a millimeter ruler. Subsequently, VAS scores ≤ 5 millimeters were recoded to zero, because a study on the recording of the measurement of the pain intensity in interviews with children showed that those scores turned out to be 'no pain at all'.[30] To score the child's behavior due to pain the positively answered items of the PBCM were summated. To obtain an average pain intensity score, the VAS scores (and for participants aged 0-11 years also the PBCM scores) were divided by the number of VAS recordings or days in pain, respectively. Subjects with more than 25% missing values on VAS or PBCM in the diary were excluded from the analyses. The frequency of occurrence of pain was defined as the percentage of the number of recordings indicating the presence of pain divided by the total number of recordings (VAS and PBCM). For example, a pain frequency of 33% means that the pain was present in 21 (score > 5 mm) of the 63 VAS recordings, or in 7 (score > 0) of the 21 PBCM recordings.

Table 1
Outcome measures and instruments used in this study

Instrument	Reported by	Subjects	Period of recall	Items
Family demographics	Parents	Family	At present	Age, gender, nationality, position-order of child in family, family size, education level, marital status, and chronic pain in parents
Pain list	Parent or adolescents	Children and adolescents	1 month	Characteristics of pain: location, duration, course, frequency and intensity (estimated). Interference with daily activities, school absence, a medical diagnosis for the pain, comorbidity
Health care use questionnaire	Parent or adolescents	Children and adolescents	3 months, and for hospitalization 1 year	Consultation with general practitioner, specialist, physiotherapist, psychologist, social worker, and alternative health care provider, hospital admission, diagnostic tests, and medication use for pain
Functional Status II (R) Dutch version[24,25]	Parent	Children and adolescents	2 weeks	14 items assessing the impact of pain on the child's behavior, such as on eating, sleeping and mood
The Dartmouth COOP Functional Health Assessment charts / WONCA Dutch version[26]	Parent	Parent	2 weeks	6 charts concerning physical fitness, emotional feelings, social and daily activities, overall health, pain
	Adolescent	Adolescent	2 weeks	5 charts concerning physical fitness, emotional feelings, school work, social support, family
Impact on Family Scale Dutch version[27,28]	Parent	Family	At present	24 items assessing the impact of the child's pain on the family, divided in the 4 subscales 'economic burden', 'familial/social impact', 'personal strain', 'mastery'
Quality of Life Headache – Youth adapted for chronic pain[29]	Adolescent	Adolescent	1 week	69 items assessing impact of pain on day-to-day functioning in the 4 domains 'psychological functioning', 'social functioning', somatic functioning', 'functional status', and 2 visual analogue scales assessing satisfaction with life and health
Diary consisting of Visual Analogue Scales[30,31] and	Parent or adolescent	Children and adolescents	At present	Pain intensity was recorded three times daily, at breakfast, dinnertime and bedtime, during three successive weeks
Pain Behavioral Change Measure modified version of the Postoperative Pain measure for Parents[32]	Parent	Children aged 0-11 years	1 day	10 items assessing daily behavioral changes due to pain, during three successive weeks

Regarding health care use, subjects were categorized into consulters and non-consulters. Consulters were those reporting use of some form of health care; non-consulters reported no use of the health service. In this classification medication use was left out of consideration, because it was not possible to differentiate whether medication was prescribed by the physician or was over-the-counter medication. The course of chronic benign pain (CBP) was categorized into persisting and non-persisting pain. Subjects with persistent pain were those who responded thrice and reported CBP at T_0 and at T_1 and/or T_2; subjects with non-persistent pain also responded thrice but reported CBP at T_0 only.

Data were analyzed by frequencies and cross-tabulations. Differences were tested for categorical variables by chi-square tests, for ordinal variables by Mann-Whitney U (M-W) tests or Kruskall-Wallis (K-W) tests, and for continuous variables by Student's t-tests or oneway ANOVA. Linear (for ordinal and continuous variables) and logistic (for dichotomous variables) regression analyses with repeated measurements were carried out by SAS 8.0 to determine the course of pain of individual subjects. These analyses used the pain parameters, the pain-related consequences (functional status, quality of life domains, impact on family dimensions, school absence, health care use and medication use), and co-morbidity and chronic illness in the family as dependent factors and 'time' as within-subject factor. Background factors such as age and gender were used as independent factor in the case the factor yielded a significant effect in a univariate regression analysis. Additionally, we tested the interaction of 'time' with pain location, age and gender, respectively. To identify predictors of persistent pain, univariate logistic regression analyses were carried out, with persistent or non-persistent CBP at follow-up as the dependent variable and the variables which showed differences between persistent and non-persistent pain assessed at baseline as the independent variables. A *P* value of less than 0.05 was considered statistically significant.

Results

Response

Figure 1 shows the response rates and the occurrence of chronic benign pain (CBP) in the three consecutive assessments of the cohort comprising 987 children and adolescents aged 0-18 years with chronic pain (CP). An insignificant proportion of the subjects who had reported CP at T_0, T_1 and T_2 was excluded because the pain had an organic etiology. At T_0, T_1 and T_2 a total of 254/506 (50%), 150/247 (61%) and 118/255 (46%) subjects respectively, reported to have CBP.

A total of 445 subjects (45.1%) did not respond at any follow-up assessment, 255 subjects (25.8%) responded only once, 119 (12.1%) responded twice, and 168 subjects (17.0%) responded at all three assessments. Of the subjects who responded at all three assessments

39, 26, 26 and 77 subjects reported to have CBP at none of the assessments, and at 1, 2 and 3 assessments, respectively.

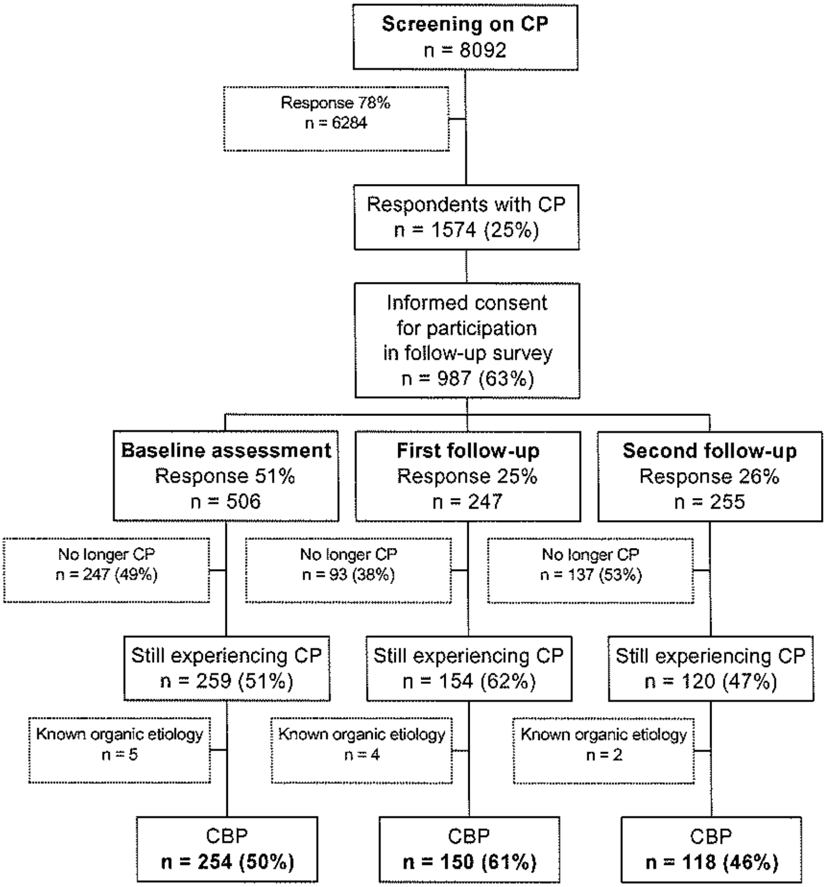

Figure 1

Flow chart of the two-year follow-up study on chronic benign pain (CBP) in children and adolescents (CP = chronic pain).

Comparability of study groups

The responders at each assessment were compared with the initial cohort (n = 987) on demographic and pain characteristics obtained at the screening on CP in order to investigate potential selection bias. In general, the responders were slightly younger than the non-responders. The results are shown in Table 2.

Table 2

Comparison between the responders and non-responders at the three follow-up assessment times on demographic and pain characteristics obtained at the screening on chronic pain

	T_0		T_1		T_2	
	Responders N = 506	Non-responders N = 481	Responders N = 247	Non-responders N = 740	Responders N = 255	Non-responders N = 732
Age						
Mean in years (SD)	9.9 (4.2)*	11.4 (4.2)	10.0 (4.3)*	10.9 (4.2)	10.1 (4.3)*	10.8 (4.2)
Gender (N, %)						
Boys	188 (37.5)	165 (34.0)	89 (36.6)	264 (35.5)	90 (35.6)	263 (35.8)
Girls	313 (62.5)	321 (66.0)	154 (63.4)	480 (64.5)	163 (64.4)	471 (64.2)
Frequency of pain last month (N, %)						
Less than once a week	181 (36.9)	164 (34.3)	92 (38.5)	253 (34.7)	83 (33.5)	262 (36.3)
At least once a week	310 (63.1)	314 (65.7)	147 (61.5)	477 (65.3)	165 (66.5)	459 (63.7)
Intensity of pain last month[a,b]						
Mean in mm on VAS (SD)	56.7 (22.7)	58.9 (24.4)	56.0 (21.6)	58.3 (24.2)	54.4 (22.2)*	58.9 (23.9)
Physician consultation ever due to pain (N, %)	320 (64.5)	292 (60.7)	159 (66.5)	453 (61.4)	151 (60.6)	461 (63.3)
Medication use ever for the pain (N, %)	208 (41.9)	199 (41.4)	116 (48.1)**	291 (39.5)	110 (44.0)	297 (40.9)

* Student's t-test and ** chi-square differences between responders and non-responders significant at $P < 0.05$.

Furthermore, we compared subjects who responded at the follow-up assessments never, once, twice, and thrice with the initial cohort on the same variables as listed in Table 2. Oneway ANOVA analysis revealed that, again, only age was found to be different (p<0.001); the mean age was 11.4 years (SD 4.2), 10.3 (SD 4.2), 9.7 (SD 4.3) and 10.0 (SD 4.3) for subjects who responded never, once, twice and thrice, respectively.

To ensure equivalence for subjects with chronic benign pain between the three assessment times, their background factors were compared, as shown in Table 3. Except for an age difference, which was expected since subjects were followed for two years, no significant differences were found between the three samples. When comparing the age obtained at the screening no significant differences were found between the three samples.

Table 3
Background factors of three samples of children suffering from chronic benign pain by time of assessment

	T_0 N = 254	T_1 N = 150	T_2 N = 118
Age of child			
Mean in years (SD)	11.1 (4.3)*	12.0 (4.3)*	13.9 (4.0)*
Gender (N, %)			
Boys	80 (31.6)	51 (34.5)	31 (26.3)
Girls	173 (68.4)	97 (65.5)	87 (73.7)
Nationality of child (N, %)			
Dutch	244 (97.2)	144 (97.3)	113 (97.3)
Non-Dutch	7 (2.8)	4 (2.7)	3 (2.6)
Birth-order of child in family (N, %)			
First-born	118 (47.6)	64 (43.5)	50 (47.6)
Later-born	130 (52.4)	83 (56.5)	55 (52.4)
Family size			
Mean number of children (SD)	2.4 (1.0)	2.4 (1.0)	2.3 (1.1)
Marital status of parents (N, %)			
Married or cohabitant	204 (85.4)	121 (87.7)	90 (85.7)
Divorced or separated	35 (14.6)	17 (12.3)	15 (14.3)
Education level of mother (N, %)†			
Low	90 (39.8)	62 (47.7)	41 (41.8)
Middle	83 (36.7)	40 (30.8)	36 (36.7)
High	53 (23.5)	28 (21.5)	21 (21.4)
Education level of father (N, %)†			
Low	49 (25.9)	33 (30.8)	25 (30.1)
Middle	79 (41.8)	35 (32.7)	38 (45.8)
High	61 (32.3)	39 (36.4)	20 (24.1)
Chronic pain in mother (N, %)‡	106 (44.5)	59 (41.8)	54 (51.9)
Chronic pain in father (N, %)‡	77 (37.6)	41 (33.3)	30 (34.5)
Co-morbidity (N, %)	23 (9.1)	11 (7.3)	8 (6.8)
Chronic illness in family (N, %)	20 (7.9)	14 (9.3)	8 (6.8)

*Significant difference between the three assessments; $P < 0.05$.

†Education level was classified based on the highest completed school level: low (primary school or lower vocational training), middle (secondary school) and high (higher vocational training and university).

‡The definition used for chronic pain in parents was identical to that used in children.

Changes over time

Of the subjects who reported CBP at baseline (*n* = 254), 49% of them (*n* = 124) still complained of CBP at 1-year follow-up and 30% (*n* = 77) at two-year follow-up.

Tables 4 and 5 show that, in general, there is little change in pain and pain-related consequences in children suffering from chronic benign pain over the two-year follow-up period. Main changes were in pain frequency and the impact on the child's behavior (FS-II), which deteriorated over time. In 35 (24%) of the 144 subjects who had reported to have CBP on at least two assessments, the pain location had switched to another location, mostly to the head. Of these 35 subjects, 14%, 39% and 56% reported to have headache at T_0, T_1 and T_2, respectively (data not shown).

The individual course of pain and its consequences was determined by regression analyses with repeated measurements. These analyses were restricted to the 144 subjects (14.6%) who had reported to have CBP on at least two assessments (44 boys and 100 girls). Of the pain variables, only the estimated pain intensity changed slightly over the follow-up period, i.e. a yearly decrease of ca. 3 mm on the VAS (95% CI 0.66-5.20). For the consequences of pain (impact of pain, health status, school absence, health care use and medication use) there was little change over time. The impact of pain on the child's behavior and the social functioning deteriorated with a 6.22 (95% CI 4.87-7.57) decrease of the score on the FS-II and a 0.09 (95% CI 0.03-0.15) decrease on the QLH-Y yearly, respectively. These results were not modified after adjustment for the pain location. The impact on the family (assessed with the IFS) remained stable, but when testing the interaction for pain location we found that, compared to the other pain types, for subjects with abdominal pain the total impact (score ↓ 2.6 yearly, 95% CI 1.23-3.97) and personal strain (score ↓ 1.0 yearly, 95% CI 0.45-1.65) diminished, and that families of subjects with limb pain were less able to master the stress of pain (score ↑ 0.7 yearly, 95% CI 0.11-1.29). Health care use (consulter versus non-consulter) diminished considerably during the follow-up period (T_0: OR 1.93, 95% CI 1.42-2.66; T_1: OR 1.48, 95% CI 1.04-2.12; T_2: OR 1.00). The course of pain over two years did not differ between boys and girls, or between different ages (age analyzed as a continuous variable).

Predictors for persistent chronic benign pain

At baseline there were a few differences for pain, its consequences and background factors between subjects with persistent pain (*n* = 93, 9.4%) and non-persistent pain (*n* = 16, 1.6%). Compared to subjects with non-persistent pain, those with persistent pain had at baseline more frequent pain in the diary period (mean 52.8% (SD 34.0) versus 32.6% (SD 30.5); p=0.039), a longer pain history (mean 3.3 years (SD 2.5) versus 2.0 years (SD 1.9); p=0.028), more often headache and less often limb pain (31.1% and 24.4% versus 6.3% and 56.3%; χ^2=9.76, df=4, p=0.045), were more bothered by emotional problems (COOP

WONCA mean score 2.6 (SD 1.0) versus 1.5 (SD 0.8); p=0.006), and their mothers rated their own health in general lower (COOP WONCA mean score 2.5 (SD 1.0) versus 1.9 (SD 1.2); p=0.022). By univariate logistic regression analyses, emotional problems of subjects (OR 4.23, 95% CI 1.35-12.50), their mother's self-reported health in general (OR 1.92, 95% CI 1.08-3.33), and pain frequency (≥ 50% pain in diary versus < 50%; OR 3.74, 95% CI 1.01-14.16) were identified as predictors of persistent CBP. Multivariate regression analysis with these factors determined emotional problems to be the only predictor which classified the pain status correctly at follow-up in 86% of the subjects.

Table 4

Changes in pain and pain-related consequences in children suffering from chronic benign pain over the two-year follow-up period

	T_0 N = 254	T_1 N = 150	T_2 N = 118
Location of pain (N, %)[a]			
Limb	71 (29.2)	31 (21.7)	26 (23.0)
Head	65 (26.7)	53 (37.1)	43 (38.1)
Abdomen	61 (25.1)	30 (21.0)	25 (22.1)
Back	20 (8.2)	14 (9.8)	14 (12.4)
Other	26 (10.7)	15 (10.5)	5 (4.4)
Course of pain (N, %)[a]			
Continuous	41 (16.1)	20 (13.3)	27 (22.9)
Recurrent	213 (83.9)	130 (86.7)	91 (77.1)
Duration of pain[a]			
Mean in years (SD)	3.1 (2.7)*	3.7 (2.7)*	4.3 (2.6)*
Frequency of pain previous month[a]			
Less than once a week	73 (29.7)	56 (38.1)	30 (26.8)
At least once a week	173 (70.3)	91 (61.9)	82 (73.2)
Frequency of pain in diary period			
Mean of % in pain on VAS (SD)	49.8 (34.1)*	52.4 (34.9)*	61.8 (34.7)*
Mean of % in pain on PBCM (SD)	24.2 (22.0)	26.1 (23.4)	22.9 (24.7)
Intensity of pain in previous month[a,b]			
Mean in millimeters on VAS (SD)	50.2 (20.3)*	44.5 (23.0)*	48.5 (21.5)*
Intensity of pain in diary period			
Mean in millimeters on VAS (SD)[b]	30.7 (15.1)	30.4 (13.1)	32.1 (14.6)
Mean of PBCM score (SD)[c]	3.1 (1.6)	3.1 (1.7)	2.7 (1.3)
Interference with daily activities[a,b]			
Mean in millimeters on VAS (SD)	32.6 (28.0)	28.3 (25.3)	34.4 (24.7)
School absence due to pain[a]			
Mean in days per month (SD)	1.0 (3.1)	1.4 (3.8)	1.0 (2.1)
Health care use due to pain (N, %)	109 (42.9)	59 (39.3)	42 (35.6)
Medication use for pain	117 (46.6)	65 (43.9)	51 (44.7)

*Significant difference between the three assessments; $P < 0.05$.

[a] Items of the Pain List.

[b] Intensity of the pain and interference with daily activities were assessed using the Visual Analogue Scale, a 100-mm long line with the verbal anchors 'no pain' versus 'the worst pain you can imagine' or 'no nuisance' versus 'unable to do daily activities', respectively, at both sides.

[c] The score of the Pain Behavioral Change Measure (PBCM) ranges from 0 (no changes) to 10 (maximum number of changes).

Table 5

Changes in health status and impact of pain on the child and family in children suffering from chronic benign pain over the two-year follow-up period. Mean scores (SD) of the different measures are presented.

	T_0 N = 254	T_1 N = 150	T_2 N = 118
Functional Status II[1,a]	80.5 (12.3)*	77.5 (16.2)*	67.7 (8.2)*
Impact on Family Scale[1,b]			
Economic impact	5.4 (2.2)	5.0 (1.8)	5.0 (1.7)
Familial/social impact	12.2 (4.0)	11.9 (3.5)	11.5 (3.1)
Personal strain	8.8 (3.4)	8.6 (2.9)	8.8 (4.0)
Mastery	13.2 (3.6)	13.0 (3.3)	13.2 (3.1)
Total	39.7 (7.3)	38.2 (6.9)	38.7 (6.7)
Coop Wonca parents[1,c]			
Physical fitness	2.3 (1.0)	2.1 (0.9)	2.4 (0.9)
Emotional feelings	2.1 (1.0)	1.9 (0.9)	1.9 (0.9)
Daily activities	1.8 (1.0)	1.8 (0.8)	1.9 (0.9)
Social activities	1.4 (0.9)	1.4 (0.8)	1.4 (0.8)
Overall health	2.5 (1.0)	2.5 (1.1)	2.5 (1.1)
Pain	2.4 (1.0)	2.3 (1.0)	2.3 (1.0)
Coop Wonca adolescents[2,c]			
Physical fitness	2.2 (1.0)	2.2 (1.0)	2.3 (1.1)
Emotional feelings	2.4 (1.0)	2.5 (1.0)	2.7 (1.0)
School work	2.2 (1.0)	2.1 (1.1)	2.3 (1.0)
Social support	1.7 (0.9)	1.7 (0.9)	1.8 (1.0)
Family	3.2 (1.1)	3.0 (1.3)	3.0 (1.1)
Quality of Life – Youth[2,d]			
Psychological functioning	1.5 (0.2)	1.5 (0.2)	1.5 (0.2)
Social functioning	1.6 (0.4)	1.6 (0.4)	1.5 (0.5)
Somatic functioning	2.2 (0.5)	2.2 (0.6)	2.3 (0.6)
Functional status	2.4 (0.5)	2.5 (0.5)	2.4 (0.5)
Satisfaction with life in general	62.2 (24.2)	66.0 (25.4)	64.6 (21.8)
Satisfaction with health	56.5 (24.8)	54.9 (26.8)	52.6 (27.1)

*Significant difference between the three assessments; $P < 0.05$.

[1] Measures used in all subjects.

[2] Measures only used in adolescents aged 12-18 years.

[a] The score ranges from 0 (total impairment) to 100 (no impairment).

[b] Score ranges differ for the four subscales and the total score on the IFS ('financial impact' 4-16; 'social impact' 9-36; 'personal strain' 6-24; 'mastery' 5-20; total score 24-96). The higher the scores on the first three subscales, the higher the psychosocial impact, and the higher the score on the fourth subscale 'mastery', the less coping strategies were employed by their families to master the stress of pain, implying that a high total score represents a high impact of pain on the family.

[c] The higher the scores (range 1-5), the less favorable the level of functional status.

[d] The higher the scores on the four domains (range 0-3), the better the self-reported quality of life. The scores for satisfaction with life in general/health range from 0 (extremely dissatisfied) to 100 (completely satisfied).

Discussion

The present study shows that chronic benign pain is common in children and adolescents in the general population and that about one-third of those who had chronic benign pain at baseline still had this pain at two-year follow-up. Assuming all those lost to follow-up would still report pain as a problem, the adjusted proportion of sufferers with persistent pain would be 45%. This worst-case scenario is not to be expected since our previous non-response survey among the non-reponders at the baseline assessment indicated that one-third of them did not respond because they no longer experienced pain.[33] Nevertheless, we found a high spontaneous remission in 55-70% of children and adolescents with chronic benign pain over two years. This corresponds well with the 48% remission of musculoskeletal pain in schoolchildren at 1-year follow-up reported by Mikkelsson et al..[22] That same study showed remission rates of 38% and 42% for widespread pain and neck pain at 1-year follow-up.[34]

In the present study, girls were twice as much likely to have CBP, and at follow-up this gender difference was still present. Overall, at baseline these children had rather mild intense, but frequent pain, and were not severely disabled by the pain. Although these pains were benign and present for several years (about 3 years), a considerable proportion of the children had used some form of health care service or used medication for the pain in the prior 3 months. In general, the pain characteristics and the pain-related consequences remained relatively stable over the two-year follow-up, as was assessed in the subsample of subjects who reported CBP on at least two assessments. Yet, the chronic benign pain sufferers deteriorated in their behavior and social functioning, but reduced their use of health care services. This partly corresponds with a Canadian longitudinal survey on persistent pain in adults which showed that pain and its consequences remained stable over two years, except for the emotional and social consequences, and the health care use.[8] However, contrary to our results, they found an improvement in the emotional and social consequences. We found that, through follow-up, a considerable proportion of the subjects changed pain location, which was mostly the head. However, there was no relation between the location of pain and the course of the behavior and social functioning that could have explained this deterioration.

Children with persistent pain over two years differed in some ways from those who did not report CBP at follow-up, but only emotional problems, their mother's self-reported health in general, and the pain frequency were identified as prognostic factors. Since the prognostic factor 'emotional problems' was operationalized by only one question on the COOP WONCA Charts and restricted to adolescents, it is therefore less reliable. However, a previous study found that, at follow-up, chronic pain patients attending a specialty clinic were still more distressed than those in the family practice, suggesting that emotional factors are probably among the most important factors in the chronic morbidity of these patients.[8] Contrary to the findings of Crook et al., we found a longer pain duration at baseline for children with persistent pain than for those who had no CBP at follow-up. However, logistic regression analysis revealed that this is not a good predictor of the two-year prognosis.

Several limitations of our study should be discussed. First, selection bias introduced by non-participation is a potential limitation to be considered. However, the small and predominantly insignificant differences in demographics, pain characteristics, physician consultation and medication use as assessed in the previous prevalence study,[3,7] between the responders at each assessment and the initial cohort, suggest that the selection bias is small. The nonsignificant differences in background factors (except for age, which was expected since we followed up subjects for two years) between responders at the three assessments, confirmed this opinion. Another drawback is use of parent ratings versus self-report. Because pain is subjective, self-report should be the 'gold standard' for pain assessment.[35] We used parent ratings for subjects aged 0-11 years because this is the best proxy measure available in young children, particularly in longer lasting pain.[36,37] Bias due to the different way of obtaining data is unlikely, since we determined the individual course of pain and its consequences by adjusting for age and gender.

The implications are that chronic benign pain in childhood and adolescence is common, and seems to persist in a considerable proportion (30%-45%). Emotional problems, mother's health, and pain frequency were identified as predictors of the two-year prognosis. Although children were not severely disabled by the pain and the pain generally did not deteriorate over time, the size of the group of children with chronic pain makes it sensible to investigate possibilities to prevent pain from becoming chronic. Future studies should focus on identifying risk factors for pain becoming chronic in children and adolescents.

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6

A comparative study of children and adolescents with chronic pain in a children's hospital and in the open population

Abstract

We investigated the clinical and demographic differences between patients referred for chronic pain (hospital sample) and a population sample of chronic pain sufferers aged 0-18 years. The hospital sample included new patients referred to a children's hospital because of chronic pain. The population sample was identified in a previously conducted prevalence study. Subjects of both samples, all with chronic pain (> 3 months), kept a 3-week diary on their pain and filled out questionnaires on background factors, medication use and (impact of) pain.

Significant differences between the hospital sample (*n* = 68) and the population sample (*n* = 254) were found for age, location and duration of pain, school absenteeism, occurrence of chronic pain in their mothers, parental education level, and functional status of subjects and parents. Although statistically significant, the impact on the family was only slightly higher for the hospital sample.

The results of this study suggest that not pain severity and quality of life of the child, but background factors seem to play an important role in consulting a specialist.

Introduction

Chronic pain is a frequent complaint in childhood and adolescence.[1] In a representative Dutch population sample of children aged 0 to 18 years (*n* = 5,424), we recently reported the three-month prevalence rate of chronic pain (> 3 months) to be 25%. Headache, abdominal pain and limb pain were the most frequently reported, particularly in older children and in girls.[2] In the adult population of the United States and many other industrialized nations chronic pain is recognized to be the most frequent cause of disability today, causing significant costs to society in both work hours lost and medical expenses.[3,4]

As in adults, chronic pain in children is often associated with a burden for the children themselves, but also for their families.[5-7] However, little is known about the relationship between pain and use of medical services. Perquin et al. (2000) studied this relationship and showed that 57% of the chronic pain sufferers aged 0-18 years in the community ever had consulted a physician and 39% ever had used medication for their pain.[8] A Finnish population study on the use of health care services in childhood migraine revealed that consultation of a physician, which was mostly a specialist, was related to the severity of complaints, school absence, and co-morbidity.[9] Only a few clinical studies have documented on chronic pain in childhood and adolescence. Rang et al. (1970) assessed the two-year hospital incidence of unexplained abdominal pain causing admission to hospital and found an incidence rate of 9% for boys and 16% for girls for the age group 10-19 years.[10]

The purpose of the present study was to identify factors that differentiate children and adolescents who were referred to a children's hospital because of chronic pain from chronic pain sufferers in the community. This examination and comparison of a hospital sample and a population sample of chronic pain sufferers may help to clarify the referral process and thereby contribute useful information for treatment strategies. We defined chronic benign pain as continuous or recurrent pain with unknown organic etiology existing for three months or longer. In order to obtain a comprehensive picture on chronic pain, we did not restrict ourselves to subgroups based on severity of pain or disability as was the case in other studies on chronic pain.[11]

The following study questions were addressed: (1) Are there differences in sociodemographic factors, pain characteristics, school absenteeism, and medication use between the hospital sample and the population sample? (2) Do these samples differ in health status, quality of life and the impact of chronic pain on the family?

Table 1

Outcome measures and instruments used in this study

Instrument	Reported by	Subjects	Period of recall	Items
Family demographics	Parents	Family	At present	Age, gender, nationality, position-order of child in family, family size, education level, marital status, and chronic pain in parents
Pain list	Parent or adolescents	Children and adolescents	1 month	Characteristics of pain: location, duration, course, frequency and intensity (estimated). Interference with daily activities, school absence, a medical diagnosis for the pain, comorbidity
Health care use questionnaire	Parent or adolescents	Children and adolescents	3 months, and for hospitalization 1 year	Consultation with general practitioner, specialist, physiotherapist, psychologist, social worker, and alternative health care provider, hospital admission, diagnostic tests, and medication use for pain
Functional Status II (R) Dutch version[24,25]	Parent	Children and adolescents	2 weeks	14 items assessing the impact of pain on the child's behavior, such as on eating, sleeping and mood
The Dartmouth COOP Functional Health Assessment charts / WONCA Dutch version[26]	Parent	Parent	2 weeks	6 charts concerning physical fitness, emotional feelings, social and daily activities, overall health, pain
	Adolescent	Adolescent	2 weeks	5 charts concerning physical fitness, emotional feelings, school work, social support, family
Impact on Family Scale Dutch version[27,28]	Parent	Family	At present	24 items assessing the impact of the child's pain on the family, divided in the 4 subscales 'economic burden', 'familial/social impact', 'personal strain', 'mastery'
Quality of Life Headache – Youth adapted for chronic pain[29]	Adolescent	Adolescent	1 week	69 items assessing impact of pain on day-to-day functioning in the 4 domains 'psychological functioning', 'social functioning', somatic functioning', 'functional status', and 2 visual analogue scales assessing satisfaction with life and health
Diary consisting of Visual Analogue Scales[30,31] and	Parent or adolescent	Children and adolescents	At present	Pain intensity was recorded three times daily, at breakfast, dinnertime and bedtime, during three successive weeks
Pain Behavioral Change Measure modified version of the Postoperative Pain measure for Parents[32]	Parent	Children aged 0-11 years	1 day	10 items assessing daily behavioral changes due to pain, during three successive weeks

Methods

Population sample

This prospective study was approved by the ethics committee of the Erasmus University. In a previous study (1996) that assessed the prevalence of chronic pain, we obtained a representative population sample of 6,636 children and adolescents aged 0 to 18 years in the Rotterdam area.[2] Additionally, a second random population sample (*n* = 1,456, 0-18 years) was obtained from the records of 11 general practices. Overall, 6,282 questionnaires on pain (response 78%) were completed. For the present study, we approached subjects who reported pain existing for more than 3 months and agreed to participate in a diary study (*n* = 988). This study started about 6 months after the screening on chronic pain.

Hospital sample

A hospital sample was obtained by recruiting retrospectively all new patients who, between January 1, 1996, and June 30, 1997, were referred to the outpatient clinics of general pediatrics and neurology or had been hospitalized in the Sophia Children's Hospital in Rotterdam, the Netherlands, for chronic pain (*n* = 394). The same procedure as in the population sample (see above) was used in this group: after subjects filled out the questionnaire on pain to confirm whether pain was still persisting (response 50%) and agreed to participate in a diary study, they were approached for the present study (*n* = 109), which on average started 1.9 years after the referral date. The Sophia Children's Hospital provides secondary care in the region and serves nationwide as a tertiary referral hospital. At the outpatient clinic, there are approximately 17,000 new visits a year with a slight preponderance of boys (56% boys and 44% girls) and a mean and median age of 5.1 and 4.0 years (SD 4.6). The departments of general pediatrics, which delivers mainly routine pediatric care, and neurology account for 35% and 5% of these contacts, respectively. The average age at these departments is 4.4 years (median 3.0, SD 4.4). In the Dutch health care system outpatient hospital care and hospital admission require referral by a general practitioner.

Written informed consent was obtained from one of the parents and from subjects aged 12 years and over.

Outcome measures and instruments

Table 1 gives an overview of the outcome measures and instruments used in this study. The structured pain list was partly based on the questionnaire used in our previous prevalence study and comprised questions on location, frequency, intensity and duration of the pain.[2] Additional questions concerned disability due to pain and co-morbidity of chronic diseases. To confirm that the pain did not have an organic etiology we asked whether a physician had made a medical diagnosis for the pain. Subjects with pain resulting from specific chronic diseases (e.g., rheumatic arthritis, malignancies) were excluded. The conditional part of the Functional Status II (R) (FSII) [12,13], asking whether the child's behavior could be attributed to the pain, was omitted because a pilot study revealed that in the written form this part caused comprehension problems when it was self-administered. The questionnaires used have shown acceptable reliability and validity.

The diary consisted of Visual Analogue Scales (VAS) [18,19] and, for subjects aged 0-11 years also the Pain Behavioral Change Measure (PBCM), to obtain the intensity and frequency of pain. All subjects were asked to record pain intensity by VAS three times daily, during three successive weeks. In addition, parents of subjects aged 0-11 years completed the PBCM, a modified version of the Postoperative Pain Measure for Parents[20], at the end of each day; the list was adapted for chronic pain and therefore shortened from 29 to 10 items. For subjects aged 0-11 years, the intensity and frequency of the pain, assessed by VAS and PBCM, showed significant associations ($r = .22$, $p = .04$ and $r = .53$, $p < .001$, respectively).

Procedure

For subjects aged 0-11 years (population sample, $n = 513$; hospital sample, $n = 86$) a pain booklet and a self-addressed envelope were sent by mail to parents (or primary caregivers). They were first invited to answer the questionnaires and then to keep the diary to report their child's pain characteristics and behavioral consequences of the pain for three successive weeks. Subjects aged 12-18 years (population sample, $n = 475$; hospital sample, $n = 23$) and their parents were each sent a pain booklet. The adolescents were first invited to answer the questionnaires and then to keep the diary to register pain intensities on their own. Their parents were also asked to fill out some questionnaires.

In case the child did not experience pain during the previous three months, only demographic data and a possible reason why the pain had ceased were requested. Subjects who had previously reported more than one location of pain were asked to report only on the pain that troubled them most. Subjects also received a calendar chart as an aide-mémoire.

Non-response

To detect whether non-response bias in the population sample occurred we conducted a telephone survey among the non-responders ($n = 481$). All interviews were carried out by one research fellow, using a structured questionnaire. The participants or their parents were firstly questioned about the reason for not responding. Then we asked: "Do you/does your child still experience pain?" If the answer was "yes", additional information was requested concerning the location, duration, course, frequency and intensity of the pain. Questions were also asked about interference with daily activities, school absence due to pain, utilization of health care services, medication use, a medical diagnosis for pain and co-morbidity of chronic diseases. Most questions were open-ended, except for those about the intensity of pain and interference with daily activities. The subjects or their parents could give scores ranging from 0 to 10; the higher the score the less favorable. The period of recall used was the previous month as the questionnaires used in the present study.

Data reduction and analysis

To obtain intensity scores, the VAS markings were first converted into scores from 0 to 100 by reading off each mark against a millimeter ruler. Subsequently, VAS scores ≤ 5 millimeters were recoded to zero, because previous data showed that a VAS score ≤ 5 millimeters indicated the absence of pain.[19] To score the child's behavior due to pain the positively answered items of the PBCM were summated. To obtain an average pain intensity score, the VAS scores (and for participants aged 0-11 years also the PBCM scores) were divided by the number of VAS recordings or days in pain, respectively. Subjects with more than 25% missing values on VAS or PBCM in the diary were excluded from the analyses. Frequency of pain was operationalized as the proportion of recordings of pain (VAS and PBCM).

Data were analyzed by frequencies and cross-tabulations. Differences were tested for categorical variables by chi-square tests, for ordinal variables by Mann-Whitney U (M-W) tests or Kruskall-Wallis (K-W) tests, and for continuous variables by Student's t-tests. Univariate and multivariate logistic regression analysis were carried out to test the effect of the assessed factors (demographics, pain characteristics and impact of pain) on the dependent variable 'referred to a children's hospital for chronic pain' (yes = hospital sample; no = population sample). A *P* value of less than 0.05 was considered statistically significant.

Results

Response

Five hundred seven participants (51%) of the population sample returned the pain booklet; of these, 248 reported that the pain had ceased during the previous three months, and 259 still suffered from chronic pain. Of the hospital sample 80 participants (73%) returned the pain booklet. The majority of them ($n = 69$) still suffered from chronic pain.

Five subjects of the population sample and one subject of the clinical sample were excluded on account of a diagnosed chronic disease related with chronic pain, leaving a population sample of 254 participants and a hospital sample of 68 participants.

Non-response

Of the population sample, 213 non-responders were interviewed. The remainder could not be contacted due to relocation or lack of a telephone number. One-third of the interviewed non-responders stated that the pain had ceased and about a quarter had not responded for lack of motivation; the remainder had not responded for various reasons including moving house, etc. In total, 85 of the interviewed non-responders (40%) still suffered from the same pain, which was mostly located in the limbs (37%), head (27%), abdomen (23%) or back (10%). In 65% of them pain was experienced weekly, and in 10% the pain was continuous. The mean pain intensity and the mean of interference with daily activities was 6.8 (SD 2.9) and 5.3 (SD 2.9), respectively. Because of pain, 13 non-responders missed one or two schooldays monthly. No medical diagnosis for the pain or co-morbidity was reported.

Compared with the data of the previous prevalence study, in which 988 children and adolescents in the population had reported chronic pain and were willing to participate in the present study, the present population sample (responders, *n* = 254) had somewhat higher frequencies of pain (68% had weekly pain versus 60% in the non-responders; M-W, Z=2.28, p=.023), consulted a physician more often (70% versus 58% in the non-responders; M-W, Z=3.40, p=.001) and used medication more often (48% versus 40% in the non-responders; M-W, Z=2.16, p=.030) than non-responders (*n* = 734).[2] There were no significant differences for age, gender and pain intensity between responders and non-responders.

Demographic differences

The main characteristics of the population and hospital sample are reported in table 2. The average age of subjects was significantly lower in the hospital sample (8.9 years, SD 3.3) than in the population sample (11.1 years, SD 4.3). In the hospital sample the parental education level was lower and their mothers reported more often chronic pain than in the population sample. In logistic regression analyses using parental education level and occurrence of chronic pain in mother as independent variables and 'referred to a children's hospital' as dependent variable, these differences were not modified after adjustment for age.

Clinical differences

Table 3 gives the retrospectively and prospectively measured characteristics of pain of the study samples. The severity of pain, assessed by frequency and intensity of the pain, and interference with daily activities due to pain, were similar. The location and duration of pain did differ for both groups; the hospital sample comprised mainly of subjects with abdominal pain and headache, whereas limb pain and back pain were hardly represented or not at all, and the duration of pain was approximately 1.4 years longer. After adjustment for age and duration of the pain by logistic regression analysis, we found an increase of the proportion of headache compared to the other pain conditions for referral to a children's hospital (headache, univariate OR: 3.87; 95% CI: 1.08-13.81 and multivariate OR:7.88; 95% CI: 1.93-32.24). In a logistic regression analysis the course of the pain, adjusted for age, also yielded a significant difference between the samples; children with continuous pain compared with recurrent pain had an increased risk for referral to a children's hospital (continuous pain; univariate OR: 1.47; 95% CI: 0.76-2.85 and multivariate OR: 2.38; 95% CI: 1.16-4.92). The difference in pain duration was not modified in a multivariate analysis using age and pain location as independent variables.

Co-morbidity of chronic diseases was reported infrequently in both groups (13.4% of hospital sample and 9.1% of population sample), with asthmatic complaints as the most frequently reported (7.4% of hospital sample and 5.9% of population sample). The hospital sample reported significantly more often use of medication for the pain than the population sample (69% versus 53%; χ^2=5.39, df=1, p=.020), but after adjustment for the location of pain by a logistic regression analysis this difference disappeared.

Table2

Differences in background factors between children and adolescents who were referred to a children's hospital for chronic benign pain and a population sample of chronic pain sufferers aged 0-18 years

	Hospital N = 68	**Population** N = 254	P
Age of child			
Mean in years (SD)	8.9 (3.3)	11.1 (4.3)	< .001
Median in years	9.0	12.0	
Gender (N, %)			
Boys	28 (41.2)	80 (31.6)	.139
Girls	40 (58.8)	173 (68.4)	
Nationality of child (N, %)			
Dutch	66 (98.5)	244 (97.2)	.547
Non-Dutch	1 (1.5)	7 (2.8)	
Position-order of child in family (N, %)			
First-born	18 (54.5)	118 (47.4)	.440
Later-born	15 (45.5)	131 (52.6)	
Family size			
Mean of number of children (SD)	2.4 (1.1)	2.4 (1.0)	.832
Marital status of parents (N, %)			
Married or cohabitant	52 (81.3)	204 (85.4)	.420
Divorced or separated	12 (18.8)	35 (14.6)	
Education level* of mother (N, %)			
Low	39 (66.1)	91 (40.3)	.002
Middle	11 (18.6)	82 (36.3)	
High	9 (15.3)	53 (23.5)	
Education level* of father (N, %)			
Low	25 (53.2)	49 (25.9)	.001
Middle	15 (31.9)	79 (41.8)	
High	7 (14.9)	61 (32.3)	
Chronic pain in mother (N, %)**	42 (65.6)	106 (44.5)	.003
Chronic pain in father (N, %)**	19 (35.8)	77 (37.6)	.818

*Education level was classified based on the highest completed school level: low (primary school or lower vocational training), middle (secondary school) and high (higher vocational training and university).

**The definition we used for chronic pain in parents was identical to that in children.

Table 3

Differences in pain characteristics and direct consequences of pain between children and adolescents who were referred to a children's hospital for chronic benign pain and a population sample of chronic pain sufferers aged 0-18 years

	Hospital N = 68	**Population** N = 254	P
Location of pain (N, %)[a,c]			
Limb	4 (6.0)	71 (29.2)	<.001
Head	29 (43.3)	65 (26.7)	
Abdomen	31 (46.3)	61 (25.1)	
Back		20 (8.2)	
Other	3 (4.5)	26 (10.7)	
Duration of pain[a]			
Mean in years (SD)	4.5 (2.7)	3.1 (2.7)	<.001
Course of pain (N, %)[a]			
Continuous	15 (22.1)	41 (16.1)	.253
Recurrent	53 (77.9)	213 (83.9)	
Frequency of pain in previous month[a]			
Less than once a week	19 (28.8)	74 (30.2)	.801
At least once a week	47 (71.2)	171 (69.8)	
Frequency of pain in diary period			
Mean of % in pain on VAS (SD)	46.0 (32.6)	49.5 (34.2)	.422
Mean of % in pain on PBCM (SD)	30.5 (28.7)	22.5 (22.1)	.073
Intensity of pain in previous month[a,b]			
Mean in millimeters on VAS (SD)	52.7 (21.5)	50.2 (20.3)	.376
Intensity of pain in diary period			
Mean in millimeters on VAS (SD)[b]	32.8 (16.2)	30.6 (15.0)	.321
Mean of PBCM score (SD)[d]	2.9 (1.5)	3.1 (1.6)	.654
Interference with daily activities[a,b]			
Mean in millimeters on VAS (SD)	38.1 (26.1)	32.6 (28.0)	.149
School absence due to pain (N, %)[a]	25 (38.5)	60 (25.2)	.035
Mean in days per month (SD)	3.8 (3.8)	4.1 (5.1)	.814

[a] Items of the Pain List.
[b] Intensity of the pain and interference with daily activities were assessed by using the Visual Analogue Scale, a hundred millimeters long line with the verbal anchors 'no pain' versus 'the worst pain you can imagine' or 'no nuisance' versus 'unable to do daily activities', respectively, at both sides.
[c] The analyses for the location of pain used the sum of all other locations as reference category.
[d] The score of the Pain Behavioral Change Measure (PBCM) ranges from 0 (no changes) to 10 (maximum number of changes).

Differences in impact of pain on the child and the family

Table 4 shows the impact of chronic pain on the sufferers, their parents and the family for the population sample and the hospital sample. The health status of subjects of the hospital sample as assessed by the Functional Status II was significantly worse than for the population sample. The same picture was seen for the functional status of the parents, concerning their daily activities, social activities and overall health. The impact on the family was signifi-

Table 4

Differences in health status and impact of chronic pain on the child and family in children and adolescents who were referred to a children's hospital for chronic benign pain and a population sample of chronic pain sufferers aged 0-18 years

	Hospital N = 68 mean (SD)	Population N = 254 mean (SD)	P
Functional Status II[1,a]	75.7 (15.9)	80.5 (12.8)	.012
Impact on Family Scale[1,b]			
Economic impact	5.8 (2.3)	5.4 (2.2)	.132
Familial/social impact	13.9 (4.7)	12.2 (4.0)	.005
Personal strain	10.4 (3.8)	8.8 (3.4)	.002
Mastery	12.3 (3.0)	13.3 (3.7)	.028
Total	42.5 (8.8)	39.8 (7.3)	.029
Coop Wonca parents[1,c]			
Physical fitness	2.4 (1.1)	2.3 (1.0)	.327
Emotional feelings	2.3 (1.1)	2.1 (1.0)	.063
Daily activities	2.2 (1.1)	1.8 (1.0)	.008
Social activities	1.7 (1.0)	1.4 (0.9)	.023
Overall health	3.0 (1.1)	2.5 (1.0)	.001
Pain	2.6 (1.1)	2.4 (1.0)	.225
Coop Wonca adolescents[2,c]			
Physical fitness	1.7 (0.9)	2.2 (1.0)	.064
Emotional feelings	2.4 (1.3)	2.4 (1.0)	.813
School work	1.9 (1.0)	2.2 (1.0)	.284
Social support	1.8 (1.0)	1.7 (0.9)	.931
Family	2.9 (1.3)	3.2 (1.1)	.444
Quality of Life – Youth[2,d]			
Psychological functioning	1.6 (0.2)	1.5 (0.2)	.619
Social functioning	1.5 (0.4)	1.6 (0.4)	.447
Somatic functioning	2.3 (0.4)	2.2 (0.5)	.628
Functional status	2.3 (0.7)	2.4 (0.5)	.839
Satisfaction with life in general	75.7 (19.9)	62.2 (24.2)	.040
Satisfaction with health	52.5 (27.7)	56.5 (24.8)	.533

[1] Measures used in all subjects.

[2] Measures only used in adolescents aged 12-18 years (17 of the clinical sample and 131 of the population sample).

[a] The score ranges from 0 (total impairment) to 100 (no impairment).

[b] Score ranges differ for the four subscales and the total score on the IFS ('financial impact' 4-16; 'social impact' 9-36; 'personal strain' 6-24; 'mastery' 5-20; total score 24-96). The higher the scores of the first three subscales, the higher the psychosocial impact, and the higher the score of the fourth subscale 'mastery', the less coping strategies were employed by their families to master the stress of pain, implying that a high total score represents a high impact of pain on the family.

[c] The higher the scores (range 1-5), the less favorable the level of functional status.

[d] The higher the scores of the four domains (range 0-3), the better the self-reported quality of life. The scores for satisfaction with life in general/health range from 0 (extremely dissatisfied) to 100 (completely satisfied).

cantly higher for the hospital sample, but their families could master the pain better than in the population sample. Adolescents of the hospital sample were more satisfied with life in general than the population sample. However, after adjusting for location and duration of pain by logistic regression analysis the differences in children's functional status and impact on the family disappeared or diminished. The hospital sample still reported a somewhat higher social and personal strain, but differences in coping with the pain disappeared. Differences in parental functional status disappeared after adjustment for parental education level and occurrence of chronic pain in the mother.

Discussion

To our knowledge this is the first study that describes the differences between children and adolescents with chronic benign pain who were referred to a children's hospital and those in the community. We found that, compared to chronic pain sufferers in the community, those who were referred to a children's hospital were younger and had more often headache and abdominal pain, had pain for a longer period, had parents with a lower education level and mothers who had more often chronic pain. Furthermore, we observed moderate differences for health status of subjects and their parents, and the impact of pain on the child and family, but except for the slightly higher social impact and personal strain in the hospital sample, these differences disappeared in multivariate analyses. Surprisingly, adolescents of the hospital sample were more satisfied with life compared with the population sample.

To interpret these results a few remarks have to be made. First, it is possible that the quality of life of the hospital sample is more poor than our data suggest because the diary assessment took place almost two years after the referral date, so that the quality of life could have been improved as a result of the hospital visit. To exclude a possible positive effect of the hospital visit on the quality of life another, prospective, study design would be needed to test this hypothesis. Obviously, this is also applicable to the child's health status. Secondly, the length of time between the identification of subjects with chronic pain (referral or screening), and the diary assessment differed for both samples. This was approximately 1.3 years longer for the hospital sample compared to the population sample, which presumably accounts for the longer pain duration in the hospital sample. Thirdly, differences in age of subjects and location of pain, which could have had an effect on the other factors we assessed, could be the result of the way we obtained the hospital sample. The recruitment of patients of the departments of general pediatrics and neurology only probably accounts for the under-representation of limb pain and back pain in the hospital sample. Further, younger children are being referred to the department of general pediatrics compared with the overall outpatient clinic population (mean age is 4.1 versus 5.1 years), which might partly explain the differences for age. However, other studies have also reported that young children visit more often a physician than older children.[8,21] By multivariate logistic regression analyses we have attempted to adjust for this influence of age and location of pain.

Lastly, selection bias introduced by nonparticipation is a potential limitation which must be considered. Our telephone survey among 213 non-responders however did not show significant differences in pain severity between these non-responders and the present population sample, suggesting the selection bias to be small. The relatively small differences in demographics, pain characteristics, physician consultation and medication use, as assessed in the previous prevalence study, between the present population sample and the non-responders, support this interpretation.[2,8]

Despite indications in the literature we found no differences between the two samples for birth order, nationality and marital status of the parents.[22,23] Although not significant, more boys were referred to hospital than girls, which is in agreement with earlier studies.[24]

An unresolved question is the problem of causality. There is, for example, insufficient evidence to support the hypothesis that a high impact of pain on the child and the family affects utilization behavior due to pain. Other sociodemographic, psychological and social factors may also play a role.[25,26] Prospective studies on the determinants of chronic pain and medical help-seeking behavior are therefore needed.

In conclusion, pain severity and the impact of pain on the child and his family appeared to be similar for a hospital sample and population sample of chronic pain sufferers. This finding suggests that background factors like parental socioeconomic status and having a mother with chronic pain play a more important role in referral to a children's hospital for chronic pain than clinical characteristics. This corresponds with a Dutch study in which the morbidity of the parents, in particular the mother, appeared to be the most important factor related to health service use by children.[22] Education and advice for children and their parents how to cope with pain remains important in the management of pain by physicians.

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Comparison between children and adolescents with and without chronic benign pain: consultation rate and pain characteristics

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Abstract

Chronic pain is a common experience in childhood and adolescence. Although not based on evidence, many healthcare providers consider chronic pain sufferers as extensive healthcare users. The aim of the present study was to determine whether children and adolescents with chronic benign pain contact their GP more frequently than those without chronic benign pain.

A random sample of children and adolescents aged 0-18 years was drawn from GP records in the Rotterdam area. Subjects or their parents were sent a self-administered questionnaire on pain. Children and adolescents were assigned to the chronic benign pain group if the reported pain existed for more than three months. The control group comprised subjects who reported pain lasting less than three months or no pain at all. The medical records of all subjects were examined to assess the GP consultation rate.

The chronic benign pain group (n = 95) and the control group (n = 105) had an average GP consultation rate of 2.64 (SD 1.9) and 2.63 (SD 2.5) contacts per year, respectively. No significant age and gender differences were found for the consultation rate between the groups.

These data indicate that chronic benign pain is not related to increased use of healthcare services in childhood and adolescence, and suggest that somatisation does not play a major role in children and adolescents suffering from chronic benign pain.

Introduction

Chronic pain is a common complaint in childhood and adolescence. In a recent epidemiological community survey, a quarter of children aged 0-18 years reported chronic pain (recurrent or continuous pain for more than 3 months).[1] Many chronic pain complaints in children and adolescents are somatically unexplained and are viewed as functional, psychogenic or as an expression of a somatisation disorder.[2] Chronic benign pain is a multidimensional phenomenon. For example, regarding the aetiology of recurrent abdominal pain in children, a family model of illness behaviour, anxiety and depression, a climate of somatic and emotional distress as well as a family history of visceral hypersensitivity have been found to play a role.[3] A wealth of evidence suggests that somatisation in children and adolescents, particularly in the form of recurrent pain complaints, is quite common.[4-16] Increased use of healthcare services among somatising children and adolescents has been reported, [4,17-20] which is consistent with Lipowski's definition of somatisation.[21] However, little is known about the use of healthcare services among children and adolescents with chronic pain, because most studies have been hospital-based, taking children with chronic pain as point of departure for investigations. Such an approach does not allow for a direct comparison of healthcare use between children with and without chronic pain, nor is it possible to directly generalise these findings to the open population. Nevertheless, many healthcare providers consider that chronic pain is related to extensive healthcare utilisation for physically unexplained pain, which they often associate with somatisation, although there are no data to support this. Healthcare providers probably encounter a relatively small and selected group of patients with chronic benign pain, which may explain this viewpoint.[17,22]

We hypothesised that children and adolescents experiencing chronic benign pain contact their general practitioner (GP) more frequently than do those without chronic benign pain. Because it has been reported that healthcare utilisation among chronic pain sufferers (aged 0-18 years) in the community is associated with various characteristics of pain and sociodemographic factors,[23] it is also important to examine how healthcare utilisation is distributed in subgroups of chronic pain subjects. In the Dutch healthcare system everybody is registered with a GP who is the first link in the chain of all healthcare services, therefore we consider the GP consultation rate to be a good measure for healthcare utilisation. This paper addresses the following questions: Do children and adolescents with chronic benign pain consult their general practitioner more often than children and adolescents without chronic benign pain, and do characteristics of pain (localisation, severity and persistence of pain) affect the consultation rate with the GP?

Methods

Study sample

This survey was approved by the ethics committee of the University Hospital Rotterdam and forms part of a larger study on chronic pain in children and adolescents, examining the prevalence, healthcare use, quality of life and prognosis across a two-year period.

In March 1998, a 25% random sample of all children and adolescents aged 0-18 years was drawn from the records of 10 general practitioners in the greater Rotterdam area (*n* = 1,316). These GPs were all part of the ROHAPRO-network: a computerised network of general practices in Rotterdam,[24] and given the possibility to exclude subjects from this survey. Written informed consent was obtained from the parents of the subjects to examine the medical records of their children and for participation in a longitudinal survey. After scrutinising the medical records, subjects with chronic pain of known organic aetiology (e.g., rheumatic arthritis, malignancies) were excluded. Subsequently, the chronic benign pain (CBP) group was invited to participate in a two-year follow-up study (March 1998-March 2000).

Instruments and outcome measures

Subjects or their parents were sent a self-administered questionnaire on pain and were asked to return the completed questionnaire in a pre-stamped addressed envelope. If the answer to the first question, "Did you/your child experience pain in the previous three months?" was affirmative and subjects indicated on a three-point scale that the pain lasted longer than 3 months, they were assigned to the CBP group. The control group consisted of subjects who reported pain lasting less than three months or no pain at all. Additional questions concerned the localization, frequency and intensity of pain, and age, gender and ethnicity of subjects. Subjects reporting multiple pains were asked to fill out the questions for the pain that troubled them most. Parent ratings were used for subjects aged 0-11 years and self-report was used for subjects aged 12-18 years. This questionnaire has been described in detail by Perquin et al.[1]

The CBP group was followed yearly for two successive years (baseline assessment in March 1998, and follow-up in March 1999 and March 2000) by means of a mailed pain booklet, which consisted of questionnaires on background factors, healthcare use and quality of life, and a three-week diary to record pain. Details of this longitudinal survey have been described elsewhere.[25, 26]

After the follow-up period, we examined the medical records in the general practices of all subjects to assess the annual consultation rate with their GP. Medical record review is considered to be a valid method for calculating consultation rates.[27] All contacts of the subjects with their GP, including home visits, consultations and telephone calls, were counted. We excluded the contacts in which exclusively renewal of prescription was requested because such contacts are usually with the receptionist only. The annual consultation rate over a three-year period was calculated starting one year prior to the survey (March 1997) and including the two-year follow-up period (March 1998-March 2000). Additionally, we calculated the lifetime consultation rate of each subject by dividing the total number of contacts by the number of person years. The number of person years was counted by measuring the time span between the date of registration into the practice and the date of data collection, or the date of moving out of the practice.

For both groups, the number of contacts due to CBP was also counted. Contacts were labelled as CBP contacts when a subject contacted the GP for a particular pain that, on the basis of the medical record, was not of organic aetiology and clearly persisted longer than three months, or when there had been at least two previous contacts due to this particular pain in one year. The consultation rate excluding contacts due to CBP was calculated because CBP itself may influence the number of contacts with the GP. There are contacts due to CBP in both groups, because CBP can emerge both before or after the inclusion of respondents in the survey.

Analysis

We evaluated data in three age categories (0-4, 5-11 and 12-18 years) because age-specific problems may have a different effect on healthcare utilisation.[28]

Independent Student's *t*-tests were used to compare the mean consultation rates of the CBP group and the control group. Linear regression analyses were carried out with adjustment for age and gender to test the effect of CBP on the consultation rate. Differences in age-related trends between the groups were tested for the interaction between age (as a continuous variable) and presence of CBP by a linear regression analysis.

Additionally, we compared the consultation rate of two CBP subgroups (severe and persistent chronic pain) to the control group by independent Student's *t*-tests and by linear regression analyses with adjustment for age and gender. Severe chronic pain was defined as CBP with baseline estimated intensities of more than 50 mm on the Visual Analogue Scale (VAS) and occurring weekly, and persistent chronic pain as CBP persisting across the two-year follow-up period. We further examined whether the localization of CBP influenced the consultation rate within the CBP group by One-way ANOVA. A P value of less than 0.05 was considered significant.

Results

Respondents

From the random sample of 1,316 subjects, 123 subjects were excluded by the involved general practitioners because of moving away, language barriers and various aggravating circumstances (e.g. terminal illness in the family), leaving a study sample of 1,193 subjects. A total of 819 questionnaires were completed (response 69%). Of these respondents 205 (25%) experienced chronic pain, of which 109 (53%) gave their consent to study their medical records. Although not specifically asked, 105 of the respondents without chronic pain also gave their consent. At this stage the number of respondents were 109 subjects in the chronic pain group and 105 subjects in the control group. However, 14 subjects in the chronic pain group were excluded because the pain was of organic aetiology (e.g. 10 subjects had recurrent upper respiratory tract infections). The average age of the 14 excluded children (6.9 years, SD 4.0) was significantly lower than of the 95 chronic benign pain subjects ($t = 3.939$, df = 107, $P < 0.001$). Finally, the group of children with CBP ($n = 95$) comprised 41 boys and 54 girls, with an overrepresentation of older children; the average age for boys was 11.4 years (SD 3.8) and for girls 11.1 years (SD 4.5). The control group ($n = 105$) comprised 62 boys and 43 girls; the average age for boys was 8.6 years (SD 4.8) and for girls 7.1 years (SD 5.3).

Consultation rate

The consultation rate in the three-year period ranged from 0 to 13.7 contacts per year for both groups together. The average consultation rate was 2.6 contacts per year (SD 2.2); the median was 2.0 contacts per year.

Table 1 shows the average consultation rate of subjects with and without CBP, adjusted for age and gender, during the three-year study period by age and gender. The CBP group and the control group had an equal average consultation rate of 2.6 (SD 1.9) contacts per year (excluding contacts for CBP). For both groups, children aged 0-4 years had the highest consultation rate. No age or gender differences were found for the consultation rate between the two groups, also after adjustment for age and gender by linear regression analyses. Table 1 also shows differences in the age-related trend between the CBP and the control group; the consultation rate decreased less with increasing age in the CBP group than in the control group. However, these differences were not statistically significant. The consultation rate including the contacts due to CBP for the CBP group and the control group was 2.8 (SD 2.0) and 2.7 (SD 2.5) contacts per year, respectively.

A total of 48 subjects (51%) of the CBP group had contacts with their GP because of CBP compared to 14 controls (13%); the average number of these contacts was 2.3 (SD 1.8) in the CBP group and 1.5 (SD 0.9) in the control group. When controls with CBP contacts were excluded still no significant differences were found for the consultation rates between the CBP group and controls.

When the 14 excluded subjects (subjects with chronic pain of known organic aetiology) were included, the consultation rate of the chronic pain group was 4.8 contacts per year for subjects aged 0-4 years, 3.3 for subjects aged 5-11 years, and 2.4 for subjects aged 12-18 years. The lifetime consultation rate for CBP and control subjects showed no significant differences.

Table 1

Annual GP consultation rates during a three-year period, including / excluding chronic benign pain (CBP) contacts, for chronic benign pain subjects and controls by age and gender

	Chronic benign pain group			Control group		
	N	Including CBP contacts	Excluding CBP contacts	N	Including CBP contacts	Excluding CBP contacts
		Mean (SD)			Mean (SD)	
Total	95	2.8 (2.0)	2.6 (1.9)	105	2.7 (2.5)	2.6 (2.5)
Age category						
0-4 years	8	3.1 (2.4)	3.0 (2.4)	32	3.6 (3.1)	3.6 (3.1)
5-11 years	44	2.8 (2.0)	2.7 (1.9)	48	2.5 (2.3)	2.5 (2.3)
12-18 years	43	2.7 (2.0)	2.5 (1.9)	25	1.7 (1.3)	1.6 (1.3)
Gender						
boys	41	2.2 (1.7)	2.1 (1.7)	62	2.5 (2.5)	2.5 (2.5)
girls	54	3.2 (2.1)	3.0 (2.1)	43	2.9 (2.5)	2.8 (2.5)

Differences in consultation rates between the CBP and the control group, including or excluding CBP contacts, were all not significant.
Differences were tested by linear regression analyses with adjustment for age and gender.

In the CBP group 26 subjects experienced severe chronic pain, and 20 subjects still suffered from chronic pain after the two-year follow-up period (persistent chronic pain); for both (severe and persistent) CBP subgroups the consultation rate was 2.5 contacts with their GP per year. No significant differences in the consultation rate were found for severe or persistent CBP subgroups compared to the control group. Regarding the localization of CBP, limb pain (34%), abdominal pain (31%) and headache (28%) were reported most often, whilst back pain (3%) and other pains (4%) occurred in only a minority of the subjects. We found no significant differences in the consultation rate for different localizations of pain.

Discussion

As far as we know, this is the first study to compare the healthcare use of a general practice sample of children and adolescents with chronic benign pain to their peers without chronic benign pain. Our results show that the GP consultation rate was equal for both groups; moreover, that the average number of GP contacts per year corresponds with the consultation rate of children and adolescents from the general Dutch population (2.9 contacts per year).[29] When the contacts due to CBP were included the consultation rate remained equal for both groups, suggesting that the GP is not frequently consulted for CBP. Although about half of the chronic pain sufferers had contacted their GP because of CBP, the relatively low number of contacts in the CBP group supports this.

Looking closer at the consultation rate in relation to age (Table 1), we see that, although the consultation rate for both groups decreased with increasing age, the consultation rate for CBP subjects decreased more slowly. This suggests that, although today's adolescent CBP sufferer shows no significant difference in consultation rate from the control group, tomorrow's adult CBP sufferer might have more contacts with health care. Furthermore, the lower consultation rate among CBP children of the youngest age category (0-4 years) can be explained by the fact that most of the excluded subjects were excluded because of recurrent infections, which occurred mainly in the youngest children (without exclusion, the consultation rate of chronic pain subjects aged 0-4 years was considerable higher than for controls).

One of the limitations of our study is the small power, which does not allow to test for a difference in age-related trend. Moreover, it should be noted that since a cross-sectional study design was used we have to be cautious about making longitudinal inferences. Many subjects of the CBP group no longer experienced chronic pain during the follow-up period, which might explain the small difference in the consultation rate between the CBP and control group. Nonetheless, even in subjects with persistent chronic pain throughout the follow-up period, no difference was found. Further research is needed to establish whether CBP sufferers tend to somatise more in adulthood.

Although Perquin et al.[23] found that the intensity and frequency of pain were associated with physician consultation, our study showed no differences in the consultation rate for various pain characteristics (i.e. localization, severity and persistence of pain). These results seem to be contradictory, but can be explained by the difference in outcome measures: Perquin et al. investigated whether a chronic pain subject ever consulted a physician because of the pain, while this study assessed all contacts with a GP, irrespective of the reason for the contact. Despite evidence suggesting that somatisation, particularly in the form of recurrent pain complaints, is quite common in children and adolescents,[5] our results indicate that somatisation does not play a more prominent role in children and adolescents with chronic benign pain than in those without chronic benign pain.

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8

General discussion, conclusions and suggstions for further research

The main aim of this thesis is to determine the extent of the chronic benign pain problem in children and adolescents aged 0-18 years in the general population. More specifically, the focus is on the assessment of the prevalence, the use of health care services, the impact of pain on the child and the family, and the course of chronic benign pain. To achieve this aim we conducted a population-based cross-sectional study. The subjects with chronic pain who were identified in this study were asked to participate in a two-year follow-up study, using mailed questionnaires and a three-week diary. In addition, a sample of children and adolescents referred for chronic pain was obtained, and assessed during a follow-up period of two years in the same way. This hospital sample was compared with the population sample on background factors, pain perception, behavior, and its impact on the child and the family. A third sample of children and adolescents was drawn from general practitioner records, and consultation rates between children and adolescents with and without chronic benign pain were compared. We now discuss the major findings along the lines of the research questions formulated in chapter one, and give suggestions for further research.

Prevalence of chronic pain

In our cross-sectional study among 6,636 children under 18 years of age in the greater Rotterdam area (chapter 2), a satisfying response rate of 82% was obtained. We defined chronic pain to be continuous or recurrent pain existing for three months or longer. It should be noted that our definition of chronic pain differs from that used by many others. To obtain a comprehensive picture on long-term pain, we did not impose restrictions regarding frequency or severity of pain.[1] The main outcome of this thesis is that chronic benign pain is a common finding in children and adolescents: 25% of the respondents reported to have chronic pain. Also severe chronic pain turned out to be quite prevalent, especially among older girls. About one-third of the chronic pain sufferers reported to have severe chronic pain, which was defined as weekly occurring pain with high intensities (> 50 mm on a visual analogue scale) for more than three months. This is in line with previous population-based studies that focussed on just one pain condition, such as abdominal pain and headache.[2-7]

We found in our cross-sectional study a marked increase in the reported prevalence of short-lasting pain (pain lasting less than four weeks) at the age of 8 years, which was probably partly due to the change in method of obtaining data (parent-report below 8 years versus self-report above 8 years). Because parents may not always be aware of their children's pains, pain problems could have been underestimated by their parents. However, the increase in the prevalence of chronic pain with age was gradually and did not coincide with the age on which the method of obtaining data changed, indicating that for the assessment of chronic pain in various age groups information bias was presumably not present. Besides, it should be noted that parent ratings may be the best proxy measure available in very young children, particularly in longer lasting pain.[9,10] The significant increase of the prevalence rate of chronic pain in girls between the ages of 12 and 14 years could be due to the onset of the menstruation.

In our cross-sectional study, headache, abdominal pain and limb pain were the most frequently reported types of pain; this is not unexpected since many previous studies reported high prevalence rates for these regional pain conditions. More than a quarter of all the children, or about half of the children who reported pain, had experienced pain at multiple sites in the past three months. The combination of headache and abdominal pain was reported most frequently (prevalence rate 3.5%), especially in older girls.

The high prevalence of chronic pain, and severe chronic pain in particular, found in this cross-sectional study should be a concern for health care services and calls for follow-up investigations documenting the various bio-psycho-social factors related to the experience and extent of this pain in children. These factors may be potential starting points for intervention. A salient outcome in this study is that adolescent girls predominate at the occurrence of severe chronic pain and multiple pain. We wonder to what extent this pain is associated with the onset of menstruation, particularly when a considerable proportion of the multiple pains were reported to be a combination of headache and abdominal pain. As we limited our questionnaire to pain in order to get a high response and compliance, particularly since this study was designed to identify children and adolescents with chronic pain for participation in our two-year follow-up survey, we cannot answer this question. Besides, studying etiological factors such as menstruation was not part of the objective of this thesis and requires a different (longitudinal) design. Little is known about the prevalence and impact of dysmenorrhoea in adolescents in the general population, and therefore we suggest that future research should include this condition. Obviously, other factors like psychological changes during puberty and switching from primary to secondary school may also play a role.

Health care use

The results of our population-based cross-sectional study further show that chronic pain in children involves a large amount of medical consumption with differences found for sociodemographic factors and pain characteristics (chapter 3). Of the 1,358 subjects who reported chronic pain 57% had ever consulted a physician for the pain, and 39% had ever used medication for the pain. About 15% of our sample consulted a physician for chronic pain, which is slightly higher than the overall consultation rate of 11% in children aged up to fourteen years (regardless of symptoms) in general practice reported by Bruijnzeels et al.[11]

Children with earache, intense and frequent pain, children aged 0-3 years and 12-18 years, and children attending lower vocational training were more likely to consult a physician for the pain than the average respondent. Children with earache, sore throat, headache, intense pain, multiple pain, children aged 0-3 years, and girls were more likely to use medication for the pain.

Although many of these findings were expected two remarks have to be made. First, based on reports addressing consultation in adults, we expected to find more girls consulting a physician.[12-14] However, our study indicated that for children under 4 years of age boys were more likely to consult a physician than girls, whereas for the other age groups no gender difference was found. Reports that this gender difference in adults is more related to behavioural than biological factors might explain our findings.[15] In children, behavioural factors may play a different role than in adults. Reports on consultation rates in children are inconsistent about whether or not a gender difference exists.[11,13,16-18] Second, the finding that those with lower education level seem to be more likely to seek medical attention for their pain might have implications for both the children and the health care system in different areas. Education on pain focusing on health services in socio-economic deprived areas may benefit both patients and the society.

We explored the relationship between chronic pain and the utilization of health care services more comprehensively by using the cohort of 987 children and adolescents with chronic pain. These children were identified in the above-mentioned population-based cross-sectional study and participated in a two-year follow-up study using questionnaires and a three-week diary (chapter 4). Data from the baseline assessment of this follow-up study were used to determine the extent of utilization of health care services in children and adolescents with chronic benign pain, and to compare those subjects using health care services for chronic benign pain and those not using medical services on background factors, pain perception, behavior, and its impact on the child and the family.

Firstly, we have to remark that the response on the baseline assessment of this follow-up study (51.3%) was less than optimal. Therefore, the possibility of selection bias must be considered. However, the relatively small differences in demographics, pain characteristics, physician consultation and medication use between the responders and the non-responders, as assessed in our cross-sectional study (chapters 2 and 3), suggest the selection bias to be small. Furthermore, the results of this baseline assessment show that in a high number of subjects (about half of the responders) the pain had ceased during the preceding 3 months. This is possibly a consequence of our definition of chronic pain including both continuous and recurrent pain, and taking chronicity of pain to be only 3 months. Nevertheless, other studies on migraine[14,18] and idiopathic musculoskeletal pain syndromes in children[19] also reported high 'remission' rates for pain.

In this subsample, we found a relatively high use of medical services; of the children who reported still to have pain at baseline 43% had used some form of health care services, and 53% had used medication for the pain in the previous three months. Since these pains were benign and already existed for a long period (about 3 years), we had expected less use of health care services and probably other coping procedures than medication use. Our figures on hospital admission because of chronic pain in the preceding year (6.4%) are relatively high compared with the data from the Central Bureau of Statistics, which indicated that, overall, 4% of the pediatric population was admitted to hospital (not for pain only) over the years 1997/1998.[20] We also found a relatively high application of diagnostic tests (15.9%) for chronic pain in the previous three months. On the other hand, we had not expected to find such a low utilization of psychosocial care (2.8%) and of alternative health care (4.0%). Krauss et al. reported that 33.9% of adult chronic pain patients listed at an outpatient vocational rehabilitation facility in New York consulted an alternative health provider in the past year.[21]

Many indicators of pain severity used in this study appeared to be associated with the use of medical services, which is in accordance with the results of our cross-sectional study (chapter 3). Children and adolescents with continuous pain or frequent and intense pain, with disability or school absenteeism due to the pain were more likely to use health care services for pain. Contradictory to our findings in the cross-sectional study, in this follow-up study, girls over 4 years of age used more often health services than boys of the same age. This contradiction can be explained by the difference in outcome measures: the cross-sectional study investigated whether a subject with chronic pain ever consulted a physician, while the follow-up study assessed the use of different kinds of health services in a three-month period. However, the findings of our follow-up study are in agreement with earlier reports.[13,16,22] Except for gender, background factors appeared to be similar for consulters and non-consulters, suggesting that pain severity plays a more important role in health care utilization. Noteworthy is the high occurrence of chronic pain (about 40%) among the parents of children and adolescents with chronic pain. Apley (1975) reported that abdominal pain was six times more likely to occur in siblings and parents of abdominal pain patients than in controls, suggesting that those pain sufferers come from 'pain-prone' families.[23] Another explanation could be that our respondents were modeled by the pain behavior of their parents. Prospective studies, which start before the onset of chronic pain, are needed to reveal the determinants of the development of chronic pain.

Summarising, we were surprised on the one hand about the relatively high number of referrals and diagnostic tests and on the other hand about the relatively low utilization of psychosocial care. This could possibly promote somatization through which these children and adolescents stay in the medical circuit. Although background factors seem to play no role in determining whether to utilise health care resources, we argue that physicians should consider the psychosocial background of chronic pain patients.

Referral

In chapter 6 we attempted to answer the question 'Do children and adolescents with chronic benign pain who were referred to a specialist for this condition and those not referred differ in background factors, pain perception, behavior, and its impact on the child and the family?'. We obtained a sample of new patients (n = 394) referred to a children's hospital because of chronic pain. We studied the clinical and demographic differences between this sample and the population sample of chronic pain sufferers aged 0-18 years who were identified in our population prevalence study (chapter 2).

We found that children who were referred to a children's hospital for chronic pain, compared to chronic pain sufferers in the community, were younger, had more often headache and abdominal pain, had pain for a longer period, had parents with a lower education level and mothers who had more often chronic pain. Furthermore, we observed moderate differences for health status of subjects and their parents, and the impact of pain on the child and family, but except for the slightly higher social impact and personal strain in the hospital sample, the differences in health status and other dimensions of the impact on the child and the family disappeared in multivariate analyses. Surprisingly, adolescents of the hospital sample were more satisfied with life compared with the population sample.

To interpret these results a few remarks have to be made. First, it is possible that the quality of life of the hospital sample is lower than our data suggest because the diary assessment took place almost two years after the referral date, so that the quality of life could have been improved possibly as a result of the hospital visit, or as a function of time. To exclude a possible positive effect of the hospital visit and/or a time-effect on the quality of life, another, prospective, study design would be needed. Obviously, this also applies to the child's health status. Secondly, the length of time between the identification of subjects with chronic pain (referral or screening), and the diary assessment differed for both samples. This was approximately 1.3 years longer for the hospital sample compared to the population sample, which presumably accounts for the longer pain duration in the hospital sample. Thirdly, differences in age of subjects and location of pain, which could have had an effect on the other factors we assessed, could be the result of the way we obtained the hospital sample. The recruitment of patients of the departments of general pediatrics and neurology only may account for the under-representation of limb pain and back pain in the hospital sample. Further, younger children are being referred to the department of general pediatrics compared with the overall outpatient clinic population (mean age is 4.1 versus 5.1 years), which might partly explain the differences for age. However, Riley et al. and our cross-sectional study (chapter 3) have also reported that young children visit a physician more often than older children.[24] By multivariate logistic regression analyses we have attempted to adjust for this influence of age and location of pain.

We have to be cautious about our findings that pain severity and the impact of pain on the child and his family did not differ significantly between patients referred for chronic pain and a population sample of chronic pain sufferers. However, we suggest that background factors like parental socioeconomic status and having a mother with chronic pain play a more important role in referral to a children's hospital for chronic pain than clinical characteristics. This corresponds with a Dutch study in which the morbidity of the parents, in particular of the mother, appeared to be the most important factor related to health service use by children.[25] Education and advice for children and their parents how to cope with pain remain important in the management of pain by physicians.

GP consultation rate

We have drawn a third sample (*n* = 1,456) of children and adolescents under 18 years of age from general practitioner records, which was used to compare consultation rates between children and adolescents with and without chronic benign pain (chapter 7). The medical records of all subjects were examined to assess the GP consultation rate.

The results of this study show that the GP consultation rate was equal for both groups. The average number of 2.9 GP contacts per year found in this study corresponds with the consultation rate of children and adolescents from the general Dutch population.[20] Although about half of the chronic pain sufferers had contacted their GP because of chronic benign pain, the relatively low number of contacts in the chronic benign pain group supports the suggestion that the GP is not frequently consulted for chronic benign pain in this age group.

Further we noticed that, although the consultation rate for both groups decreased with increasing age, the consultation rate for chronic benign pain subjects decreased more slowly. Unfortunately, the power of this study is too small to test for a difference in age-related trend. Longitudinal studies are needed to test the hypothesis that although today's adolescent chronic benign pain sufferer consult the GP not more often than their peers, tomorrow's adult chronic benign pain sufferer might have more contacts with health care; in other words, that chronic benign pain sufferers tend to somatise more when becoming adults. Many subjects of the chronic benign pain group no longer experienced chronic pain during the follow-up period, which might explain the small difference in the consultation rate between the subjects with and without chronic benign pain. Nonetheless, even in the subjects with persistent chronic pain throughout the follow-up period, no difference was found.

Despite evidence suggesting that somatisation, particularly in the form of recurrent pain complaints, is quite common in children and adolescents,[26] our results do not indicate that somatisation does play a prominent role in children and adolescents with chronic benign pain as compared with those without chronic benign pain.

Prognosis of chronic benign pain

In chapter 5, we describe the natural course and prognosis of chronic benign pain in childhood and adolescence in the general population over a two-year period. The cohort of 987 children and adolescents with chronic pain, who were identified in our population-based cross-sectional study was studied by using questionnaires and a three-week diary, and followed-up annually for two successive years.

Our follow-up study shows that about one-third (77/254) of those who had chronic benign pain at baseline still had this pain at two-year follow-up. Assuming all those lost to follow-up would still report pain as a problem, the adjusted proportion of sufferers with persistent pain would be 45%. This worst-case scenario is not to be expected since our previous non-response survey among the non-reponders at the baseline assessment indicated that one-third of them did not respond because they no longer experienced pain. In the best case, when all those lost to follow-up would not report pain as a problem anymore, the proportion of persistent pain sufferers would still be 30%. Nevertheless, we found a high spontaneous remission in 55-70% of children and adolescents with chronic benign pain over two years, which corresponds well with the studies on musculoskeletal pain, widespread pain and neck pain in schoolchildren of Mikkelsson et al..[27,28]

An interesting outcome in this study is that girls predominate in the occurrence of chronic benign pain at all three time intervals, although there was no sex-related difference in the course of pain. Experimental studies in adults found greater pain stimulus thresholds and greater pain tolerance in males,[29] but a greater ability to discriminate for experimentally delivered somatic stimuli, less somatic stimulus tolerance,[30] and a greater tendency to report negative affect in females.[31] The gender differences found in our study can to some extent be explained by these biological factors. However, since pain in the head and abdomen make about 52% to 60% of the reported pain over the three years, and 77% to 87% of the pain is reported as recurrent, we believe that the gender differences we found in this study can also be explained, at least partly, by menstruation in adolescents. To what extent this pain is associated with menstruation we do not know. As already mentioned there is a need for future research aimed at assessing the prevalence of dysmenorrhoea in adolescents and its correlates (e.g. health care use, quality of life).

Overall, the 254 children who reported chronic benign pain at baseline had rather mild intense, but frequent pain, and were not severely disabled by the pain. Although this pain was benign and present for several years (on average about 3 years), a considerable proportion of the children had used some form of health care service or used medication for the pain in the prior three months. In general, the pain characteristics and the pain-related consequences remained relatively stable over the two-year follow-up, as was assessed in the subsample of subjects who reported chronic benign pain on at least two assessments. This corresponds with a Canadian longitudinal survey on persistent pain in adults which showed that pain and most of its consequences remained stable over two years.[32] Except for emotional and social consequences, Crook et al. found this to be improved, whereas the health care use increased. Yet, in our follow-up study, chronic benign pain sufferers deteriorated in their behavioral changes due to pain and social functioning, but reduced their use of health care services. We found that, through follow-up, the location of pain changed for a considerable proportion (24%) of the subjects with pain persisting over the two years, which was mostly to the head. However, there was no relation between the location of pain and the course of the behavior and social functioning that could explain this deterioration.

Children with persistent pain over two years differed in some ways from those who did not report chronic benign pain at follow-up, but only emotional problems, their mother's self-reported health in general, and the pain frequency at baseline were identified as prognostic factors for the persisting of chronic benign pain. Since the prognostic factor 'emotional problems' was operationalized by only a single question on the COOP WONCA charts and restricted to adolescents, we should be cautious in interpreting this result.

An earlier mentioned drawback of our study from the point of view of generalizability of the results may be the selection bias related to the recruitment process. The recruitment was dependent on the willingness to participate in a time-consuming diary and questionnaire study for two years. However, the small and predominantly insignificant differences in demographics, pain characteristics, physician consultation and medication use as assessed in our cross-sectional study (chapter 2), between the responders at each assessment and the initial cohort, suggest that the selection bias is small. The nonsignificant differences in background factors (except for age, which was expected since we followed up subjects for two years) between responders at the three assessments, confirmed this opinion. A large bias due to the different way of obtaining data (parent ratings in children aged 0-11 years and self-report in adolescents) is unlikely, since we determined the individual course of pain and its consequences by adjusting for age and gender.

The implications of this study are that chronic benign pain in childhood and adolescence is common, and seems to persist in a considerable proportion (30%-45%). Although children were not severely disabled by the pain and the pain generally did not deteriorate over time, the size of the group of children with chronic pain makes it sensible to investigate possibilities to prevent pain from becoming chronic. Future studies should focus on identifying risk factors for pain becoming chronic in children and adolescents. Because in the Dutch health care system the general practitioner is the first health care professional (gate-keeper) to turn to, recruiting children and adolescents who are consulting their general practitioner with pain (< 3 months) could be a good approach. By follow-up of these subjects using mailed questionnaires or telephone interviews, risk factors can be identified. Based on these factors interventions can be designed to focus on the group of children and adolescents with a higher chance of becoming chronic pain patients. Preventing pain from becoming a chronic problem will be beneficial for the quality of life of these children and adolescents, but also for their family and even for society. Another group to study is of course the group of children and adolescents with chronic pain; will they still be chronic pain sufferers when they are adults?

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Summary

Chapter 1 is the introduction of this thesis. Epidemiological data on pain in children and adolescents are only limited available. A better understanding of pain in childhood and adolescence is needed to gain more insight in the etiology of pain, to relieve the associated burden for children and their families, and for the adequate allocation of health care resources. Therefore, the main aim of this thesis is to determine the extent of the chronic benign pain problem in children and adolescents aged 0-18 years in the general population, by assessing the prevalence, the health care use, the impact of pain on the child and the family, and the course of chronic benign pain. Additionally, this thesis aims to determine whether there are risk factors for health care use and referral to a specialist in children and adolescents with chronic benign pain, and whether those children consult their general practitioner more often than a control group.

Chapter 2 presents a cross-sectional study to assess the prevalence of pain in Dutch children and adolescents aged 0-18 years in the open population, and the relationship with age, gender and pain parameters. A random sample of 1,300 children aged 0-3 years was taken from the register of population in Rotterdam, and 41 schools in the Rotterdam area were selected to obtain a representative sample of 5,336 children aged 4-18 years. A questionnaire was either mailed to the parents (0-3 years) or distributed at school (4-18 years). Of

6,636 children surveyed, 5,424 (82%) responded. Of the respondents, 54% had experienced pain within the previous 3 months. Overall, a quarter of the respondents reported chronic pain, which was defined as recurrent or continuous pain for more than 3 months. The prevalence of chronic pain increased with age, and was significantly higher for girls. In girls, a marked increase occurred in reporting chronic pain between 12 and 14 years of age. The most common types of pain in children were limb pain, headache and abdominal pain. Half of the respondents who had experienced pain in the previous 3 months reported to experience multiple pains, and one-third of the chronic pain sufferers experienced severe pain. These multiple pains and severe pains were more often reported by girls. The intensity of pain was higher in case of chronic pain and multiple pains, and for chronic pain the intensity was higher for girls. These findings indicate that chronic pain is a common complaint in childhood and adolescence. In particular, the high prevalence of severe chronic pain and multiple pain in girls aged 12 years and over calls for follow-up investigations documenting the various bio-psycho-social factors related to this pain.

Chapter 3 describes the physician consultation and medication use in the group of subjects with chronic pain, who were identified in the above-mentioned survey, in relation to sociodemographic factors and pain characteristics. Of the 1,358 respondents who had reported chronic pain, 57% had ever consulted a physician and 39% had ever used medication for the pain. Children with earache, more intense pain, more frequent pain, and children attending lower vocational training were more likely to consult a physician for the pain than the average of the respondents. Children with earache, sore throat, headache, more intense pain, multiple pain, children aged 0-3 years, and girls were more likely to use medication for their pain. The most significant predictive factors for physician consultation were pain intensity, age, and earache, and in children aged 12-16 years the education level. The use of medication was merely predicted by earache, headache, limb pain, intensity of pain, and age. The results of this study imply that chronic pain in childhood and adolescence results frequently in consultation of a physician and medication use. Concerning physician consultation, children with lower education level seem to be a group at risk.

In **chapter 4** health care utilization and medication use in children and adolescents with chronic benign pain are described more comprehensively, by using a prospective study design. Subjects who had reported chronic pain in the above-mentioned population-based cross-sectional survey and given their consent for participation in a two-year follow-up study (*n* = 987) were asked to keep a 3-week diary on their pain and to fill out questionnaires on background factors, pain characteristics, pain behavior (health care use, medication use and school absence) and pain-related consequences (impact on the child and the family). This was repeated annually for two years. This chapter presents the results of the baseline assessment. During a three-month period, in 53.4% of the cases medication was used for the pain, and general practitioners and specialists were consulted for pain in 31.1% and 13.9% of subjects, respectively. Physiotherapists, psychologists and alternative health care providers were visited by 11.5%, 2.8%, and 4.0%, respectively. In the preceding year, 6.4% had been hospitalized due to pain. The most important factors linked to utilizing medical services were gender (0-3 years: boys > girls; 4-18 years: girls > boys), various pain characteristics, school absenteeism and disability. Although consulters reported to be less physically fit and less satisfied with health, their parents were better adapted to the pain, by talking and sharing, mutual support, normalization of the child and heightened self-esteem, than non-consulters.

Chapter 5 presents the results of the above-mentioned follow-up study of a cohort of 987 children and adolescents with chronic pain, and describes the natural course and prognosis of chronic benign pain in childhood and adolescence over the two-year follow-up period. At baseline, 254 subjects reported to have chronic benign pain, and of those, 124 (48%) and 77 (30%) subjects still experienced chronic benign pain at 1-year and 2-year follow-up, respectively. For the subgroup of children with persistent pain during the two-year follow-up the pain remained stable over this period, except for the retrospectively measured pain intensity which decreased marginally. Minor changes occurred in the consequences of pain; main changes were a decrease of the impact on the child's behavior, the social functioning and of health care use. Subjects with persistent pain (9.4%) differed from those with non-persistent pain in frequency, history and location of the pain, emotional problems and their mother's health. The implications are that chronic benign pain in childhood and adolescence is common, but does persist in only a minor proportion and in general does not deteriorate over time.

In **chapter 6** a hospital sample of children and adolescents referred to a children's hospital because of chronic pain was compared with the above-mentioned population sample of 987 chronic pain sufferers on background factors, pain characteristics, pain behavior (medication use, school absenteeism), and its impact on the child and the family. The hospital sample was followed up in the same way as the population sample was. This chapter reports on the differences at baseline. Significant differences between the hospital sample (n = 68) and the population sample (n = 254) were found for age, pain location and duration, school absenteeism, occurrence of chronic pain in their mothers, parental education level, and functional status of subjects and their parents. Although statistically significant, the impact on the family was only slightly higher for the hospital sample. Thus, not pain severity and quality of life of the child, but background factors seem to play an important role in referral to a children's hospital for chronic pain.

Chapter 7 describes a comparison of the general practitioner (GP) consultation rate between children and adolescents with and without chronic benign pain, and its predictors. A random sample of children and adolescents drawn from the records of ten general practices in the greater Rotterdam area was used for this study. Subjects or their parents were sent the same pain questionnaire as in the above-mentioned population-based cross-sectional survey. Respondents were assigned to the chronic pain group if the reported pain existed for more than three months. The control group consisted of subjects who reported pain lasting less than three months or no pain at all. The medical records of all subjects were examined to assess the GP consultation rate. Both, the chronic benign pain group (n = 95) and the control group (n = 105) had an average GP consultation rate of 2.6 contacts per year. No significant age and gender differences were found for the consultation rate between the groups. Concluding, chronic benign pain in childhood and adolescence is not related to increased use of health care services.

In **chapter 8** the main results of these studies are discussed, and conclusions and suggestions for future research are given.

Samenvatting

Hoofdstuk 1 is de inleiding van dit proefschrift. Epidemiologische gegevens over pijn bij kinderen en adolescenten zijn alleen beperkt beschikbaar. Een beter begrip van pijn in de kinderjaren en adolescentie is noodzakelijk voor het verkrijgen van meer inzicht in de etiologie van pijn, voor het verlichten van de impact die de pijn heeft op het kind en het gezin en voor de adequate allocatie van gezondheidszorginstanties. Het hoofddoel van dit proefschrift is derhalve het vaststellen van de uitgebreidheid van het chronisch benigne pijnprobleem bij kinderen en adolescenten van 0-18 jaar in de open populatie, door middel van het meten van de prevalentie, het gebruik van de gezondheidszorg, de consequenties van de pijn voor het kind en het gezin en het beloop van chronische benigne pijn. Dit proefschrift heeft daarnaast tot doel het bepalen van mogelijke risicofactoren voor het gebruik van de gezondheidszorg en verwijzing naar een specialist bij kinderen en adolescenten met chronisch benigne pijn. Tevens werd onderzocht of deze groep kinderen hun huisarts vaker consulteert dan een controlegroep.

Hoofdstuk 2 beschrijft een dwarsdoorsnede-onderzoek naar de prevalentie van pijn in Nederlandse kinderen en adolescenten van 0 tot 18 jaar in de open populatie en de relatie met leeftijd, geslacht en pijnkenmerken. Uit het bevolkingsregister van de gemeente Rotterdam werd een aselecte steekproef van 1300 kinderen van 0 tot 3 jaar getrokken. Tevens werden aselect klassen van 41 scholen geselecteerd in Rotterdam en omgeving voor het verkrijgen van een representatieve steekproef van 5336 kinderen van 4 tot 18 jaar. Een vragenlijst werd of per post naar de ouders gestuurd (0-3 jaar) of op school uitgedeeld (4-18 jaar). Van de 6636 benaderde kinderen respondeerden er 5424 (82%). Van de respondenten had 54% de afgelopen 3 maanden pijn gehad. Totaal had een kwart van alle respondenten chronische pijn (recidiverende of continue pijn welke langer dan 3 maanden bestaat) gerapporteerd. De prevalentie van chronische pijn nam toe met de leeftijd en was significant hoger voor meisjes. Bij meisjes trad een enorme toename op in de rapportage van chronische pijn tussen 12 en 14 jaar. De meest voorkomende pijnsoorten waren pijn in armen of benen, hoofdpijn en buikpijn. De helft van de respondenten die gedurende de afgelopen 3 maanden pijn had ervaren rapporteerde multipele pijnen en een derde van de chronische pijnlijders rapporteerde ernstige pijn. Deze multipele pijnen en ernstige pijnen werden vaker gerapporteerd door meisjes. De pijnintensiteit was hoger in het geval van chronische pijn en multipele pijn; bij chronische pijn was de intensiteit hoger voor meisjes. Deze bevindingen geven aan dat chronische pijn een veel voorkomende klacht is in de kinderjaren en adolescentie. Vooral de hoge prevalentie van ernstige chronische pijn en multipele pijn bij meisjes van 12 jaar en ouder vraagt om longitudinaal onderzoek naar de verschillende bio-psycho-sociale factoren die gerelateerd zijn aan deze pijn.

Hoofdstuk 3 beschrijft het doktersbezoek en medicatiegebruik in de groep kinderen met chronische pijn, die geïdentificeerd werden in de voorgaande studie, in relatie tot sociaaldemografische factoren en pijnkarakteristieken. Van de 1358 respondenten die chronische pijn hadden gerapporteerd had 57% ooit een arts geconsulteerd en 39% ooit medicatie gebruikt voor de pijn. Kinderen met oorpijn, intense pijn, frequente pijn en kinderen die het lager beroepsonderwijs volgden consulteerden vaker een arts dan het gemiddelde van de respondenten. Kinderen met oorpijn, keelpijn, hoofdpijn, intense pijn en multipele pijn, kinderen van 0 tot 3 jaar en meisjes gebruikten vaker medicijnen voor de pijn. De meest significante predictoren voor doktersbezoek waren pijnintensiteit, leeftijd en oorpijn; voor kinderen van 12 tot 16 jaar was dat het opleidingsniveau. Medicatiegebruik werd voornamelijk voorspeld door oorpijn, hoofdpijn, pijn in armen en benen, pijnintensiteit en de leeftijd. De resultaten van deze studie impliceren dat chronische pijn in de kinderjaren en adolescentie vaak resulteert in doktersbezoek en medicatiegebruik. Betreffende doktersbezoek zijn kinderen die het lager beroepsonderwijs volgen een risicogroep.

In **hoofdstuk 4** worden het gebruik van de gezondheidszorg en medicatie door kinderen en adolescenten met chronisch benigne pijn meer gedetailleerd beschreven, door middel van een studie met een prospectief design. Respondenten uit de bovengenoemde cross-sectionele populatiestudie, die chronische pijn hadden gerapporteerd en schriftelijke toestemming hadden gegeven voor deelname aan een follow-up studie (*n* = 987), werd gevraagd een dagboek bij te houden over de pijn gedurende 3 weken en vragenlijsten in te vullen over achtergrondfactoren, pijnkarakteristieken, pijngedrag (gebruik van de gezondheidszorg en medicatie, schoolverzuim) en de consequenties van de pijn voor het kind en het gezin. Dit werd jaarlijks herhaald gedurende 2 jaren. Dit hoofdstuk presenteert de resultaten van de nulmeting. Gedurende een periode van 3 maanden had 53,4% van de respondenten medicatie gebruikt en werd de huisarts en specialist geconsulteerd in 31,1% en 13,9%, respectievelijk. Fysiotherapeuten, psychologen en alternatieve hulpverleners werden geconsulteerd door 11,5%, 2,8% en 4,0%, respectievelijk, van alle respondenten. In het jaar voorafgaand aan de meting was 6,4% van de kinderen opgenomen geweest in een ziekenhuis in verband met de pijn. De belangrijkste factoren die gerelateerd zijn aan het gebruik van de gezondheidszorg waren geslacht (0-3 jaar: jongens > meisjes; 4-18 jaar: meisjes > jongens), verschillende pijnkarakteristieken, schoolverzuim en pijngerelateerde hinder. Ondanks dat gebruikers van de gezondheidszorg rapporteerden lichamelijk minder fit te zijn en minder tevreden te zijn over hun gezondheid konden hun ouders beter omgaan met de pijn van hun kind dan niet-gebruikers van de gezondheidszorg, door middel van praten en medeleven, wederzijdse steun en verhoging van zijn/haar zelfrespect.

Hoofdstuk 5 presenteert de resultaten van de bovengenoemde follow-up studie van een cohort van 987 kinderen en adolescenten en beschrijft het natuurlijke beloop en de prognose van chronisch benigne pijn in de kinderjaren en adolescentie gedurende een periode van 2 jaar. Tijdens de nulmeting rapporteerden 254 respondenten chronisch benigne pijn en van deze groep kinderen hadden na 1 jaar en 2 jaar follow-up 124 (48%) en 77 (30%) respondenten, respectievelijk, nog steeds chronisch benigne pijn. Voor de subgroep met persisterende pijn tijdens de 2 jaar follow-up bleef de pijn stabiel over deze periode, met uitzondering van de retrospectief gemeten pijnintensiteit welke marginaal afnam. De consequenties van de pijn veranderden weinig; de voornaamste veranderingen waren een afname van de impact op het gedrag van het kind, het sociale functioneren en het gebruik van de gezondheidszorg. Respondenten met persisterende pijn (9,4%) verschilden van diegenen waarbij de pijn niet persisteerde in frequentie, locatie en duur van de pijn, emotionele problemen en de gezondheid van hun moeder. Implicaties van deze studie zijn dat chronisch benigne pijn vaak voorkomt in de kinderjaren en adolescentie, maar slechts in een klein deel persisteert en in het algemeen niet verslechtert in de tijd.

In **hoofdstuk 6** wordt een steekproef van kinderen en adolescenten, die verwezen werden naar een kinderziekenhuis in verband met chronische pijn, vergeleken met de bovengenoemde populatiesteekproef van 987 kinderen met chronische pijn op achtergrondkenmerken, pijnkarakteristieken, pijngedrag (medicatiegebruik, schoolverzuim) en de impact van pijn op het kind en het gezin. Deze ziekenhuissteekproef werd op dezelfde manier vervolgd als de populatiesteekproef gedurende 2 jaar. Dit hoofdstuk geeft de verschillen weer die gevonden werden met de nulmeting. Significante verschillen tussen de ziekenhuissteekproef (n = 68) en de populatiesteekproef (n = 254) werden gevonden voor de leeftijd, pijnlocatie en duur, schoolverzuim, voorkomen van chronische pijn bij de ouder(s), opleidingsniveau van ouders en de functionele status van het kind en zijn/haar ouders. Alhoewel dit statistisch niet significant was, was de impact van de pijn op de familie iets groter voor de ziekenhuissteekproef. Achtergrondkenmerken lijken dus een belangrijkere rol te spelen in de verwijzing naar een kinderziekenhuis dan de ernst van de pijn en de kwaliteit van leven van het kind.

Hoofdstuk 7 beschrijft een vergelijking van de huisarts consultatiefrequentie tussen kinderen en adolescenten met en zonder chronisch benigne pijn en de factoren die hiermee samenhangen. Hiertoe werd een aselecte steekproef van kinderen en adolescenten getrokken uit de patiëntenregisters van 10 huisartsenpraktijken in Rotterdam en omgeving. Kinderen of hun ouders kregen dezelfde pijnvragenlijst toegestuurd als in bovengenoemde cross-sectionele populatiestudie. Respondenten werden ingedeeld in de chronische pijngroep wanneer de gerapporteerde pijn langer dan 3 maanden bestond. De controlegroep bestond uit kinderen die rapporteerden pijn korter dan 3 maanden te hebben of helemaal geen pijn. De medische dossiers van alle respondenten werden bestudeerd om het aantal contacten met de huisarts te kunnen meten. De chronisch benigne pijngroep (n = 95) en de controlegroep (n = 105) hadden een gemiddelde consultatiefrequentie van 2,6 contacten per jaar. Er werden geen significante leeftijds- en geslachtsverschillen gevonden tussen de groepen. Concluderend blijkt chronisch benigne pijn in de kinderjaren en adolescentie niet gerelateerd te zijn aan een toegenomen gebruik van de gezondheidszorg.

In **hoofdstuk 8** worden de voornaamste resultaten van dit proefschrift bediscussieerd. Tevens worden hierin de conclusies beschreven en suggesties gedaan voor toekomstig onderzoek.

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Curriculum vitae

Christel Perquin was born on April 15th 1965 in Voorschoten. She graduated from high school in 1985 at the Huijgens Lyceum in Voorburg. The same year she started to study medicine at the Erasmus University Rotterdam, and graduated as doctor in 1992. For two years she worked at the departments of internal medicine and cardiology of the Schieland Hospital in Schiedam, and subsequently for another two years in general practices in Schiedam. In 1996 she followed vocational training for general practitioner in Leiden for one year. Since 1997 she has worked on the research project at the department of General Practice of the Erasmus University Rotterdam, resulting in this thesis. Currently, she is working at the child health centre in Waalre.

She is married to Gerrit Slooter and they live in Borkel en Schaft with their three daughters Floor, Lotte and Hayke.