Pain in Children and Adolescents with Cerebral Palsy: A Cross-sectional Survey Study

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Abstract

Aim This study aims to investigate the prevalence, intensity, and location of pain in children and adolescents with cerebral palsy (CP) and analyze pain-related symptoms and participation restrictions.

Methods Children and adolescents aged 2 to 16 years diagnosed with CP were invited to participate in a pain survey. The questionnaire was based on the German Pain Questionnaire for Children, Adolescents and Parents (DSF-KJ). It was administered to children (2–11 years) by their caregivers, while adolescents (12–16 years) were asked to complete the questionnaire themselves or with the help of their caregivers.

Results Fifty-seven of 133 children and adolescents with CP (43%) reported having pain in the past 12 months, of whom 17 (30%) reported chronic pain. Patients with Gross Motor Function Classification System (GMFCS) IV–V reported more frequent pain ($p = 0.003$) and higher pain intensity ($p = 0.011$). Lower extremity pain was the most common. Twenty-three percent of participants with pain did not receive any treatment. Pain often restricted participation, specifically by reducing sports activity in patients with GMFCS I–III, focusing attention on patients with GMFCS IV–V, and activities with the family in both GMFCS level categories.

Interpretation Pain is common in children and adolescents with CP and frequently restricts their participation. Therefore, it must be consistently recorded and addressed during the consultation. The goal of treatment should be not only to reduce pain but above all to increase participation.

Keywords
- cerebral palsy
- pain
- children
- adolescents
- participation

Cerebral palsy (CP) is the most common cause of physical disability in childhood.[1] It describes a group of permanent movement and posture development disorders attributed to non-progressive disturbances occurring in the developing fetal or infant brain that cause activity limitations.[2] The causes of CP are diverse and include antenatal, perinatal, and postnatal factors.[3] The localization of the lesion determines a patient's neurological symptoms.[4] The severity of CP and patients' functional abilities vary widely. A commonly used classification tool for patients with CP is the Gross

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Motor Function Classification System (GMFCS), which divides gross motor function into five levels based on self-initiated movement ability.[5]

Pain is a complication of the physical disability associated with CP. The prevalence of pain reported in the literature varies widely. In one population-based registry study, 32.4% of the participants reported pain, including significantly more children with GMFCS IV or V than children with GMFCS I.[6] In another cross-sectional study, the overall prevalence of pain was 44%. Female sex and older age appeared to be risk factors for pain, but there were no statistically significant differences between GMFCS I and II–IV.[7] In another cross-sectional study, 67.1% of children and adolescents with CP reported acute pain, while 32.1% reported chronic pain.[8] International European multicenter studies have reported a pain prevalence of 60 to 75% in children and adolescents with CP.[9,10] A systematic review of CP studies[11] found an even higher prevalence (75%). Pain can interfere with activities of daily living and participation,[12] thereby significantly affecting quality of life.

There are various pain assessment tools used for children with CP. One study compared 31 measures of chronic pain in CP and found that most focused primarily on pain intensity and location while underrepresenting the functional impact of pain on participation and quality of life.[13] According to a systematic review of studies on pain in CP, there is a paucity of studies on the impact of pain on participation restrictions.[14] One of these studies found that pain often interfered with sleep, attention, and enjoyment.[8]

The aim of this study was to investigate the prevalence, intensity, and location of pain in 2- to 16-year-old children and adolescents with CP in two regions of Switzerland by age and GMFCS level. We also aimed to analyze the accompanying symptoms and triggers of pain, as these may help to identify pain. In addition, we wanted to further explore the impact of pain on participation, as this area is severely underrepresented in the literature. We addressed the following research questions.

1. How often do children and adolescents with CP experience acute and chronic pain?
2. What are the characteristics of pain in children and adolescents with CP regarding intensity, location, accompanying symptoms and triggers, and are those with more severe disabilities also more affected by pain?
3. In what domains does pain restrict participation in children and adolescents with CP?

Methods

Design

This study used a population-based, questionnaire design based on data from the Swiss Cerebral Palsy Registry (Swiss-CP-Reg). This registry was established in 2017 and is located at the Institute of Social and Preventive Medicine (ISPM) at the University of Bern.[15] Its aim is to promote research into the etiology of CP and the health care of affected children. All patients' families gave written consent for inclusion in the registry. The Swiss-CP-Reg was approved by the Ethics Committee of Bern (2017-00873). The Swiss-CP-Reg includes persons diagnosed with CP at the age of 0 to 18 years who were born and are treated or live in Switzerland. The Surveillance of Cerebral Palsy in Europe (SCPE) decision tree[16] is used to include or exclude children with CP in the registry. In contrast to the SCPE, the Swiss-CP-Reg also includes children who died before the age of 2 years. Data from the Swiss-CP-Reg are recorded in REDCap (Research Electronic Data Capture).[17,18]

Participants

Patients aged 2 to 16 years treated at the Children's Hospital of Eastern Switzerland in St. Gallen and the pediatric department of the University Hospital Bern and registered in the Swiss-CP-Reg were included in this study. The questionnaire was sent to a total of 222 patients, 131 from St. Gallen and 91 from Bern.

Study Procedure

A paper questionnaire was mailed to the potential participants in St. Gallen in October 2021 and the potential participants in Bern in December 2022. The questionnaire recorded school, home, and pain situations and GMFCS levels. The pain-related questions were based on the validated German Pain Questionnaire for Children, Adolescents and Parents (DSF-KJ).[19–21] Some minor adaptations were made to the questionnaire to assess the specific situation of people with CP, mainly to allow non-verbal assessment of pain. Information was collected on the prevalence of acute and chronic pain and pain intensity based on the Numeric Rating Scale (NRS),[22] pain duration, pain location, pain management, care received, accompanying symptoms of pain, pain triggers, and pain-related participation restrictions.[23] For detailed information, see the questionnaire in ►**Supplementary Material S1** (available in the online version only). Two versions of the questionnaires were used: Version A for children (2–11 years), completed by caregiver proxy report, and Version B for adolescents (12–16 years). Where possible, adolescents were asked to complete the questionnaire themselves or with the help of their caregivers. The questions were identical in both versions, but Version B was worded in the familiar form of address. Participants returned the completed paper questionnaires by post and the data collected were entered into a REDCap database at the ISPM at the University of Bern.[17,18]

Statistical Analysis

Categorical variables were expressed as absolute and relative frequencies and were compared between groups using Fisher's exact test. Numerical variables were summarized as medians and interquartile ranges and were compared between groups using the Wilcoxon rank-sum test. An α level of 0.05 was considered to indicate a difference. GMFCS scores and age were recorded in two categories (GMFCS I–III and IV–V, corresponding to ambulant and non-ambulant patients, and ≤ 11 and >11 years, based on the two versions of the questionnaire). Missing data were not imputed; so the analyses were based on the available data. All statistical analyses were performed in the R programming language (version 4.2.2).[24]

Table 1 Study population

Variable	Category/Level	Overall	Unreturned questionnaires
Population, *n*		133	89
Sex, *n* (%)	Female	53 (39.8)	40 (44.9)
	Male	80 (60.2)	49 (55.1)
Age, median [IQR]		10.1 [6.9, 13.4]	–
Questionnaire version, *n* (%)	A (children) B (adolescents)	81 (60.9) 52 (39.1)	54 (60.7) 35 (39.3)
Center, *n* (%)	Bern	51 (38.3)	40 (44.9)
	St. Gallen	82 (61.7)	49 (55.1)
Gross Motor Function Classification System, *n* (%)	I	54 (40.9)	34 (38.2)
	II	32 (24.2)	17 (19.1)
	III	20 (15.2)	11 (12.4)
	IV	19 (14.4)	11 (12.4)
	V	7 (5.3)	16 (18.0)

Abbreviation: IQR, interquartile range.

Results

Of the 222 questionnaires sent out, 133 (60%) were returned (St. Gallen, 63%; Bern, 56%). The characteristics of groups (sex, age, and GMFCS level) and a comparison of the data of participants with returned and unreturned questionnaires are shown in ►**Table 1**. Sixty percent ($n = 80$) of the participants were male and 40% ($n = 53$) were female. The participants from St. Gallen and Bern were comparable, as there were no major differences in the characteristics of the groups. The questionnaire was completed by the caregivers of all children (2–11 years old). Among the adolescents (12–16 years), 56% ($n = 29$) completed the questionnaire on their own or with the help of their caregivers, while 44% ($n = 23$) of the questionnaires were completed by caregiver proxy report. Some participants did not complete all the questions. This resulted in missing data for some variables. A total of 57 patients (43%) reported pain related to CP in the past 12 months, of which 30% ($n = 17$) reported chronic pain.

The proportion of participants who had experienced CP-related pain in the past 12 months was 33% in GMFCS I, 34% in GMFCS II, 45% in GMFCS III, 68% in GMFCS IV, and 71% in GMFCS V. Patients with GMFCS IV–V were therefore more likely to experience pain than patients with GMFCS I–III ($p = 0.003$). ►**Figure 1** shows pain intensity in relation to GMFCS levels. Patients with GMFCS IV–V had an average pain intensity of 6.5 out of 10, while patients with GMFCS I–III had an average pain intensity of 4.0 out of 10 ($p = 0.011$). The most common pain locations were the legs (35%), knees (35%), feet (33%), hips (28%), and abdomen (27%), followed by head (22%), back (19%), and muscles (18%). The most common accompanying symptoms of pain (►**Fig. 2**) were restlessness, breathlessness, tension, tears, screaming, and sleeplessness. A common association with pain was sleep disturbance. This was reported to occur at least sometimes by 42% ($n = 16$) of the patients with GMFCS I–III and 67% ($n = 12$) of the patients with GMFCS IV–V. Sweating was more common in patients with GMFCS IV–V than in those with GMFCS I–III ($p = 0.011$). The prevalence of constipation was higher in children younger than 11 years ($p = 0.025$). The most common pain triggers were physical activity and muscle tension (►**Fig. 3**). Physical activity seemed to be a more frequent trigger in older children (>11 years) than in younger children ($p = 0.006$). There were no apparent differences in pain triggers between GMFCS levels. Regarding recognition of the onset of pain, 32% ($n = 17$) of patients or caregivers who had experienced pain in the past 12 months reported that they recognized the onset of pain early, 56% ($n = 30$) reported that they sometimes recognized the onset of pain early and 13% ($n = 7$) reported that they did not recognize the onset of pain early (three missing responses). Forty-eight percent ($n = 25$) of participants who had experienced pain in the past 12 months received analgesics, while

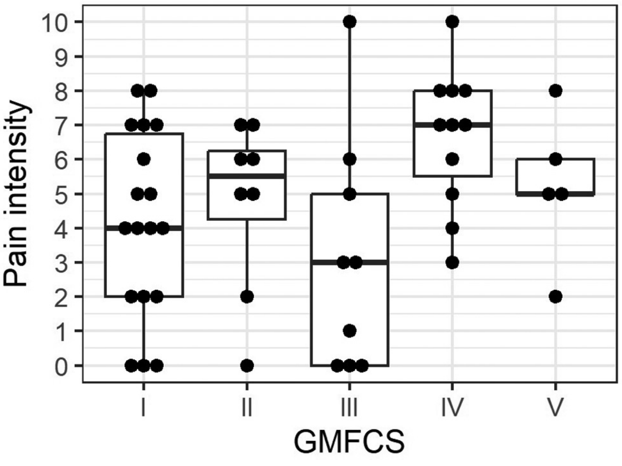

Fig. 1 Pain intensity based on the Numeric Rating Scale (NRS) in the previous 4 weeks as a function of Gross Motor Function Classification System (GMFCS) levels. The box plots show medians (lines inside the boxes), first quartiles (Q1: bottoms of the boxes), third quartiles (Q3: tops of the boxes), and potential outliers (points beyond the whiskers). The raw values are indicated by dots (five missing answers).

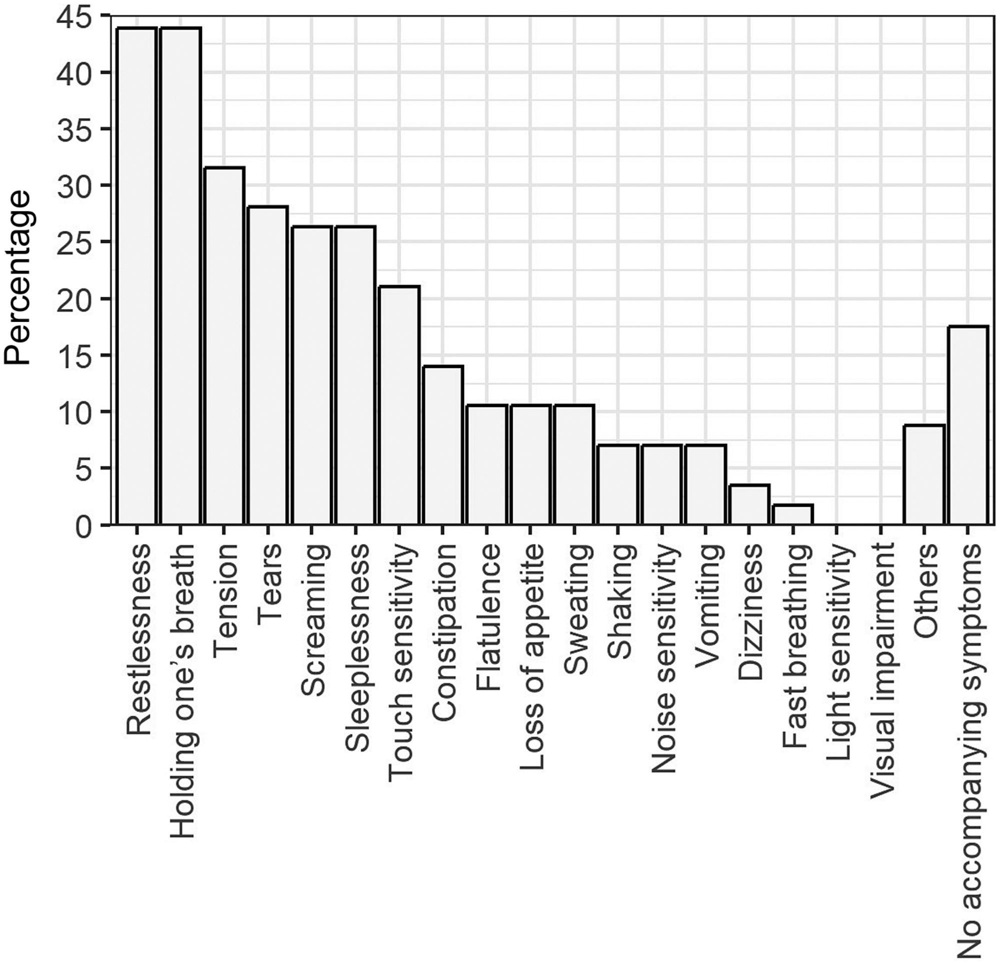

Fig. 2 Accompanying symptoms of pain.

52% ($n = 27$) did not (5 missing responses). Analgesic use was much more common in children and adolescents with GMFCS IV–V ($p < 0.001$). Other pain treatments, such as physical therapy, massage, osteopathy/chiropractic, or surgery, were applied in 61% ($n = 33$) of participants (three missing responses). Twenty-three percent ($n = 13$) of participants received neither analgesics nor other pain treatments. Patients or caregivers self-reported that pain directly restricted participation. The most commonly affected activities were focusing attention, sports activities, meeting friends, activities with the family, and school attendance. For patients with GMFCS I–III, 47% ($n = 18$) reported that pain restricted participation in sports, and 29% ($n = 11$) reported it restricted family activities, whereas for patients with GMFCS IV–V, 50% ($n = 9$) reported that it restricted the ability to focus and 33% ($n = 6$) reported that it restricted family activities (►**Fig. 4**).

Discussion

This study investigated the prevalence of pain in children with CP and its relation to disability severity and participation restrictions. We also examined associated trigger factors, symptoms, and comorbidities, as well as the most frequent pain locations. Consistent with previous studies, our results indicate that pain affects nearly half of the patients (43%). This underscores the critical importance of systematically and proactively asking about pain in children and adolescents with CP in daily clinical practice to identify and address its underlying causes.

Assessing pain intensity and frequency in children with severe disabilities is challenging. In our study, we observed that children with severe motor impairments (GMFCS IV–V) often experience higher pain levels and more frequent pain episodes, likely due to a higher incidence of comorbidities such as hip problems, digestive issues, osteoporosis, and sleep disorders. Disability severity was assessed using the GMFCS, emphasizing the complex relationship between motor impairment and pain. Many patients with high GMFCS levels have difficulty speaking or effectively communicating their pain, leading to frequent underestimation of their pain.[12,25] This highlights the critical need for clinicians to adopt a vigilant and systematic approach to pain assessment in these vulnerable patients to ensure that their pain is accurately identified and appropriately managed.

Consistent with previous studies,[14] pain was most common in the lower extremities. This is probably due to the heavy weight bearing on the legs, both in ambulant and non-ambulant patients. Abdominal pain was the fifth most

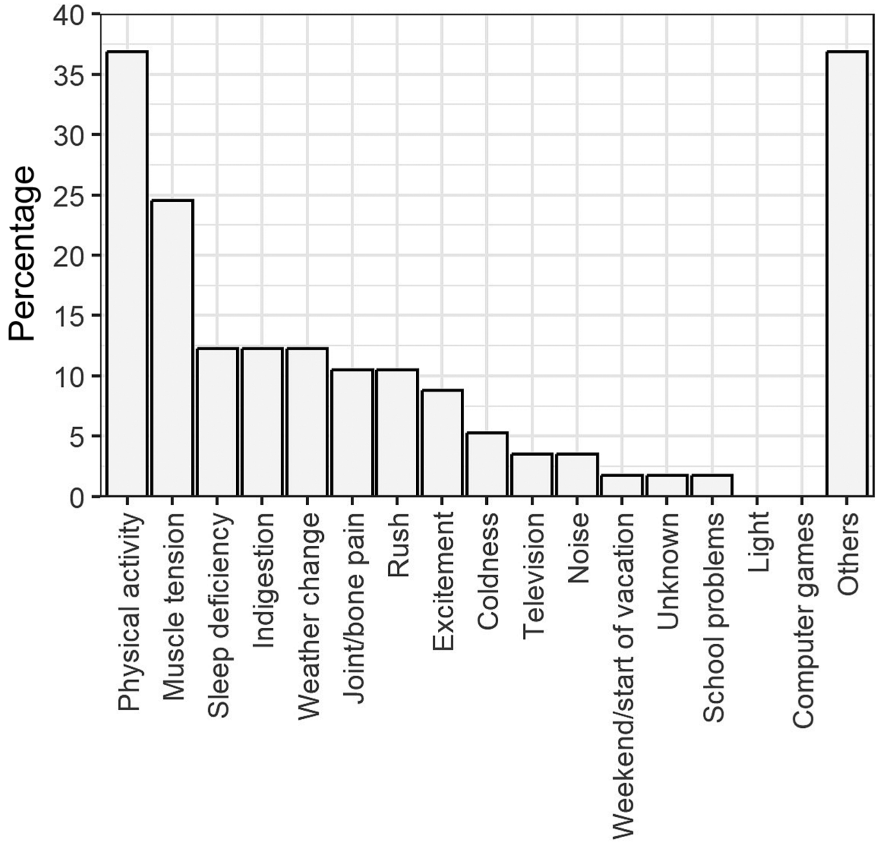

Fig. 3 Pain triggers.

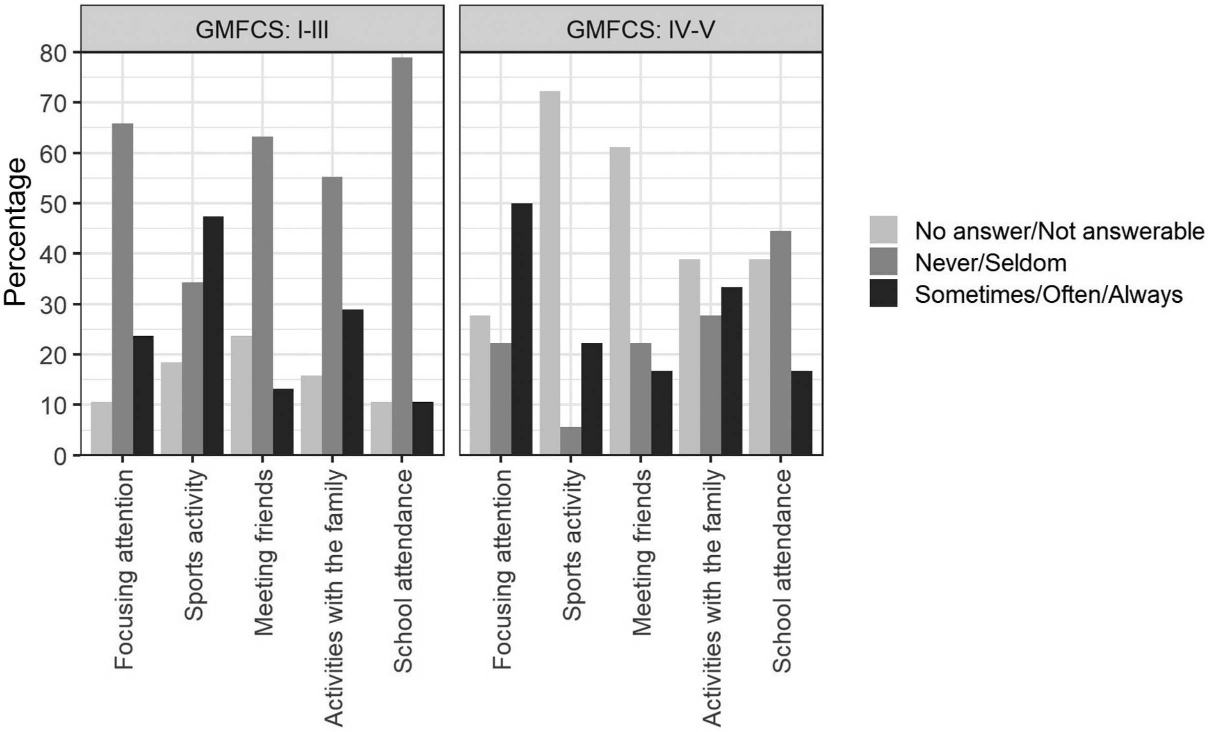

Fig. 4 Participation restrictions as a function of Gross Motor Function Classification System (GMFCS) levels. The percentages are based on the number of patients in each subgroup: GMFCS I–III, $n = 38$ and GMFCS IV–V, $n = 18$.

common pain location. Gastrointestinal symptoms were also frequently reported as accompanying symptoms or triggers of pain, suggesting that such symptoms are common in CP, especially in those with high GMFCS levels. In a study, the frequency of gastrointestinal symptoms in children and adolescents with CP was 81.7%.[26]

As mentioned previously, assessing pain in children and adolescents with CP, especially in those who cannot speak, is particularly challenging. Therefore, we wanted to focus on the accompanying symptoms of pain that could help identify a child's pain. The most common symptoms associated with pain were restlessness, holding one's breath, tension, tears, screaming, and sleeplessness. Sleep impairment due to pain seems to be very common in children and adolescents with CP. This should be further investigated in relation to CP severity and patient age to improve management. Pain triggers can also provide an indication of the development of pain. The most common pain triggers in this study were physical activity, muscle tension, and "others." The high proportion of "other" triggers indicates that there are substantial differences in pain among persons with CP. Examples of individual pain triggers included poor posture, surgery, use of orthoses, and psychological stress. We believe that knowledge of the general and individual triggers and accompanying symptoms of pain can play an important role in its early detection. More than 80% of patients and caregivers reported that they at least sometimes recognized the onset of pain early. Our clinical experience supports this. Most caregivers can tell when their children are in pain. This is a good starting point, but it needs to be improved. An easy-to-understand non-verbal pain assessment tool might be helpful for use by all those involved in a child's or adolescent's care. Some tools already exist. For example, the Non-Communicating Children's Pain Checklist-Revised (NCCPC-R)[27] has been used successfully at the Children's Hospital of Eastern Switzerland. It is important to consistently assess pain in non-communicating patients with a validated instrument. However, it is even more important to train caregivers and professionals in the use of this instrument. It should be used not only in the hospital and at home, but also in all facilities where people with CP go to school, work, or live. This can help to standardize pain detection and can be used as an argumentation tool to draw attention to pain.

Less than half of the participants who had pain in the past 12 months received pain medication, while this was more common among people with GMFCS IV–V. This may be due to the higher intensity of pain in this subgroup or because they are more accustomed to taking medication. Other treatments reducing pain were slightly more common but still used by less than two-thirds of the participants. However, it is possible that these treatments, such as physical therapy, were not used primarily to reduce pain. It is important to note that 23% of people with pain did not receive any treatment. Although this may be because the pain was not severe enough or did not last long enough to require treatment, it suggests that a considerable proportion of people with CP-related pain are not receiving adequate treatment.

Numerous studies in different countries have investigated the participation of children with CP in social life. Among other things, it has been shown that children with CP participate differently in various aspects of social life than children of the same age and that the degree of severity of the disability is a decisive factor in how well children and adolescents with CP can be integrated into social life.[26,27] It was found that the children in our study population also experienced restrictions on participation, such as focusing attention, sports activity, meeting friends, activities with the family, and school attendance. This corresponds to restrictions in four different International Classification of Functioning, Disability and Health (ICF) domains of activities and participation, namely learning and applying knowledge, mobility, major life areas, and community, social, and civic life.[23] In the GMFCS I–III subgroup, sports activity seemed to be particularly affected by pain. In the GMFCS IV–V subgroup, focusing attention and activities with the family seemed to be the most severely affected, but the other three activities mentioned above were also affected. Caregivers in this subgroup may have been more alert to a reduced ability to focus attention than the patients in the self-rated GMFCS I–III group. Notably, the "no answer/not answerable" option was selected more frequently in the GMFCS IV–V subgroup, as many of these patients are unable to perform certain activities, such as meeting friends or sports activity, due to their impairment. However, the fact that these questions were not answerable for patients with GMFCS IV–V reflects their restricted participation in these areas. In conclusion, participation in all activities was severely impaired in both GMFCS subgroups.

Study Limitations

There are several limitations to this study that limit the generalizability of the results. First, not all the families contacted responded to the questionnaire, so the results may not be representative of the entire study population. Random samples showed that the children of the families who responded did not differ from the children of the families who did not respond. Nevertheless, the results should be generalized with great caution. In addition, the selected sample is not representative of the whole of Switzerland, as only two centers were involved. Although the populations and results of the two centers were not significantly different, conclusions about children in other regions of Switzerland are limited. Caregivers or patients whose first language was not German may not have been able or willing to complete the questionnaire. The completion of the questionnaire by caregivers of younger and non-communicating older children may have introduced another possible bias, as the perception of others does not always match the self-perception. The choice of questionnaire can also be criticized. We chose a questionnaire that has been used in many clinical settings and has been found to be very useful. However, the questionnaire was not specifically designed and validated for children with CP. Therefore, some adaptations were made to the questionnaire, which means that the results should be generalized with caution. Future studies should therefore include questionnaires and assessments developed specifically for children and adolescents with disabilities that optimally and reliably measure pain and participation. Chronic pain in children and adolescents with CP and gender differences should also be further analyzed. The patient sample was rather small. For a more representative study, a larger study population is needed, and comparisons should be made between different, preferably multinational, centers. Finally, we would like to point out that CP represents very different clinical profiles and that pain is a subjective symptom with individual needs.

Conclusion

Our results showed a high prevalence of pain in children and adolescents with CP. Patients with GMFCS IV–V experienced pain more frequently and had higher pain intensity. However, we would like to emphasize that patients with low GMFCS levels also experience pain. Pain was most commonly located in the lower extremities and frequently caused restriction of activities and participation. Pain assessment in children and adolescents with CP is challenging, especially in patients who cannot speak. Knowledge of the triggers and accompanying symptoms of pain can undoubtedly play an important role in the early detection of pain. Our findings suggest that a large proportion of people with CP-related pain are not receiving adequate treatment. However, the first step in treating pain is to recognize it. Therefore, pain as well as participation restrictions due to pain must be consistently recorded and addressed during the consultation. The goal of treatment should be not only to reduce pain but above all to increase participation.

It is our concern to ensure that more attention is paid to pain in the care of children and adolescents with CP throughout Switzerland. Thus, we aim to improve the care and management of these patients to prevent or detect and treat pain early, to help patients increase their participation, and to improve their quality of life.

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Conflict of Interest
None declared.

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