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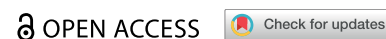


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RESEARCH ARTICLE



“Pain is one piece of a complex jigsaw puzzle” – experiences of raising a child with cerebral palsy who has pain

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ABSTRACT

Purpose: To explore experiences of parenting a child with CP and pain.

Method: Fourteen mothers and one father of children (9–16) with CP were included. All children had pain regularly, but the frequency and intensity of their pain experiences varied. Their motor function varied from GMFCS level I to V. Cognitive abilities varied from normal to moderate cognitive deficits. All children could express themselves verbally. Semi structured individual interviews were carried out, and results were developed using inductive thematic analysis.

Results: The analysis resulted in the main theme “My child’s pain is just one piece of a complex jigsaw puzzle”. The main theme was developed by four mutually exclusive, but related themes: “My child’s struggle burdens me”, “Pain and CP direct our everyday life”, “I want to be in control, but cannot always be” and “We are the only ones who understand the complexity”.

Conclusion: Parents of children with CP experience pain as one aspect of a bigger picture. They need help and support to cope with their child’s pain, and professional helpers need to address the complexity pain is a part of.

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> IMPLICATIONS FOR REHABILITATION

- Parents of children with cerebral palsy (CP) experience their child’s pain as one piece in a jigsaw puzzle, and counseling needs to address the complexity rather than the separate parts of the picture.
- Health professionals should support parents in evaluation and management of their child’s pain, as a feeling of competence in pain management is important to reduce parental stress.
- Health professionals should inform themselves about the life situation of parents whose child with CP has pain, and encourage them to seek practical support and apply for relevant support schemes that can make their everyday life easier.
- Parents of children with CP should be encouraged to take part in a diagnosis-specific support group, where they can meet with others in a similar situation, in order to reduce their feeling of being alone with their challenges.


Introduction

The focus of this study is parents’ experience of raising children with pain related to cerebral palsy (CP). CP is a permanent condition defined by movement disorders caused by brain injury around birth or during early infancy. The movement disorders vary in type and severity depending on characteristics and timing of the initial brain injury. While some children have invisible movement challenges, others are unable to move around, and depend on a wheelchair. Cognitive, sensory, communicative, behavioral and perceptual impairments are also common, in addition to epilepsy, and likewise occur to various degrees depending on the initial injury [1]. Children with CP often experience pain [2], both as a secondary condition to the musculoskeletal affections and because of treatment interventions [3].

Consequently, raising a child with CP can pose additional parental challenges compared to raising a child without functional deficits. Parents have reported reduced mental and physical health, increased stress and lower quality of life compared to the population in general [4,5]. Low perceived self-efficacy in this group of parents is found to increase their risk of stress [4,6].

Various aspects of parenting a child with CP have been studied, aimed at increased understanding of what contributes to parents’ challenges. Cognitive impairments and maladaptive behavior in children seem to increase parental stress [6–8]. Pain is also one of the risk factors pointed out [9–11]. Pain is an individual experience resulting from an interplay between sensory, emotional, cognitive and social components [12]. Because of the social aspects of pain, it affects not only the child experiencing the pain, but also their

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parents. Pain in children with CP can be difficult to evaluate and treat [13,14], and thus it may decrease parents' trust in their own competence as a parent, and thereby increase their stress [4,6]. Feelings of competence and social support, on the other hand, seem to reduce the risk of stress in parents of children with CP [7,15].

There are few studies describing how parents experience the combination of CP and pain, but existing studies have pointed out that parents see themselves as their child's pain interpreter, advocate and mentor, that the caregiving task is demanding, and that there is a need for more family-centered help with pain management [13,14,16]. However, these studies included only parents of children with severe motor impairments, who were unable to self-report pain because of communication deficits. Since CP is a heterogeneous condition, we do not know if their experiences are also representative for parents of children who can express themselves verbally.

Quantitative studies confirm a correlation between the combination of CP and pain in children, and parental stress [9–11]. However, more in depth understanding of how pain in children with CP influences parents' daily life and psychosocial well-being is needed, to suggest interventions that may reduce parental burden. To offer better help, we should also know more about what support parents need to cope with their child's pain.

The aim of this study was to explore the experiences of daily life and psychosocial well-being among parents raising a child with CP living with pain. Two aspects were explored: how the child's situation influenced the parent's daily life; and the parent's experiences of support in managing the child's pain.

Materials and methods

Design

This qualitative interview study had an inductive descriptive design [17]. We conducted the study as part of a project addressing the pain burden and pain-related support experienced by children and adolescents with CP and their parents. The children's own experiences have been described separately [18].

Procedures

Sample and setting

Fifteen parents (14 mothers and one father) of children with a CP diagnosis participated. They were part of child-parent dyads recruited for the overall project where child characteristics determined the dyads eligibility for participating. In addition to a verified CP diagnosis, inclusion criteria were child age 8–17 years, ability to communicate verbally, and experiencing pain regularly. We aimed to include a heterogeneous sample with regard to the children's sex, age, physical and cognitive abilities.

Clinicians at two pediatric rehabilitation units in southeastern Norway identified potential children eligible to be interviewed. The clinician then contacted their parents with information about the study. If they were interested, and pain was confirmed based on the parent's answers to a verbal question derived from Dalhousie Pain Interview [19], a researcher contacted them to secure informed consent and schedule an interview with one of the parents. The parents' demographic data are presented in Table 1.

The children with CP were nine boys and five girls between nine and sixteen years old. Based on information from parents, the group of children can be described as follows: Gross motor function ranged from level I (walking without assistance) to level

Table 1. Demographic data.

Participants	N = 15
Mothers/Fathers	14/1
Age [mean / median / range] in years	42 / 44 / 36–50
Education	
College/university > 3 years	5
College/university ≤ 3 years	3
High school	6
Primary school	1
Employment	
Full time	12
Part time	1
Student	1
Unemployed	1
Family situation / custody	
Living together with other parent	10
Living apart from other parent with shared custody	4
Living apart from other parent, sole custody	1

V (transported in wheelchair) according to the Gross Motor Function Classification System (GMFCS) [20], with a majority of children ($n=11$) in GMFCS levels I–II. Degree of cognitive impairment was not known for all children, but four had adaptive training in school. Two of the children were diagnosed with autism, and one with moderate intellectual disability.

Data collection

Data were developed in semi-structured individual interviews [17]. Prior to the interviews, the interview guide was discussed with a user panel consisting of parents of children with CP and an adult living with CP. It was also piloted in one interview with the mother of a girl who was not included because she was above eighteen. No need for changes was identified. Participants were asked to talk about how their child's pain influenced their everyday life, thoughts and emotions related to their situation, and what kind of support they felt they had or were in need of in relation to their child's pain. The interview guide was used to ensure that these topics were covered, but parents' stories were not necessarily limited to the topics in the interview guide (Supplementary Material). If they brought up other related topics, these were explored. At the end of the interview, parents were also encouraged to talk about whatever they thought was relevant, but had not been asked about.

The interviewer was a psychologist with several years of experience from the pediatric rehabilitation unit. Some parents knew the interviewer from prior clinical consultations, but none had an ongoing clinical relation at the time of the interview. Parents chose the time and place for their interview. Four interviews were conducted by telephone and the rest face-to-face at their home ($n=5$), the rehabilitation unit ($n=4$), their workplace ($n=1$), or their child's school ($n=1$). Interviews lasted from seventeen to ninety minutes, and the average length was fifty-two minutes. One interview was conducted with the help of a professional language interpreter, between a non-Nordic language and Norwegian.

Interviews were digitally recorded and transcribed verbatim. However, to protect personal information, all names of people and places were changed in the transcripts.

Data analysis

The analysis started by the first author checking the accuracy of the transcripts against the recorded material. Further, thematic analysis as described by Braun and Clarke [21] was based on the

written transcripts. Initially, all four authors read four of the transcripts separately to identify themes. Afterwards, all authors met to agree on the themes to guide further coding. The first author then reread and coded all transcripts. Next, the first author organized the codes into the preliminary themes and subthemes covering similar content. In the next step, all authors discussed organization of tentative themes and subthemes, rearranged and discussed again until agreeing on the final thematic structure. The aim of this process was to find a thematic structure consisting of themes with internal consistency and minimal overlap. Thereafter, the final thematic map was checked against the entire data set. In the last step, all four authors together revised names of themes, to ensure the name reflected the essence of each theme.

Analyst triangulation, as described above, was used to increase trustworthiness [17]. The four female researchers had different professional and academic backgrounds. Findings were also discussed with the user panel, consisting of an adult living with CP and two parents raising children with CP.

Ethical considerations

Participation was voluntary. All participants received oral and written information about the study, and had the opportunity to ask questions before providing written informed consent.

The study was approved by the Norwegian Regional Committee for Medical and Health Research Ethics (REC South-East 46124). The research institution approved the processing of personal data, based on advice from the institution's Data Protection Official for Research (19/02788), in accordance with the European General Data Processing Regulation (GDPR) and the Norwegian Personal Data Act.

Quotes from parents are used to illustrate themes in the results, but to ensure anonymity, quoted parents are not described by more than a specific number which could only be traced by the researchers involved. All names in the quotes have been changed.

Results

The data analysis resulted in the main theme "My child's pain is just one piece of a complex jigsaw puzzle". Parents described experiencing their child's pain as one of many factors combining to influence the family's everyday life and psychosocial well-being. Four themes were identified within this main theme: "My child's struggle burdens me"; "Pain and CP direct our everyday life"; "I want to be in control, but cannot always be"; and "We are the only ones who understand the complexity". These themes illustrate different perspectives of the parental experience of daily life, including support and need of support in managing the child's pain. An overview of the main theme, themes and subthemes is presented in Figure 1.

My child's struggle burdens me

Having a child living with pain meant an emotional burden for parents. They experienced sadness, grief and feelings of helplessness, and they were worried about the child's future. They also found the responsibility for keeping the balance between minimizing pain and optimizing development stressful.

I Feel tormented and powerless

Parents described watching their own child in pain as a heavy emotional burden. They used expressions like "it's terrible", that it "hit [them] right in the heart", and they thought it was the worst

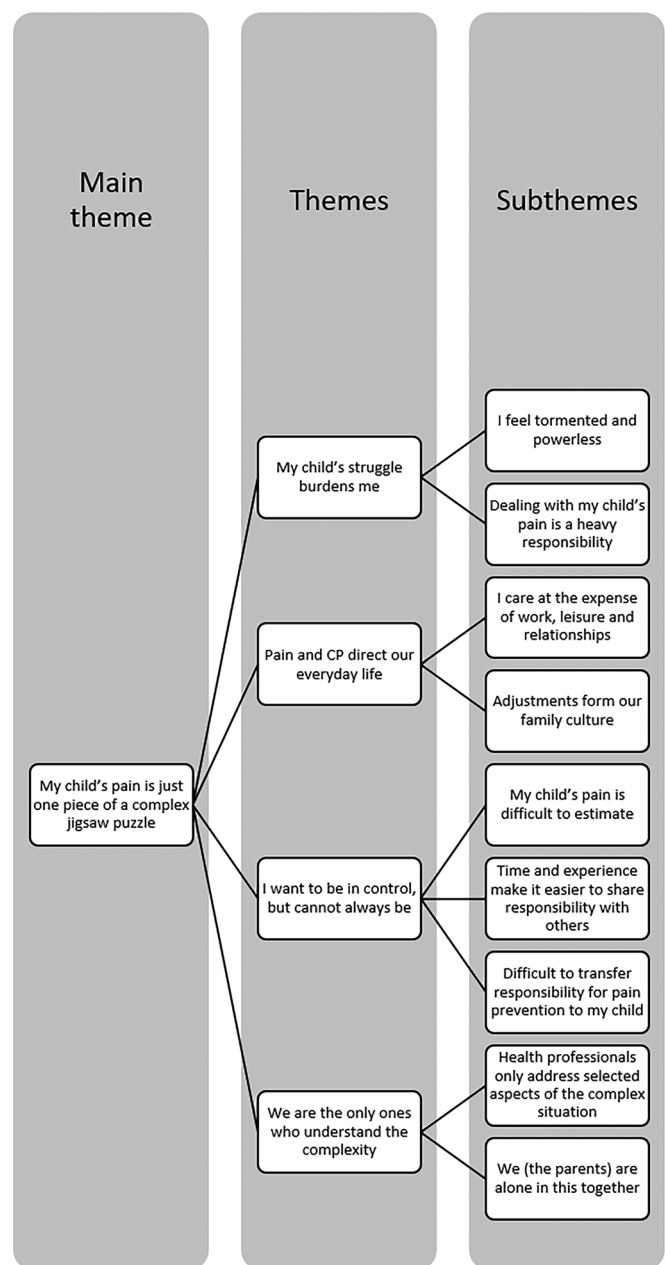


Figure 1. Overview of main theme, themes and subthemes.

This figure illustrate our findings. The main theme, My child's pain is just one piece of a complex jigsaw puzzle, is to the left, with lines connecting to themes and their respective subthemes, placed to the right in the figure. The four themes are:

1. My child's struggle burdens me.
2. Pain and CP direct our everyday life.
3. I want to be in control, but cannot always be.
4. We are the only ones who understand the complexity.

The subthemes are described in the text under each theme.

one could experience as a parent. These negative feelings were also related to the consequences of their child's pain, like the child having to skip joyful or social activities:

... Well it's painful. It's very painful to sit and watch [that pain makes her withdraw from social activities]. Because she misses out on the social aspects.

...

And I think it's almost the worst. Eh, in terms of feeling included.

Included, that is... There wasn't anyone who didn't include her, I mean, she wasn't always left out, but she shut herself out. #15 (Child with GMFCS level I-II)

Not knowing how to ease their child's pain resulted in parents experiencing a feeling of despair and powerlessness. They could be there for their child, and offer comfort and medication, but still felt they had no tools to fight severe pain. A mother described this feeling of helplessness and of feeling inadequate as a mother like this:

Yes, you actually feel a little helpless, if you, yeah, that's probably the right word: helpless and inadequate. Yeah, somehow there's nothing you can do [to lessen the pain]. And then it kind of makes you feel overwhelmed, and you kind of just have to withdraw from the situation a bit, because it's just overwhelming, sort of, in a negative sense. #11 (Child with GMFCS level III-V)

It was also an emotional challenge for some parents when their child preferred to be alone when experiencing pain, and withdrew from them. Some children refused hugs in such situations, as this increased the pain. This gave parents a sore feeling of being rejected by their child.

Adding to their burden, some mothers felt responsible for their children's CP because they felt they had overlooked that something was wrong during the pregnancy. Consequently, they struggled with self-blame and a lingering feeling of guilt.

Dealing with my child's pain is a heavy responsibility

Having a child with CP who experienced pain resulted in extended parental responsibility, including worries about the future. Parents felt responsible for their child's future development, and wanted them to achieve the best possible motor function, without increasing their pain. This included the responsibility of finding the right balance between physical exertion and rest for their child, since too much exertion could increase pain. It was described as emotionally stressful to force measures or insist on interventions against the child's will, and more so when at the same time feeling uncertain about the optimal amount of exercise and rest.

The burden of parental responsibility increased when the child did not understand the necessity of interventions, and therefore protested when the parent interrupted play for stretching. It was also burdensome when interventions meant that parents had to inflict pain and discomfort on the child. In addition, interventions became burdensome because they were a constant reminder of possible difficulties and pain in the child's future.

A central concern for many parents was that they wished to help their child live their best life, despite the pain. Parents perceived pain as an unavoidable aspect of CP, and believed that some level of pain was unavoidable. Consequently, they did not want to cultivate the pain or give it more space in their lives than necessary. Some thus downplayed the child's pain a bit, despite their own grief, to "toughen them up". Others tried to help the child focus on the positive rather than dwelling on pain and other negative aspects of CP. One parent said:

And, there are times now too, when she says that she wishes she didn't have CP. And obviously, it hits me right in the heart. But we've deliberately tried not to dig too deeply into the negative stuff, because we kind of can't do anything about it. She has the diagnosis. She has the stiffness. Our job it is to make the best of it. #8 (Child with GMFCS level I-II)

Parents were used to their child's pain, and worried about their ability to distinguish the "normal" pain from new or more severe pains that needed more attention, such as follow-up by a health care provider. To experience pain as the norm, rather than the

exception, made it difficult to judge the best measures to take. For example, when the child expressed a wish to stay home, it could be difficult to decide when the child needed to stay home from school, and when they should go despite the pain. Deciding when to use pain medication could also be challenging. Some parents were reluctant to use pain medication due to concerns about the safety when used too frequently; others restricted use of pain medication because it only addressed the symptoms and could not reduce the underlying causes of pain.

Pain and CP direct our everyday life

Pain and CP directed families' everyday life. It occupied significant amounts of time, sometimes at the expense of work, leisure activities and relations. It could also form family culture, and set boundaries for family life and activities.

I Care at the expense of work, leisure and relationships

Pain prevention and management affected parents' everyday life both emotionally and by limiting their free time. For some, the combination of helping their child in everyday situations, comforting them when they were in pain, and carrying out treatment and accompanying them to medical appointments became very controlling in everyday life.

Parents wanted to be present for their child when the child was in severe pain. Some believed that their child coped better with the pain at home in a safe and familiar environment, and thus chose to pick up their child from school or respite care when they experienced various levels of pain.

Preventive measures such as exercise and stretching took place several times a day in some families, and required time and planning. Some also spent additional time preparing for stretching with fun and games, or conversations about why to stretch, before stretching, to reduce the child's experience of pain. Despite allocating a considerable amount of time to managing the child's pain, some parents still felt they never did enough and that their child should have had more exercise or the parent should have accompanied the child to various facilitating activities more often.

In addition, children frequently required more supervision compared to their peers to avoid injury and pain from falls. Some parents were constantly on the alert, even when their child was not present. They lived with a constant and exhausting fear that something bad could happen to the child at any time:

...and the feeling that you can't ever relax, it's terribly exhausting, and you keep your phone in your pocket, right, and you have a special ringtone for school, right, in case the school calls, yeah, that's not all right at all. #1 (Child with GMFCS level I-II)

Not only did treatment and prevention of pain frequently take a lot of time out of their day; some parents were often awakened during the night, when their child was in pain and crying or coming to their parent for help. Even when their child was sleeping, concerns about seizures or pain could impair the parent's sleep. Some chose to sleep with their door open to hear if something happened, or go to bed late, making sure the child was fast asleep before allowing themselves to fall asleep. The impaired sleep caused fatigue in parents.

The child's extensive care needs left parents with less capacity and time for work, and some managed to keep up with their job simply because the employer was flexible and accommodating. In some families, parents' social life was reduced. They did not have the time or energy to be social and active in the little

spare time they had left. Other parents chose to avoid socialization to safeguard the child's need for peace and quiet. The extensive demands could also burden the relationships between the parents:

It's like – when the afternoon comes, and dinner is over, and homework is done, you're exhausted. You sort of don't have the energy for anything. So putting on your shoes and walking the dog is sort of the easiest and best thing, just walk alone and not bother anyone [with my problems], and maybe my husband and I have started feeling irritated at each other, and that's not good either. #1 (Child with GMFCS level I-II)

Some experienced being divorced and having shared custody as a life-saver. It gave them time to recover and rest when the child or children were with the other parent.

Adjustments form our family culture

Some families lived what the parent considered a normal life despite the child's pain. Others adapted their family's way of life to avoid making the child with pain feel like a burden:

...at least I'm trying to think to myself that we shouldn't... He shouldn't feel like we have to do anything extra for him. He's just a natural part of the family; we're not doing anything special... He shouldn't feel he is a burden. #4 (Child with GMFCS level I-II)

Despite this, some had adapted their activity level to such an extent that they usually did not notice it was adapted; rather they were used to living the life they did. The whole family just lived a quieter life than they might otherwise have done. However, many deliberately limited or avoided certain activities or situations to avoid fatigue and triggering of the child's pain. For example, they took fewer and shorter walks or avoided outdoor activities in the cold. They planned according to the child's daily form, and avoided making appointments in advance because they often had to cancel them in the end. They ensured the child had time to rest before and after special activities, they tidied up for their child, drove them to school and training, opted out of participating in organized leisure time at school, and turned down many activities and events for the whole family to take care of the child's need for quietness and rest. Others planned active leisure time because the child needed activity to prevent pain.

For the sake of siblings' needs, some chose separate family activities, to ensure that siblings were able to take part in activities that were not feasible for the child with CP. However, caring for the child with CP could also happen at the expense of siblings. As a result, parents felt siblings received too little time and attention, or were given too much responsibility. In addition, some parents found it challenging to provide both the child with CP and siblings with good conditions for their upbringing, because they needed different arrangements. For example, what the sibling without disability was expected to manage alone, the child with CP might need help with to save energy and avoid increased pain.

I Want to be in control, but I cannot always be

Parents wanted to be in control of their child's health and well-being, but difficulties assessing and managing their child's pain weakened their sense of control. In addition, parents at times had to relinquish control by handing over responsibility for their child to professional caregivers, or giving the child more freedom and responsibility, as they grew older.

My child's pain is difficult to estimate

Challenges in assessing their child's pain contributed to parents' feelings of not being in control. It could be difficult to know whether the child was in pain or not, and how severe the pain was. Even though the children were verbal, they could have difficulties expressing their pain in words. According to the parents, some preferred to talk only a little or not at all about their pain, were annoyed if asked about it, or pulled away when in pain. Some children were so accustomed to their pain, that they did not think of it as pain, and used other words to describe their experience. These could be words like stiff, tight, it aches, and "my leg is stupid today". Tired was also a word parents assumed could mean pain. Some thought that they themselves had used the word pain so seldom that it had not become a familiar term for the child:

I don't know, maybe we haven't talked enough [about pain], or used the term pain in such a way that it would actually have been recognizable to him as well. #7 (Child with GMFCS level I-II)

Because of these difficulties parents had to interpret their child's non-verbal signs of pain, and often applied a process of trial and error to determine the pain situation. Although parents routinely interpreted body language and behavior to estimate pain, they sometimes felt unsure of their own judgement, and were afraid they might have overlooked or underestimated pain in their child:

It's sort of so sad that he has pain, and he doesn't tell us, or he doesn't express it, and then maybe we don't see it, and that's really sad. #10 (Child with GMFCS level III-V)

On the other hand, some parents believed their child would sometimes make false complaints about pain, to escape activities or situations they did not like. This made it even more complicated for parents to determine whether their child was in pain, and how severe the pain was.

Time and experience make it easier to share responsibility with others

When their child required a lot of care, some of the parents needed support to manage their everyday life. This was emotionally demanding; they wanted to manage on their own and did not trust others' ability to take proper care of their child. They were afraid that others would not take good enough care to avoid accidents, resulting in pain, as well as ignoring or overlooking signals of pain.

...so it's a bit tough, I often find that when Michael is at school, I often wonder, "Can the others see?" or I feel, I have the feeling that others may not understand Michael very well.

...so it's rather important to include this, I think, because that's what it's all about. Is he in pain? Can they interpret his facial expressions? Do they understand what he's trying to say? #11 (Child with GMFCS level III-V)

With time, some parents found it easier to accept help. It was described as a process. They gradually learned to trust others' ability to take care of the child, and realized that they could not do everything themselves.

Personal assistants in the home provided good support for those who had been offered this service. The assistants provided the help parents and children needed, without the disadvantages of sending their child away for respite care.

Difficult to transfer responsibility for pain prevention to my child

Parents wanted to help their child make good choices to prevent or reduce pain. This was easy when the child was young, and their parents made decisions for them. As the child grew older, parents felt the child should be allowed to take on more responsibility for such decisions themselves. Nevertheless, parents found it difficult to determine what their child should be allowed to decide, and when it was appropriate to push or coerce the child to do what the parent felt was in their best interest. It caused the parents frustration to see their child getting stiffer due to not following their stretching regimen, or experiencing headaches due to too little sleep.

Parents sometimes struggled to make their children use aids. Their children and adolescents were reluctant to do so because they desired to be like their peers despite their CP. For example, a child wanted “cool” shoes instead of built-up shoes, and others did not want to sit inside with a teacher, when the rest of the class went for a walk, just because the walk could cause pain.

It could also be difficult to give children the freedom to play like their peers. Some parents wanted to keep their child close because they had increased risk of falls, injuries and subsequent pain. Although they did not want to let their child out of sight, they felt guilty that they thereby restricted the children’s freedom to play:

...whereas she might prefer to run around in the underbrush and enjoy it. So yes, we’re probably kind of depriving her of liberty. We feel it....”
#1(Child with GMFCS level I-II)

We are the only ones who understand the complexity

Parents felt that they as parents were the only ones who really understood the complexity of their child’s situation. The challenges associated with their child’s pain were intertwined with many other difficulties caused by the CP diagnosis, associated diagnoses or difficulties, but they believed that the support system did not grasp this complexity.

Health professionals only address selected aspects of the complex situation

The parents regarded it as a problem that no one, besides themselves, saw the complexity, or the connections between their child’s various difficulties. Additional diagnoses or difficulties associated with the CP, such as epilepsy, cognitive deficits, autism, migraine or digestive problems could result in pain, or considerably increase the challenges of managing pain. For example, the parents experienced that having cognitive impairments could limit the child’s ability to take responsibility for using aids, pacing their activity or doing other things that helped reduce pain. Furthermore, for children with autism, it could be difficult to make necessary adjustments to prevent pain, such as change of chairs or shoes, because the child had difficulties accepting changes. Autism could also be related to school refusal, often stating pain as the reason for needing to stay home. Epilepsy complicated everyday life if children had to be under surveillance to avoid falls and resulting pain.

The parental awareness of the complexity greatly influenced how they assessed and responded to their child’s pain. However, their experience was that the professional health care system seldom considered the complete picture: pediatric mental health services gave advice on autism, and pediatric rehabilitation followed up on CP. Thus, parents might be advised about prevention of spasticity, but not about how to make their child with autism accept the necessary interventions:

Well, the rehabilitation center focuses on the CP, while the pediatric psychiatry clinic looks into the autism. And it’s never, well there aren’t many of them who say: “Let’s take a look at the overall situation,” so to speak. #6 (Child with GMFCS level III-V)

Another part of complexity was the fact that parents experienced having a mild degree of CP could sometimes involve its own challenges. Some children experienced a lot of pain, despite their mild CP, but sometimes this pain was not taken seriously, because it could not be easily explained as resulting from CP.

It’s not rare for me and Dad, or us and the siblings, to exchange glances, when she’s quietly hurting and doesn’t say anything. We see that she is tormented. It is not rare that, when she is frustrated and sad, and says something, that we feel hopeless. And then there’s a bit of frustration again, because there’s no real explanation for it, either with CP or with rheumatism or.... There is no diagnosis that can explain it. And (...) we’ve felt that it’s been maybe the professionals don’t believe in our child, about how intense these pains actually are, and that they are there all the time, just because she has such mild CP. #12 (Child with GMFCS level I-II)

In addition, mild CP resulted in fewer check-ups and less follow-up from the child habilitation unit. Arrangements, such as handicap parking permissions might be needed to avoid overload, but were difficult to obtain because the child only had mild CP.

We are alone in this together

Although many had support from family and friends, they also felt alone with their challenges, as others did not fully understand how demanding their life situation was.

It was more difficult to ask for and receive assistance when service providers did not understand or acknowledge the demanding situation parents lived in all day, every day, all year. One mother described the difference between her own situation and the professional caregivers’ situation in this context, underlining how they are on duty eight hours, while parents are on duty continuously, and are more emotionally involved.

Many felt that only the two parents really understood the situation, and thus the other parent was an important conversation partner. Nonetheless, parents also highlighted the usefulness of talking to others in the same situation. However, some had opted out of this because they did not perceive the CP association or similar arenas as relevant.

When the child experienced severe pain over time, some had experienced the wait time for an appointment at the rehabilitation unit as far too long. When it later turned out that Botox was helpful, this experience was reinforced; they would have liked to receive this help sooner. They also wanted more counseling from the pediatric rehabilitation unit on pain and pain relief, for both themselves and their child.

Overall, parents felt they received sufficient help aimed at CP in general, but too little or none at all related to managing their child’s pain. They had had to find out for themselves what could ease their child’s burden:

I might have wanted to say something about precisely that: the need for knowledge, somehow [a mother speaking about her own need for more knowledge]. About CP, and about pain, and about pain relief, and recognizing things. I wish that maybe there had been a closer follow-up...to get a little trickle of the knowledge that you professionals have, I would really have appreciated that. #7 (Child with GMFCS level I-II)

Discussion

The aim of this study was to explore the experiences of daily life and psychosocial well-being among parents raising a verbal child with CP living with pain. Participating parents found it difficult to report experiences with pain detached from other challenges. The child's pain was part of a bigger picture, which shaped parents' emotional reactions, thoughts and concerns, as well as what they did to manage their child's pain. Parents implicitly and explicitly expressed a need for more professional support in managing their child's pain, but at the same time they expressed a need to be in control.

Below, our findings will be discussed in relation to previous research, and suggestions for support will be offered. Previous research has shown that parents of children with CP and pain are at increased risk of stress and reduced quality of life [5,22], and our results illustrate some of the strain parents may experience.

Participants in this study represent a broader spectrum of the CP population than previously published studies including only parents of children with more severe degrees of CP [13,14,16]. Yet, there are several common findings, like the experience of a demanding caregiving task and the expressed need for more help with pain management. However, parents in our study did not express the same need to act as their child's advocate or spokesperson, as parents in these previous studies [13,14,16]. This may be explained by the fact that the children in the present study were able to communicate verbally.

Parents described feeling tormented and powerless when their child suffered from pain. This emotional burden was increased if they felt unable to help. A feeling of incompetence and lack of self-efficacy has been found to be associated with stress in parents of children with CP in general [4–6], and our results indicated that feelings of powerlessness also increased parental stress related to children's pain. In a recently published study on children's own experience of pain and CP, children described being understood, for example by their parents, as important help [18]. This indicated that despite parents feeling powerless and unable to take the pain away, they offered important support to their child.

Parents sometimes found it difficult to estimate their child's pain. Finding the right balance between giving enough emotional support without giving the pain too much space was challenging, partly because of this difficulty. This supports the point of view that health professionals should evaluate pain in children more systematically [23–25], and not solely leave this responsibility to the parents.

Since participants described feelings of both incompetence and powerlessness, our results underlined the importance of a family-centered approach when it comes to pain in childhood CP [5]. King et al. [26] described family-centered service as an approach where parents' knowledge of their child is respected, families are given sufficient information to make informed choices, and family and professional health workers cooperate. Such support might lessen the parent's feeling of incompetence and powerlessness, as this approach was found to increase parents' feeling of competence and self-efficacy [26].

Parents experienced the child's pain as one aspect in a complex context, but felt that health professionals related to the individual parts and not to the whole. The importance of understanding pain in a bio-psycho-social context is supported by the model of the International Classification of Functioning, Disability and Health (ICF) [27]. In ICF, health and disability [in this specific case pain] are understood as resulting from the interaction of medical phenomena and a diversity of personal, social and environmental factors. Our results indicate that health professionals do not always

adopt such a view, and that a more holistic approach would be more in line with parents' perspective of their child's pain in a complex context. For example, appropriate interventions should be developed together with the child and parents based on knowledge of both family situation and the child's strengths and limitations.

Parents' idea that their own reaction to their child's pain influences their child's experience is in line with the social communication model of pain. This model describes how children's experience of pain is formed through interaction with others [12]. If we are able to give parents better support in managing their children's pain, we will also support the children better.

Several parents in our study had given up their own social life because the caregiving task had higher priority. They felt alone with the challenges related to CP and pain. This may cause a vicious circle, leading to meeting with less friends who could potentially offer support. This could be negative for the parents, as perceived social support is one of the factors found to reduce stress in parents of children with CP [6,15,28]. Encouraging parents to participate in diagnosis-specific associations may be important to reduce their feeling of being alone with their challenges. To reduce the vicious circle, parents should also be encouraged to seek practical support and apply for relevant support schemes that can make their everyday life easier, and leave them with more time and energy for their own social life. A study by Kalleson et al. [29] showed that having a multidisciplinary team was positively associated with family empowerment. Team knowledge about parental empowerment and associations with family characteristics and received services can contribute to further reinforcement of family empowerment and identification of parents in need of additional support.

Strengths and limitations

A strength of the study is that we recruited parents of children with different degrees of physical and cognitive impairments, as well as children of different ages. The families who participated chose whether the child's father or mother should talk to the interviewer. As a result, the sample consisted of 1 father and 14 mothers. Since it is known that mothers and fathers may have different experiences related to raising children with CP [30,31], this may be a weakness of the study. In addition, all but one family had a Norwegian cultural background, and this may also limit the generalizability of results.

The first author conducted all interviews, and she knew some of the parents from previous consultations at the pediatric rehabilitation unit. This could be both a strength and a weakness of the study. It may have made it easier for parents to speak openly because they trusted the researcher's good intentions and knowledge of their situation. On the other hand, earlier consultations may have influenced the topics parents chose to speak about in unknown ways. Having one author conduct all interviews also increases the possibility of data being influenced by this researcher's pre-assumptions, and may thereby reduce the results' credibility [19]. On the other hand, researcher triangulation was used to increase credibility. The four female researchers involved in all stages of data collection and analyses had different professional backgrounds. The user panel was also involved in planning the study and discussing results, to increase credibility of results.

Most of the interviews were face-to-face conversations, but three were telephone-interviews. This variation in data collection strategies may have influenced our results. However, the stories parents told us

over the telephone and face-to-face interviews were similar, and we assume this variation has not significantly influenced the results.

Future research is needed to clarify whether the results in this study are valid for fathers and parents from other cultures as well. Future research should also develop and evaluate improved treatment approaches.

Conclusion

Parents of verbal children with CP experienced their child's pain as one piece in a complex jigsaw puzzle. They experienced an emotional burden and implicitly and explicitly expressed a need for help to cope with their child's pain. However, they had adapted their lives so that they could take a large part of the responsibility when the child was in pain, and also take responsibility for preventing pain in the child. Since pain was experienced as part of a complex picture, and the parents' life was influenced by the CP and pain, help and support should be developed with a family centered approach to address the complexity pain is a part of.

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