RESEARCH PAPER

“It’s fun, but . . .” Children with cerebral palsy and their experiences of participation in physical activities

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Abstract

Purpose: To explore the experiences of children with cerebral palsy (CP) regarding participation in physical activities, and to describe facilitators and barriers. Methods: Sixteen children with CP 8–11 years old who varied in gross motor, cognitive and communicative function participated in either an individual interview or a focus group. Results: Two categories and 10 sub-categories emerged from the content analysis. The category “Being physically active, because . . .” describes facilitators for being physically active divided into the sub-categories “Enjoying the feeling”, “Being capable”, “Feeling of togetherness”, “Being aware it is good for me”, and “Using available opportunities”. The second category “Being physically active, but . . .” describes barriers to being physically active, divided into the sub-categories “Getting tired and experiencing pain”, “Something being wrong with my body”, “Being dependent on others”, “Not being good enough” and “Missing available opportunities”. Conclusions: Asking children with CP about the physical activities they enjoy, and giving them the opportunity of trying self-selected activities with the right support is important for facilitating an increased participation in physical activities. Having fun with family and friends when being physically active, and enjoying the sensation of speed should be taken into consideration when designing interventions. When supporting children to become and remain physically active, attention should be paid to pain, fatigue and the accessibility of activities and locations.

Implications for Rehabilitation

- Children want to be physically active together with friends or others.
- Children want to have fun and enjoy the sensation of speed when being physically active.
- Self-selected physical activities and the opportunity of trying new activities with the right support is essential for facilitating an increased participation in physical activities.
- Service planning and design may be facilitated by asking children about the physical activities they enjoy.

Introduction

Health conditions in childhood are important for health throughout life [1]. The health of people with disabilities can be improved by increased social participation, decreased obesity and increased physical activity [2]. Participation in physical activity brings benefits to all children, including those with disabilities [3–5], and the global daily recommendations for children aged 5–17 years consist of at least 60 min physical activity of moderate to vigorous-intensity [6]. Participation is defined as involvement in life situations according to the International Classification of Functioning, Disability and Health (ICF) [7]. For children with physical disabilities, the attributes of the child, the family, the environment, and the physical and social conditions, as well as the degree of self-engagement, are crucial with regard to participation [7, 8]. Social participation embraces interactions with others, and is associated with age and gross motor function for children with cerebral palsy (CP) [9].

CP is the most common physical disability in childhood, and can be accompanied by a variety of conditions [10]: three of four children with CP experience pain, one in two has an intellectual disability, one in three cannot walk, and one in four has epilepsy, cannot talk or has a behavioural disorder as shown in a meta-study of clinical prognostics [11]. Children with CP are at risk for reduced habitual physical activity and increased sedentary time [12]. The differences in the frequency of physical activity increase with the severity of limitations in gross motor and/or cognitive function [8,13,14]. An active lifestyle and increased physical fitness are recommended for promoting the health of children with CP [4,15].

Factors which are considered to have a major impact on being and staying physically active in children with CP are provision of overall facilities, access to mobile equipment such as balls and skipping ropes, and perceived encouragement [16,17]. In focus
group interviews with children aged 7–17 years with CP, the physical ability of the child, child-related psychological factors, parental factors, opportunities for physical activities, practical feasibility, social environment, and facility factors emerged as both facilitators and barriers to physical activity. However, the inclusion criteria in Verschuren et al.’s [18] study were the ability to walk without an assistive device and the ability to understand and respond to interview questions. The results of the focus groups consisting of children and their parents were presented in conjunction, which implies that the children’s perceptions were not distinguished. Further analysis of the interviews and additional questionnaires for the parents provided insights about their physical activity behaviour by organising identified facilitators and barriers according to three stages of change (pre-intention, intention and action) [19]. In interviews with children aged 9–21 years with CP with different gross motor function limitations, environmental and personal factors, limitations in body structure and function, the perception that health benefits alone do not motivate children to be physically active, and variation in preferences for the delivery of activity was identified as facilitators and barriers to physical activity [20]. Early exposure to activities, lack of opportunities close to home, competitiveness, family support and peer interest were found to be important factors affecting physical activities for adolescents without disability, aged 13–18 years and living in rural areas [21]. However, there is a lack of knowledge about the ways in which enjoyable physical activities could be organised, conducted and evaluated in order to achieve increased participation, especially when focusing on physical activities in leisure-time and physical education at school for children with CP with various limitations in gross motor and cognitive functions [14]. In addition, there is a lack of studies that include children who use augmentative and alternative communication. There is a need for studies with samples that are more representative of the variability in gross motor, cognitive and communicative function than previous studies. It is essential to ask children with CP what experiences they have of physical activity; their statements can be used to develop interventions intended to increase physical activity. Therefore, the purpose of this study was to explore how children with CP with different limitations in gross motor and cognitive functions experience participation in physical activities and to describe facilitators of, and barriers to, being physically active.

Method

Design

The study had an inductive qualitative design in which children with CP were interviewed. In order to obtain a deeper understanding, the children were asked to participate in a focus group or in individual interviews. Together with their parents, the children decided whether they wanted a proxy (parent or a personal assistant acting as advocate for the child) or an interpreter during the interview.

Procedure

A letter of invitation with information about the study was sent in January to June 2012 by an administrative assistant at the Child and Youth Habilitation Services to all parents of children with CP aged 8–11 in the Skåne region in southern Sweden (N = 117). The information was given both to each child and their parents, including an easy-to-read child-appropriate version. After 2 weeks, a reminder was sent to all parents who had not answered. Parents of 26 children answered, and 10 of them declined to participate. The first author contacted the parents of the 16 children for verbal information, to determine the time and place for the interview and for information about whether the child wanted to participate in a focus group or an individual interview.

Participants

Nine girls and seven boys with various gross motor and cognitive functions were interviewed. Eleven of the children had mild motor function limitations, while five had moderate or profound motor function limitations. Thus, nine children had no cognitive function limitation, whereas seven of them had mild or moderate to profound mental retardation according to the International Classification of Diseases [22]. The sample’s distribution of gross motor and cognitive function was similar to the findings of other studies using data from a National Quality Registry [14,23]. The children came from different places in the Skåne region, with some living in cities, and others in rural areas. Nine of the children had one or both of their parents born abroad; five of these parents came from European countries and 10 from non-European countries. Fifteen children were living with their biological parents, and one child was living in a foster home. From this point on the term ‘‘parent’’ will be used to represent both biological and foster home parents. Twelve children were living in families with both parents and four with one parent; five parents were employed as personal assistants for their child. Four children used augmentative and alternative communication in the form of sign language interpretation using various picture systems, such as concrete photos or the graphical language of Bliss symbolics, during the interview [24,25]. One child had both a language interpreter on the phone and a parent as a sign language interpreter; one child had only a language interpreter. The five children participating in the focus group had various gross motor functions and none required an interpreter. The characteristics of the children are shown in Table 1.

Data collection

Interviews were carried out from March to June 2012. Eleven children chose to participate in individual interviews, and five children in a focus group. The individual interviews took place according to each child’s preference; seven children were interviewed in their homes, three children at their local habilitation centre and one child at school. The individual interviews were conducted by the first author and lasted between 30 and 50 min, whereas the focus group with five children, conducted at the habilitation centre, was moderated by the first author, with the second author as an observer and took 65 min. In order to make the children feel more relaxed, refreshments were offered and there was some general chat before each interview. All interviews started with the research question: ‘‘What do you like doing when you are physically active?’’ To get a better understanding of what ‘‘physically active’’ meant to each child, a few minutes were used talking about this, using pictures or small play figures for illustration. The children were asked to narrate their perceived experiences of physical activity in different environments: at home, during leisure time, at school and at their habilitation centre. To maintain a playful manner throughout the interview and to facilitate talking about their experiences, pictures with different activities and/or small play figures were used in the conversation. During the interviews, additional questions were asked, intended to encourage further and more reflective narration, such as: ‘‘Can you tell me more about this?’’, ‘‘What do you mean?’’ or ‘‘Can you give me an example?’’ All interviews were audiotaped and transcribed verbatim by the first author.
Table 1. Characteristics of the children (N = 16).

<table>
<thead>
<tr>
<th>Child</th>
<th>Age</th>
<th>GMFCS-E&amp;Ra</th>
<th>Cognitive levelb</th>
<th>Augmentative and alternative communication</th>
<th>Language interpreter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child 1c</td>
<td>9</td>
<td>II</td>
<td>Mild mental retardation</td>
<td></td>
<td>X</td>
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<tr>
<td>Child 2c</td>
<td>8</td>
<td>III</td>
<td>No mental retardation</td>
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<tr>
<td>Child 3c</td>
<td>8</td>
<td>I</td>
<td>Mild mental retardation</td>
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<tr>
<td>Child 4c</td>
<td>9</td>
<td>III</td>
<td>No mental retardation</td>
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<tr>
<td>Child 5c</td>
<td>11</td>
<td>II</td>
<td>Moderate to profound mental retardation</td>
<td>X</td>
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<tr>
<td>Child 6c</td>
<td>11</td>
<td>IV</td>
<td>Mild mental retardation</td>
<td>X</td>
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<tr>
<td>Child 7c</td>
<td>8</td>
<td>I</td>
<td>No mental retardation</td>
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<tr>
<td>Child 8c</td>
<td>10</td>
<td>V</td>
<td>Moderate to profound mental retardation</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Child 9c</td>
<td>8</td>
<td>II</td>
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<td>Child 10c</td>
<td>9</td>
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<td>No mental retardation</td>
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<tr>
<td>Child 11c</td>
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<td>II</td>
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<tr>
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<td>I</td>
<td>No mental retardation</td>
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<tr>
<td>Child 13c</td>
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<td>I</td>
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<tr>
<td>Child 14c</td>
<td>8</td>
<td>I</td>
<td>No mental retardation</td>
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<tr>
<td>Child 15c</td>
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<tr>
<td>Child 16c</td>
<td>10</td>
<td>II</td>
<td>No mental retardation</td>
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</table>

aGross Motor Function Classification System Expanded and Revised [36].
bWHO’s International Classification of Diseases (ICD): F70 and F71 – F73, ICD-10 codes for mental retardation [22].
cIndividual interview.
dFocus group interview.

Ethical considerations

In accordance with the WMA Declaration of Helsinki [26], the children gave their assent and all parents submitted written, informed consent before the interviews took place. The children and their parents were guaranteed confidentiality and the right to discontinue the interview at any time, and they agreed to the interviews being tape-recorded. The study was approved by the Regional Ethical Review Board at Lund University (Reg. no. 2011/350).

Data analysis

Content analysis was used to understand the underlying meaning of the interview texts [27,28]. The transcribed interviews were read several times, with the aim of the study in mind, by all three authors, in order to obtain a sense of the content. From all interviews, meaning units relating to the children’s experiences of physical activity were extracted. A meaning unit was described as a constellation of sentences relating to the same central meaning [28]. Taking the whole context into consideration, the meaning units were condensed and designated as codes independently by each of the authors. After determining the similarities and differences among the codes, 10 sub-categories were abstracted from all codes sharing a commonality. Agreement about codes and sub-categories was achieved after a process of reflection and critical discussion among all authors, moving between the whole and the parts of the texts. The sub-categories contained facilitating and inhibiting factors and generated two categories; based on whether they were assessed as facilitators or barriers for physical activity the sub-categories were compiled into the categories as presented in Table 2. All authors had a longstanding experience of working with children with disabilities or chronic diseases, which obviously affected the authors’ pre-understanding. During the whole process, from planning and conducting the interview, to all steps of the analysis, all authors reflected about and discussed their pre-understanding and the ways in which it might affect the analysis, abstraction and interpretation of the material. In addition, the results were discussed in the research group. To assure trustworthiness, quotations were used in the results with children participating in individual interviews were presented as Child (1–11) and children participating in the focus group as Child (12–16).

Table 2. Categories and sub-categories.

<table>
<thead>
<tr>
<th>Being physical active because . . .</th>
<th>Being physical active but . . .</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enjoying the feeling</td>
<td>Getting tired and experiencing pain</td>
</tr>
<tr>
<td>Being capable</td>
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<tr>
<td>Feeling of togetherness</td>
<td>Being dependent on others</td>
</tr>
<tr>
<td>Being aware it is good for me</td>
<td>Not being good enough</td>
</tr>
<tr>
<td>Using available opportunities</td>
<td>Missing available opportunities</td>
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</table>

Results

The children expressed that they were physically active, but gave various reasons. They played ball and running games at school and/or during leisure time, they went swimming, horse riding, biking, dancing, attended gym classes or went for walks outdoors. Playing outdoors or going on excursions with their families or school classes were described as enjoyable activities. Some children expressed that they wanted to participate in different activities and liked to decide for themselves what to do; others were told to do physical activities by their parents or other adults. All children described their peers as friends, which is why the term “friends” is used for both friends and peers. Two categories emerged from the sub-categories, the described facilitators and barriers: “Being physically active, because…” and “Being physically active, but…”.

“Being physically active, because…”

Being physically active during leisure time or at school was something that is natural for the children. They did not question participation in school activities such as school sports and excursions and expressed various reasons for participating in physical activities. Physical activities within the family or during leisure time were often initiated by the parents but mostly in accordance with the child’s wishes. On school excursions and in the context of school sports, the children expressed that they had less opportunity to influence the choice of activity.

Enjoying the feeling

The children perceived physical activities as being fun and exciting, and something that made them feel good. They described
the sensation of speed as something they really enjoyed, regardless of the chosen activity, which could be running, swimming, dancing, biking or playing active video games such as Nintendo Wii Sports [29]. One child described that rolling around on a big ball and jumping on the trampoline with an assistant produced an enjoyable feeling of speed. Others described that while biking outdoors with their friends they enjoyed the feeling of speed.

... the funniest thing is that it feels as if you are flying through water. (Child 16)

Physical activity sometimes resulted in an especially good feeling of tiredness. Playing soccer with friends was tiring but generated a good feeling because of the speed of the game. Children of parents who exercised noted that their parents seemed to enjoy sweating. One child enjoyed playing outdoors with his/her older brother even if this led to tiredness; the good feeling made it worthwhile.

I’m getting tired the fun way. (Child 11)

**Being capable**

Activities the children could perform by themselves and that they experienced they were good at made them feel competent and proud. Positive feelings resulted from being allowed to engage in an activity or being able to choose for themselves what they wanted to do.

I don’t know, it’s fun to bike...I taught myself to bike. My sister couldn’t stand helping me anymore...so I tested myself and just rode down a hill...and I could bike! (Child 10)

Competing and showing off were motivational for several children. They enjoyed ball games or other games with a competitive character when they felt they were winning. Children enjoyed showing off with family and friends watching them.

**Feeling of togetherness**

It was important for the children to belong to someone or something. They were active because they were doing activities together with the family or their friends, but being with animals also encouraged physical activity.

To go on a camp with the Scouts is the most fun...we all hike together, I know everyone there. (Child 7)

Meeting others in similar situations engendered a feeling of togetherness for the children; they did not want to stand out, but rather belong to the group. Some children described that they liked to participate in groups at the habilitation centre because they met other children with similar disabilities.

**Being aware that it is good for me**

The children were aware of physical activity being good for them; some narrated that they participated in activities because it was good training or because an activity relieved their pain. Pain and fatigue were often associated with physical activity. For example, the children could feel pain when riding a horse, but the children were convinced that it was necessary for stretching their legs. One child described that the pain caused by sedentary time, which could be improved by training; others had to take breaks from activities due to fatigue.

I don’t like standing in the shell (standing orthoses). It itches and hurts, but when I play physical computer games at the same time, I forget about it. (Child 15)

The children narrated that their parents, teachers or therapists wanted them to engage in specific activities. Mostly, these were training or stretching programme but it could be about school sports as well. They did not question that the activities had to be done.

I go to the swimming club because I have to learn to swim. (Child 12)

**Using available opportunities**

Activities such as school sports or excursions were organised by the schools, and all children said that they participated in these activities. Stimulating equipment and conditions in the environment facilitated physical activities. For example, these could be big balls in an exciting sports hall, where the child was allowed to play freely.

I think it’s fun when I’m allowed to play freely in the sports hall at the habilitation centre. (Child 14)

The inconvenience of needing more time than others to get outdoors during breaks due to having to handle orthoses can be eased by having friends waiting. Children perceived that they could participate in activities with assistance; parents driving to and from activities also helped.

**Being physically active, but...**

Children participated in physical activities because they believed they had to. However, the children opted out of specific physical activities. Some children said that nobody passed the ball to them, that they would lose all the time and that they were singled out. They described various aspects in which they differ from their friends. Children with severe limitations in gross motor function rarely participated in physical activities together with friends without disabilities, and did not describe the barrier of being singled out. However, children who were integrated in ordinary school classes, perceived being singled out to a higher extent, the more limited their motor ability was.

**Getting tired and experiencing pain**

Children would get tired from participating in physical activities and although they want to be more physically active, they don’t want to risk increased fatigue.

My legs get tired, and I need a break before I can go on...I want to do more activities but I can’t because I get too tired. (Child 4)

Physical activity was associated in a negative way with pain. Activities could be painful because of assistive devices such as orthoses, because of training or because of sitting still for too long. Some activities were uncomfortable, and sweating was often perceived as unpleasant.

I press my hands down when I’m using the walker...and my hands hurt here...I just always have to press my hands down when I’m walking. (Child 2)
Children felt that something was wrong with their bodies.

My legs are...my left leg is not straight enough. I have to wear my foot orthoses, otherwise I don't know how my legs will develop. (Child 12)

Some could not keep their balance or had poor coordination. Others were afraid of falling off a bike or a horse and some perceived activities as being dangerous. The children experienced that it was their body’s deficiencies that led to fear.

I used to like horse-riding when I was about four or five years old. But something happened, and now I am afraid of horse-riding, horses are so huge...and I'm not so strong. (Child 5)

Being dependent on others

Children saw themselves as being dependent on others, but not always getting help.

We were playing...and he was the catcher. I fell and everybody pushed me down. They just forgot about me, and nobody helped me. (Child 11)

Friends or teachers did not take them into account and some children felt that they were singled out from the group; some children did not play with friends at all. Children spoke about feeling angry towards their helper, and some said that they were always blamed for any trouble.

I stumble sometimes when I run...I don't care what they say, dumb things. (Child 10)

Not being good enough

Competitive activities without a chance to win were perceived as not being fun, with some being described as boring. Children simply did not want to participate in these activities. Their experiences of being too slow, not good, or not good enough, at the activity were reasons that many children gave for not enjoying an activity.

The school teacher says that I have to swim in a different way, otherwise I will drown. But I have not drowned yet...I always swim my way with my parents, I am not afraid, but the school says ‘no, you will drown one day’. So my way is wrong, they tell me. (Child 1)

Some activities were very hard to perform but there were other activities the child simply had to learn. The children needed more time for the same activities than their friends did, and they were not able to keep up, which caused them to feel around, or to say that they didn’t care. Children said that nobody passed the ball to them during school sports, and some expressed that they could not tell anybody about these difficulties. The feeling of losing all of the time was perceived as very negative.

You know, you get these tails...and the aim of the game is to get rid of all your tails, but I never get rid of my tails...so I have about ten of these tails in the end. Not fun. (Child 2)

Missing available opportunities

Children were aware of activities they want to participate in, but the desired activities were either not offered at all or not offered close enough for the children to be able to get there. Some children described the poor conditions of the facilities. Stimulating activities and equipment were lacking, as was assistive technology: a sports hall used for physical education at school was not accessible to a child in a wheelchair. Equipment was broken and could not be used, and sometimes training schedules collided so that children could not participate in all their preferred activities. Several children expressed that they wanted to engage in the activities they liked more often. Others said that their parents did not allow them to engage in the activity of their choice.

I love going swimming...I used to have a swimming aid thing, but I’ve grown, and need a bigger one, but there aren’t any that fit. (Child 8)

Discussion

Examining children’s experiences, this study identified facilitators and barriers relating to being physically active, for children with CP with various limitations in gross motor and cognitive functions. The children were physically active because they enjoyed the feeling, felt capable or had someone to do the activity with. They were aware that physical activity was good for them and environmental factors could be either facilitators or barriers. Having difficulties such as pain and fatigue or not being good enough were other barriers the children expressed. The results showed that all children participating in the present study were physically active either because they wanted, or felt that they had to be active. However, these children had not yet entered puberty. Shimmell et al. suggest that the perception of personal and environmental factors as supports or barriers to participation in physical activity may change between childhood and adolescence [20]. As has been shown earlier by Orlin et al. [30], children with CP have a higher rate of participation in recreational activities than adolescents or other young people. On the other hand, the findings of Orlin et al. showed no difference in participation in physical activities between children and adolescents.

Various facilitators and barriers for participating in physical activity were found by the present study. These results provide information, which may be useful when designing interventions to enhance participation. They may contribute to the understanding of how and why children with CP might change their physical activity behaviour as described in the stages of change by Verschuren et al. [19]. However, our findings confirm the essentiality of strengthening facilitators and minimising barriers for becoming and remaining physically active as described in another study [16].

Children in our study spoke of how they enjoyed the sensation of speed when being physically active, independent of which activity they were engaged in, and independent of physical and cognitive conditions. The experience of enjoyment as a facilitator for physical activity is described by Verschuren et al. [18], although without highlighting the enjoyment of the feeling of speed. The child’s motivation is a strong facilitator, and a distinction between goals-defined or experience-defined motivation can be made [31]. The enjoyment of the sensation of speed could be described as experience-defined motivation for participation in physical activities, as the children were talking about their own experiences.

The findings showed that the children clearly preferred selecting what to do by themselves, and thus feeling capable of...
performing the chosen, and sufficiently challenging, physical activity. However, they spoke of limited opportunities for expressing their wishes at school sports. The importance of participating in choices concerning physical activity was also highlighted in a review that claimed that participation-based therapy enables children with physical disabilities to participate in home and community activities [8]. The findings further showed that children were aware of the positive effects of physical activities, based on information the children were given access to by their parents, by school or by physiotherapists at the Child and Youth Habilitation Services. The children’s belief was also identified by Verschuren et al. [18] as a facilitator, associated with parental awareness of the benefits of physical activity.

The children in our study expressed the importance of their families’ support in choosing and engaging in physical activities and not least in transportation to and from activities. The accessibility to activities and locations varied. Children from rural areas described a lack of opportunities close to home, which accords with the findings of another study with participants aged 13–18 years [21]. However, parents of older children did not seem to provide support with regard to transportation to the same extent as our results indicated for parents of younger children.

Despite the practical support of the family for participation in physical activities, the children in our study identified the feeling of togetherness as being essential; being active together with members of the family, a friend or a group of friends, was a strong facilitator, as was being together with animals. On the other hand, absence of friends or being singled out was seen by the children as a barrier. The emphasis on being accepted as part of a group and being accepted by peers has also been shown by Verschuren et al. [18].

Environmental conditions, such as opportunities for desired activities and motivational equipment, were important for participating in physical activities. Other studies confirm these findings [8,18]. It seems important to investigate what the environment of the child looks like and which adaptations are needed in order to increase participation in physical activities. In addition, many children in our study were experiencing pain and fatigue as barriers to participation in physical activities. Highlighting and treating these difficulties should be prioritised, which is in accordance with the findings of other studies [8,18].

Qualitative interviews and content analysis were found to be well-suited, since interviewing young children with CP allows their stories to be heard, and their perspectives seen. However, young children often say what they think the adult wants to hear and their attention span is limited [32]. Using pictures and small play figures made it easier for children to talk about what they wanted to tell us [33]. Few of the invited families answered, which caused a low number of participants. It is conceivable that the participating families were those who were especially interested in physical activity. The letter of invitation stated that all children who got the invitation were welcome to participate in the interviews, and allowed them to use support or an interpreter if needed. The variation among the participants suggests a representativeness of the total population of children with CP aged 8–11 years in Skåne. However, the particular situation of each child needs to be taken into account when doing so. Many children in this study were born abroad or had parents born abroad, and possessed different cultural backgrounds. The boys and girls participating came from both rural and urban areas, lived in various family constellations, and had various limitations in gross motor and cognitive function. Some children communicated non-verbally or were not native Swedish speakers; interpreters, sign language interpreters or language interpreters were used for several interviews. It was a challenge for interpreters to understand both the child and the interviewer correctly [34]. By asking the same questions formulated in varying ways, the interviewer cross-checked the answers. The individual interviews took place in comfortable and non-threatening surroundings with the possibility of having a proxy present according to each child’s preference. Having a proxy advocating the interests of a child during the interview created a risk that the adult, rather than the child, would want to talk. This required special attention from the interviewer. The interviewer checked her understanding during the interviews, using summaries of what the child had narrated and follow-up questions to the child. In addition, the interviewer had previously informed the proxy about the importance of the interview being focused on the child’s narration, and sometimes a proxy had to be reminded of this during the interview. Furthermore, all authors reflected about the child’s narration, based on their different perspectives, whether they had been present at the interview or not, and by their varying degrees of pre-understanding. Using both a moderator and an observer at the focus group, ensures the children that everyone has an opportunity to talk; differences in perspectives were illuminated, and a response from one child could trigger thoughts in other participants. The interaction in the group became livelier when using pictures and play figures [33]. The sample is representative according to sex, origin, family situation, and of the variability in motor, cognitive and communicative function of children aged 8–11 years in the total population in Skåne, and the results of the study might be applicable for children with CP aged 8–11 years in Skåne. As there is a great variation among children with CP, each child’s individual situation has to be taken into account. To our knowledge, there are only a few previous studies where interviews were conducted with children with CP on all gross motor function levels [18–20]. However, inclusion criteria in those studies were the ability to understand and respond to interview questions.

The children in our study described their capacity and performance according to physical activity. Capacity means what they can do when they are at their best, while performance is what they ordinarily achieve according to the ICF [7]. Our results from children with CP narrating their experiences of participating in physical activities are closely related to the concepts of “F-words” in childhood disability [35], grounded in the ICF [7]. The “F-words”, function, fun, family, friends, fitness and future, are intended to focus on every child’s special issues and strengths [35]. When the children in our study explained in what ways they were being physically active, they described functions. Furthermore, they reported enjoying the feeling of being physically active, especially the feeling of speed, which accords with the term fun. The feelings of togetherness involved family and friends as facilitators for physical activity. The children were aware that physical activity was good for them, which might relate to the term fitness. In the interviews, the children were asked about their wishes for trying new physical activities. However, asking children with disabilities about their dreams and expectations for a future that is possible is an issue for further research as are questions about intensity of physical activity and fitness. Using the concepts of “F-words” can contribute to personalising interventions and increasing each child’s motivation to participate in joyful physical activities.

Conclusions

Giving children with CP the opportunity of trying self-selected activities with the right support is important for facilitating increased participation in physical activities. Having fun with family and friends when being physically active and enjoying the sensation of speed should be taken into consideration when designing interventions. When supporting children to become and remain physically active and to reduce sedentary time, attention
should be paid to pain, fatigue, the absence of friends, and being singled out. Another focus should be on the accessibility of activities and locations. Service planning and design may be facilitated by asking children about the physical activities they enjoy. The variation among the participants would suggest that it is possible to apply the results to the total population of children with CP aged 8–11 years and living in Skåne. However, the particular situation of each child needs to be taken into account when doing so.

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Declaration of interest

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