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How did youth with cerebral palsy perceive participation in everyday life after participating in a periodical intensive rehabilitation program based on adapted physical activity in groups? A qualitative interview study

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ABSTRACT
Purpose: Explore how youths with CP experience participation in everyday life, their experience of having participated in a periodical intensive rehabilitation programme and their expectations for the future.
Materials & methods: A qualitative design that included semi-structured interviews with 14 youths with CP (mean age 17 years).
Results: The qualitative content analysis exposed six themes, (1) Everyday life – to get the pieces of your life to fit together, (2) Participation means inclusion and belonging – the meaning of life, (3) Individual and environmental factors influencing participation, (4) Experience of physical and social activities away from home together with like-minded people, (5) To be continued locally, and (6) You do not know the future, anything can happen – visions for the future.
Conclusions: Participation in everyday life increases the meaning of life but takes energy. Periodical intensive rehabilitation programme enabled youths to try new activities, make friends and increase self-insight in their own strengths and limitations.

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Disability; intensive rehabilitation; participation; youth

➤ IMPLICATIONS FOR REHABILITATION

- Young people with cerebral palsy (CP) describe participation as the meaning of life and state that it is essential for inclusion and being able to contribute to society
- Adaptation of environmental factors including collaboration across service sectors and capacity building in young people within their preferred life situations appear to be essential
- A periodical intensive rehabilitation, including adapted physical activities in groups, is recommended to provide peer learning and mastery experiences in young people with CP.
- Young people with CP seem to have the same hopes for the future as their typically developing peers

Introduction

With a prevalence rate of between 1.5 and 3.8 per 1000 births reported worldwide, cerebral palsy (CP) is one of the most common childhood disabilities [1]. CP causes permanent functional disorders, including problems of movement, posture, perception and cognition; it can also result in communication difficulties and behavioural problems [2–4]. Secondary symptoms such as fatigue, pain, contractures, reduced muscle strength, and fitness are also common [5]. Consequently, children with CP experience more limitations of autonomy and participation in everyday life than children and adolescents without disabilities [6].

Rehabilitation for people with CP is lifelong, and due to the heterogeneity that characterises the group, it includes many different forms of interventions and services. Research in Norway [7,8] showed that intensive, goal-directed activity-focused physiotherapy in a group setting enhanced basic gross motor abilities in children with CP. These results were confirmed in further studies [9]. In 2013, the Norwegian Directorate of Health recommended that new intensive supplementary programmes be developed to accommodate the increasing demand for intensive rehabilitation and training for children with brain injury [10]. Consequently, several programmes of intensive training for children with CP have since been established in Norway. Intensive intervention encompasses the central principles of cortical plasticity, the focus of which is the intensive repetition of salient, functional and significant activities with the aim of improving motor, communication, social and/or intellectual development [11,12]. Intensive intervention is given for limited periods and its frequency and duration vary, though it is often defined as engaging in training more than twice a week [12]. Some intensive programmes emphasise multidisciplinary interventions, while others

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have a more specific and narrow training focus [12]. It is common that intensive programmes alternate between group and individual sessions and training in the child's home environment over a defined period [12,13]. There is currently a lack of evidence and consensus regarding the design and content of such interventions [1,11,14]. However, a systematic review of early intervention for children aged 0–2 years with or at high risk of CP recommends goal-oriented task-specific motor training that includes self-discovery of the environment, daily repeated practice, parental coaching, and enriched environments promoting movement variety and intense, enjoyable practice [15].

Consistent with these recommendations is the Buskerud Intensive Program (BIP) which is an intensive periodical rehabilitation programme that was established in 2003. The BIP represents a goal-directed systematic intervention for children with CP that is organised and carried out in collaboration with the families, the municipal services and two institutions within the specialist health care system: the Vestre Viken Health Enterprise and the Beitostølen Healthsports Center (BHC) [16–18]. The programme is offered to children with CP starting at the age of 1.5–2 years and lasts until the age of 15 years. The BIP is theoretically grounded in the belief that children learn best through daily life activities that align with their interests, through opportunities to learn various skills through many repetitions, and through adaptation of both their activities and their environment [19,20]. The BIP's main goal is to promote function and participation in everyday activities in a natural adapted and enriched environment at home and in kindergarten, school and during leisure time [18].

Participation is a multidimensional phenomenon defined as a person's involvement in life situations [21]. Elements that affect participation include individual factors (such as activity preferences, motor and cognitive skills and sense of self); they also extend to the activity task itself and environmental factors [22]. Environmental factors, such as accessibility, availability, and attitudes can be either a facilitator or a barrier for participation [23]. Freedom of choice and motivation are important mediators for children's participation and the development of motor and intellectual skills [24–26]. In Norway, 18% of young people with CP have participated in periods of intensive training (NorCP annual report, 2020, www.norcp.no). While several of these intensive programmes have been systematically explored and evaluated [13,16–18], until recently, most research on children and youth with CP has ignored the views of youth themselves and instead focused on the perspectives of parents and healthcare providers [5,27]. An understanding of the perspectives and experiences of youth with CP is critical, as inconsistency between youths' and parents' views of functioning and well-being often exists [5,28]. There is an urgent need to identify factors that effectively contribute to successful participation, function and active leisure time in children and youth with CP. In particular, there is a need to explore and unveil the experiences of the youths themselves to identify the optimal content and organisation of interventions [28]. In recent years, some studies have explored the experiences of children and youth with disabilities about participation in leisure activities [29–31]. In line with these studies, our objectives were to explore how youth with CP experience and describe their participation in everyday life, their experience of participating in a periodical intensive rehabilitation programme (BIP), and their expectations for the future.

Our specific research questions included:

1. How do young people with CP experience and describe participation in everyday life, especially regarding the interaction between individual and environmental factors?
2. How did young people with CP experience participating in a periodical intensive group-based rehabilitation programme several times during school years, and what has it meant for their current participation in everyday life activities?
3. What are the participants' expectations for the future?

Materials and methods

Design

This study used a qualitative design that included explorative semi-structured interviews with youth with CP which was analysed with an inductive content analysis [32]. A qualitative method was chosen to generate knowledge concerning the meaning of events and the understanding of those who experienced them. The choice of this approach enabled the possibility to provide a rich description of the views, beliefs, and meanings of the youths with CP.

Participants and recruitment

The inclusion criteria required that the youths had a diagnosis of CP, Gross Motor Function Classification System (GMFCS) [33] level I–IV, had participated in the BIP (in the periods before they start school and in at least three out of four rehabilitation periods at BHC), and were able to understand, communicate and express ideas in Norwegian, and to provide informed consent. Exclusion criteria were severe cognitive and/or communicative impairments.

An invitation letter was mailed to all the 32 youths with CP who had participated in the BIP during the period between 2003 and 2015. The last author (A.H.) then contacted the youths by email or telephone to enquire whether they were interested in participating in the study. The participants decided where and how they preferred to do the interview, which could take place face-to-face at home or at the rehabilitation centre, or alternatively, by telephone or through a digital platform like Zoom or Teams. Of the 32 participants, seven were excluded; one did not have a diagnosis of CP, four had intellectual disabilities and two had communicative disorders. Of the remaining 25 youths, 11 did not respond to the invitation or declined to participate, resulting in a total of 14 participants (56%).

Data collection

The semi-structured interviews were conducted using an interview guide (see supplement) developed by the authors. The guide included questions about how the participants perceived their participation in everyday life, especially regarding the interaction between individual and environmental factors, their experience of taking part in the intensive periodic intervention (the BIP) and their aspirations for the future. The interview guide was tested for comprehensiveness and applicability by using it with a young girl with CP. The questions were found to be easy to understand and to cover the study's objectives. Only minor amendments to the order of the questions were necessary. The last author (A.H.), a paediatric physiotherapist with 30 years of experience working with children and youth with CP, conducted all the interviews. She had met four of the youths during one of their previous BIP periods at BHC more than 10 years ago. The interviews were recorded, and notes were taken to support checking for the accuracy of data interpretation. To encourage the participants to talk about their experiences, the interviewer began the interviews with an open question (i.e., "*Could you tell me about yourself,*" and "*What does a normal day look like for you?*"). Due to the COVID-19 pandemic, most of the interviews were performed by telephone or through the digital platform Zoom. Two of the interviews took place in person – one at BHC, and one in the youth's home. The interviews lasted approximately 40–60 min and were transcribed verbatim.

The participants' descriptive demographic data, including age, diagnosis and functional ability according to GMFCS were collected from their medical records [33].

Buskerud intensive program

The BIP is a goal-directed, systematic, and periodic intensive rehabilitation programme for children with CP between the ages of 1.5 and 15 years. The BIP consists of four parts, three of which take place before the child starts school (I–III); the last part (IV) takes place during the school years.

Parts I–III take place at the child's rehabilitation centre and is led by a physiotherapist and an occupational therapist in collaboration with other professionals. In BIP the professionals from the municipality, such as physical and occupational therapists, special teachers, and kindergarten assistants, participate actively in collaboration with families and the child with CP. The programme emphasises the children's participation in daily activities in their current settings. In regular meetings that last 3 days every 6 months, individual goals of important daily activities are set. This is done in collaboration with the physiotherapist or occupational therapist and families through video analysis of the child's activity performance and using Goal Attainment Scaling and Canadian Occupational Performance Measure (COPM) [17,34–36]. Between the sessions at the rehabilitation centre, the child is practising the goal activities together with the family e.g., at home and in kindergarten. At the group meetings, group activities are interspersed with individually adapted activities for the individual child. The activities in BIP should provide varied experiences and challenges for the child regarding movement, power, pace, coordination, precision, and balance. Skills training for gross motor activities, such as moving, dressing, climbing, playing with balls, and jumping on a trampoline are also included [17,18]. Lectures on relevant topics for the families are delivered during these meetings, as well as coaching on how to explore the child's resources and limitations, guidance on appropriate stimulation and goal-directed training in activity with the child. Periods I through III emphasise collaboration within the community and between the community and the rehabilitation centre, while the focus is on the development of the child's functional abilities to participate in everyday life situations.

Part IV continues with four periods at BHC. This phase of the intervention is conducted in groups of 8–10 children and their parents and delivered by physiotherapists, sports pedagogues, and occupational therapists. The families stay at the centre for 19 days for two summer and two winter periods (for one period per year). The intervention, is intensive, consisting of physical, social, and cultural activities as well as extensive use of the outdoor facilities for 2–5 h a day, 6 days a week [37]. The intervention is based on the child's own preferred activity goals (e.g., learning to ski, climbing, bicycling), but it is also designed to strengthen their social networks and establish active leisure time in the child/youth's local environment. Professionals such as therapists, teachers and assistants from the municipality are invited to participate in a three-day course focusing on relevant topics that concern physically-active leisure time and social participation in everyday life [37–39].

Data analysis

The participants were given pseudonyms to ensure data anonymisation. The interviews were analysed according to narrative synthesis and systematic content analysis with inductive thematic coding associated with the participants' experiences of participation [40,41]. The last author (A.H.) transcribed verbatim the interviews and three authors (A.U., S.S., A.H.) familiarised themselves with the text data by individually reading and re-reading the transcribed interviews and checking all transcripts for accuracy. Then, the three authors individually extracted significant core sentences, and phrases and from these sentences representative keywords illustrating the youths' experiences of participation were identified. Thereafter, similar keywords were clustered according to their meaning; these became different preliminary categories. The categories were then revised and retested collaboratively by three of the authors (A.U., S.S., A.H.) until they provided the best fit for the text data. Finally, to gain a conceptual understanding of the phenomenon, the authors discussed the categories until a consensus was reached. Because the development of content categories was inductive, starting from the text data itself, it did not need an established theory as the starting point [42]. Table 1 provides an example of the extraction, reduction, and interpretation process used to build the categories.

Ethics

This project was submitted to the Regional Committees for Medical and Health Research Ethics (REC) South-Eastern Norway, but was considered to be outside the remit of the Medical and Health Research Act. Therefore, it could be implemented without the approval of the REC. Reference number 2020/322747.

Results

In total, 14 youth with CP (10 boys) with a mean age of 17.3 years (*SD* ± 3.22) ranging from 14 to 24 years old participated in the study. Distribution on the GMFCS E&R was: level I, seven participants (50%), level II, two participants (14%), level III, two participants (14%) and level IV, four participants (21%) (see Table 2).

Overall, the qualitative content analysis revealed six main categories and five sub-categories. Three of the categories were

Table 1. Worked example of text data extraction, reduction, and interpretation.

Question	The first extraction of pertinent phrases	Second extraction of words and phrases	Category assigned
What does participation mean to you?	"… that I can be part of the community, to always do one's best and to be able to contribute and help others, that I can contribute with my qualities and my knowledge, and that I am allowed to do that, that I am allowed to be a resource for society, the meaning of life perhaps" (Lena)	To be *part of the community*, help others by sharing my knowledge, qualities, and the *meaning of life*	Participation means inclusion and belonging – the meaning of life

Table 2. Demographic of the participants.

Youth*	Gender	Age	Diagnosis	GMFCS-level
Mats	Boy	16	CP, spast.unilateral	1
Sonya	Girl	14	CP, spast. unilateral	1
Lena	Girl	24	CP, spast.bilateral	4
Måns	Boy	16	CP, spast. unilateral	1
Anders	Boy	18	CP, spast.bilateral	2
Yngve	Boy	22	CP, spast.kvadri	4
Ebba	Girl	14	CP, spast. unilateral	2
Ylva	Girl	15	CP, ataktisk	1
Mårten	Boy	18	CP, spast. unilateral	1
Einar	Boy	15	CP, spast. bilateral	3
Noah	Boy	14	CP, spast. bilateral	4
Hans	Boy	20	CP,spast. bilateral	3
Emil	Boy	16	CP,spast.unilateral	1
Mattias	Boy	20	CP.spast.unilateral	1

*pseudonym.

related to the research question pertaining to how youth with CP experienced and described participation in everyday life: (1) "*Everyday life – to get the pieces of your life to fit together,*" (2) "*Participation means inclusion and belonging – the meaning of life*" and (3) *"Individual and environmental factors influencing participation.*"

Two categories addressed the research question pertaining to the experiences of participating in the periodical intensive rehabilitation programme (the BIP): (4) *"Experience of physical and social activities away from home together with like-minded people"* and (5) *"To be continued locally*". A final category illustrated the youths' aspirations for the future (6) *"The future is unknown, but anything can happen – visions for the future.*"

Categories of how youths with CP experienced participation in everyday life and influencing factors

Everyday life – getting the pieces of your life to fit together

The participants reported that they had active everyday lives and mentioned important parts of their life that had to fit together, including school, work, leisure activities, training, and spending time with friends. Schoolwork and work took a lot of time and the participants reported that they were tiring. "*I focus almost exclusively on schoolwork and struggle with it from morning to night. Sometimes I can hang out with friends in the evening*" (Mats, <mean age). Training at a gym or with physiotherapists was expressed to be essential for fitness, maintenance of motor function, and for attractiveness, but it was also described to be time-consuming. "*I have begun training at the gym and go there almost every day after school. I got really into it then, so I think it's fun. I feel it's very good for me, I get stronger and look better*" (Mårten, >mean age). The participants expressed that it was sometimes difficult to get the pieces of life to fit together, especially regarding having enough time and energy. The participants also explained that their everyday lives had been affected by the COVID-19 pandemic, as they had been isolated and not been able to meet friends and participate in leisure activities as they wished. "*I spend time with people online and, who share an interest in film, but it is more difficult now due to Corona*" (Anders, > mean age).

Participation means inclusion and belonging – the meaning of life

The participants reported that the opportunity to participate in various activities was essential, and participation was defined as "*to be part of the community, to always do one's best and to be able to contribute and help others*" (Lena, > mean age). The participants thought it was important to belong to a social community, and they struggled to be able to contribute and be a part of society. They also expressed that participation was about being able to "*realise oneself and doing what you want*" (Einar). In the context of the transition from childhood to adulthood, participation was expressed to be an opportunity to find your own way in life. Participation was also described as important for connections with peers and developing friendships.

> It means a lot then, it means inclusion and community, and that everyone can participate regardless of whether you are disabled or not. (Einar, < mean age)

> That I can be part of the community, and contribute, to help others, that I can contribute with my resources and my knowledge, that I am allowed to be a resource for society. I should say that participation is the meaning of life. (Lena, > mean age)

Individual and environmental factors influencing participation in everyday life

The participants reported that their CP diagnosis influenced their participation in physical activities, such as walking long distances, which could be demanding and strenuous, and that fatigue was an obstacle that often prevented them from being able to participate in everyday activities. They explained that they had to prioritise among activities because they needed to save energy to cope with everyday life activities. Previous surgeries, suffering pain, and slow motor reaction time were also reported to be barriers to, for example, participating in physical education. "*I'm getting really tired. I always do my best. It can help to take breaks to get less tired*". (Ylva, < mean age)

Some participants said that more time and a quiet environment were required for them to be able to participate and concentrate on their schoolwork.

> I use 50% more energy than others, so I get more tired in a way, and I get really exhausted every day at school, when I come home, I fall asleep because I get tired, really, I need to sleep or relax without thinking about anything. (Mats, <mean age)

The participants also mentioned a variety of environmental factors that could be facilitators or barriers to participation. The support from parents and classmates was much appreciated as a facilitator.

> I would not have these functions today if Mom and Dad had not trained with me every day when I was little. (Sonya, < mean age)

> At school, the students are very good at getting me involved. The classmates are very helpful, for example, if I need help to get things out of the bag or pick up books from shelves in the classroom. (Einar,< mean age)

The participants also highlighted their need for personal assistants, special equipment or devices, and adaptation of activities to be able to participate in school and leisure activities and maintain body functions.

> I do not participate in the activities I want. More hours of a personal assistant (BPA) would allow me to participate much more and reach my goals during the day; finish schoolwork, train and be with friends. (Noah < mean age)

> I'm sitting asymmetrically in my wheelchair. If I get enough hours with an assistant, then I can train the strength in my back, because I do NOT want to operate. (Noah < mean age)

Environmental factors may also be obstacles to participation, and the participants expressed that they had experienced exclusionary attitudes. For example, some had encountered employers who did not want to employ a disabled person. Some participants also stated that some people had sexual prejudices regarding people with disabilities, and that therefore it could be hard to find a romantic partner. "*It is a bit discriminatory then, companies that will hire a non-disabled person above a disabled person, even if they have equal conditions*" (Anders, >mean age).

The school environment was not always optimal, with limited accessibility in corridors and classrooms making mobility complicated. Some of the youths felt that they had to take great personal responsibility to get the accommodations and support they needed in school. This was especially true during the COVID-19 pandemic, when home-schooling did not always work satisfactorily, for example, due to lack of teaching assistants. Expressions of loneliness and that the youths had no one to talk to in school were also mentioned as limitations for involvement.

> Considering previous experiences, I have had with bullying and such, it is important that you feel that you belong and, in a way, feel that you have someone to talk to is important, as you are very alone having a disability. (Lena, >mean age)

Categories of how youths experienced to participate in a periodical intensive rehabilitation programme

Experience of physical and social activities away from home together with like-minded people

The main category that described the participants' experiences of intensive rehabilitation comprised three sub-categories, including *"Personal development of social and motor skills"*, "*The staff, the activity and the other participants enabled the development*" and "*Potential for improvement*".

Personal development of social and motor skills

The participants expressed that they had challenged themselves during the intensive rehabilitation periods. They learned new skills and gained physical and mental strength. Being with peers and sharing the experience of disability provided opportunities for role modelling; the participants reported that they could see what might be possible for them. They also expressed that they had gained increased knowledge, self-awareness and understanding of their disability, which contributed to self-acceptance. "*I could recognise myself in others with similar problems*." "*Parents and doctors can never understand you in the same way*" (Sonya, < mean age).

The importance of receiving intensive rehabilitation and training to maintain their motor function, such as mobility and strength, was also highlighted. The participants reported that their social skills were developed and practised naturally through different group activities.

> I think it has helped me to get better, to become more confident and comfortable with myself. (Mårten, > mean age)

> You have been allowed to try different activities, challenge yourself a little, and try to learn something new. I think it is important in relation to setting goals further in your life, if you see that it works, then you might think that, well then, I will manage it. (Hans, > mean age)

> It is an opportunity you just have to take, to experience a lot in a fairly short time, it is a variety of activities, and you get to test yourself, challenge yourself. (Mårten, > mean age)

The staff, the activity and the other participants enabled the development

The participants expressed that the staff members at BHC were competent and good at making individual adjustments to the activities according to everyone's unique needs. Having enough time and repetition to practice different activities was important for learning new skills. The participants underscored the variety of summer and winter activities that were available to them and that they felt a level of personal safety that allowed them to dare to try new activities. They reported that the environment at BHC was inviting, inspiring and adapted to the individual participants and their interactions with peers and staff fostered a sense of belonging and enjoyment. Spending time with peers was fun and motivating and sharing the experience of disability provided opportunities for deeper understanding of other people's disorders and needs; it also provided an opportunity for role modelling when learning new skills.

> You kind of get to try other new sports and activities, which you may not have thought were possible then, since you have not tried it before. You also get good guidance. (Einar, < mean age)

> I have learned a lot, seen other people, in different situations and with different disabilities, so I have learned a lot, for example how it is to be blind. (Ylva, < mean age)

Potential for improvements – highlight the individual's wishes and goals

The participants mentioned that it was important that the staff listened to their individual wishes, and that they set their rehabilitation goals for themselves. It was also desirable that the rehabilitation groups consisted of people with whom the participants were familiar. One participant commented, however, that at times there was too much play, and they would have preferred to do more individualised training. The participants also expressed that the rehabilitation centre should collaborate with stakeholders, trainers and leaders from the community or local leisure clubs.

> Being in the gym hall I did not think was so much fun, standing in a circle, playing and such, was a waste for me. I would rather do resistance exercises (Ylva, < mean age).

To be continued locally

Many of the participants continued to participate in physical activities after returning home. Common activities that were mentioned included bicycling, climbing, canoeing, slalom, and training at a gym. The participants emphasised the requirements for adaptations, special equipment, and personal assistance for them to be able to pursue activities in the local community. "*When I came home, I didn't have the right equipment for bicycling*" (Sonya,< mean age). Physical demands and other commitments were also reported to be barriers for continuing to participate in various activities. "*It does not always turn out as planned. Surgeries and more schoolwork mean that you re-prioritise your time, are less physically active when you get home*" (Lena, <mean age).

Living in a rural area was another barrier, as the variety of available activities may be limited. "*It is obvious that for me, who comes from a small place, you have to search to find something that might be interesting*" (Hans, >mean age).

Having contact with the local rehabilitation centre and regular follow-ups with physiotherapists and occupational therapists were described as essential for maintaining function and skills. The importance of consulting and receiving professional help from therapists for being able to participate became more appreciated with age. Some of the participants expressed that they "*were not motivated and could not see the point of doing the recommended exercises"* when they were younger.

The participants explained that it was sometimes hard to maintain social contact with the group participants after they went home. This was likely due to living long distances away from each other and not living in the same community. Parents often played an important role in organising social meetings with group participants and social media was also mentioned as a means of keeping in touch. "*We know each other to this day, greet each other of course, and I am friends with everyone on Facebook*." (Mårten, >mean age)

Category of the youths' aspirations for the future

You do not know the future, anything can happen – visions for the future

This category illustrated the participants' aspirations for the future and included two sub-categories: "*fears and challenges*" and "*dreams and hopes*".

Fears and challenges

The participants expressed worries about accessing higher education and described the long and complex processes that would be required for them to move to another city and find appropriate accommodations, personal assistants as well as adapted study programmes and other practicalities. They feared discrimination from employers when job seeking and were concerned that fatigue may lead to the need for fewer working hours. The participants also expressed doubts around finding a romantic partner and being able to afford to buy their own house. They raised concerns about health issues and that their motor function might deteriorate with time. Some participants expressed a fear of being dependent on others and not reaching their personal goals in life. Being lonely and not having friends was also a worry the participants reported. "*I'm afraid I'm still not going to have many friends, maybe*" (Måns, <mean age) .

Dreams and hopes

In general, the participants had bright hopes for the future and said that they would do their best to pursue their aspirations. They hoped to have a life like others their age and to be as independent as possible. They expressed dreams of having their own family, buying a house, getting an education, and finding a job based on their interests, such as helping others with disabilities.

> I want to become a paediatrician and work with children with CP. (Sonya, <mean age)

> My dream is to build 'nano-technology bones' through an electronic spine. It is a very advanced and very unlikely dream, but not impossible. Or to become a lawyer then. (Noah, <mean age)

> I hope to find the balance between activity and rest, which means that I can be happy with the life I live, that I will find the life that suits me best, move and live by myself, get the opportunity to be active without my parents being main contributors. (Lena, >mean age)

Discussion

The qualitative thematic analysis revealed six main categories and five sub-categories. Three categories illustrated how young people with CP experienced and described their participation in everyday life. Two of the categories addressed their experiences of participating in the periodical intensive rehabilitation programme (the BIP). A final category exposed the participants' aspirations for the future.

Understanding the perspectives of young people with disabilities is critical for providing adequate interventions according to their needs, preferences and goals related to community participation. The participants described participation as very important – *it is the meaning of life*. Participation in different activities provided the participants with feelings of belonging and connectedness to others that were developed through shared experiences and a diminished sense of isolation. Participation in social and physical activities influenced their psychological needs and personal growth; this is consistent with previous research, which has shown that it is crucial to establish opportunities for young people to connect with peers and develop friendships. Willis et al. and Miklos et al., for example, concluded that group settings in which children and youth had the possibility of developing and confirming their identities among equal peers with disabilities were essential to fostering feels of relatedness and acceptance [43,44].

Previous research has revealed that individual factors and activities account for between 78% and 90% of variation in participation in domestic life and interpersonal relationships among young adults with CP [45]. This variation could be explained by CP-related factors and body functions. In the current study, CP-related factors were described as barriers for some of the participants. For example, fatigue and the need to save energy to be able to participate in daily life activities were mentioned. These findings support the importance of having access to a personal assistant and assistive devices, and effective interventions should include strategies for how to balance energy costs. The BIP focuses on learning new skills for children and youths with CP through adapted physical activities, which enable opportunity to save energy while participating in meaningful physical activities. Other interventions focusing on changing the environment have proven to be effective to enhance participation in people with disabilities [46]. Pathways and Resources for Engagement and Participation (PREP), is an intervention aimed at modifying the environment and coaching youth and/or parents, that has been effective in improving youth participation in chosen community activities [47].

It has been suggested that addressing motor, communication and social skills in rehabilitation contribute to improving participation later in life [48]. All the young people with CP in this study had participated in several intensive rehabilitation periods at BHC; they reported that this contributed to new activity competencies and their physical and mental strength. Emerging evidence suggests that long-term involvement in exercise may improve the neuromuscular characteristics and functional capacity of people with CP [49].

The participants in this study underlined the competence of the BHC staff, who made individual adjustments to activities and gave the participants enough time to learn new skills, which are important mediators for successful participation. Studies have also stressed the importance of being with like-minded peers to find motivation and enjoyment and to facilitate learning through experiences of mastery and community [43,50]. The participants explained that being with peers provided them with opportunities for role modelling and inspired them to try new activities. BHC's social context was described by the participants as motivating and safe. This result is in line with previous studies that demonstrated that it is essential that one's social context be experienced as a safe place, which results in a feeling of freedom from physical, social, and environmental constraints [43,50].

Other effective key ingredients for interventions are those that include real-life tasks and activities that are goal-directed and fun. It is also important that tasks should be practised regularly and often enough to make a change [51]. During the intensive 3-week rehabilitation period at BHC, the participants practised goal-directed activities for 2–5 h a day, 6 days a week. The intensity of the activity practice was reported to be essential for gaining activity competency. A main goal of the BIP is that the participants should continue to participate in physical activities when they returned to their local environments. Sustained participation in physical activities must take a life-course perspective and consider the impact of transition points, especially since participation in physical activity reduces with age [22,52,53]. Few guidelines exist, however, about what defines sustained participation and what dose, or intervention time frame of activity is required to maintain a meaningful change. In the BIP, the participants were followed up 3 months after the intervention. A previous study revealed that 32% of young people achieved their activity goals at the 3-month follow-up after an intensive period at BHC and 57% had made progress [54], while other authors suggest that 6 months post intervention may not be long enough to demonstrate a required behaviour change [30,55,56]. Many of the participants reported that they continued to participate in physical activities, such as going to the gym or wall climbing, over the years. The participants described that environmental factors such as the need for personal assistants, special equipment or devices, and adaptation of activities were essential for them to continue participating in school and leisure activities. This result is in line with previous research that found that common barriers for participation included attitude, physical environment, transportation, policies, and lack of support from staff and service providers [23]. Parents' own lack of knowledge or ability to follow up with an activity could also hinder a child's or youth's participation [57].

Research has found that in many situations, especially those involving children and youth with disabilities, making changes to the child's or youth's environment is more feasible than changing a person's abilities or body functions [23,47]. The youth's network (e.g., health professionals, peers and services in the community) is also important and can support their sustained participation in physical activities [44]. Therapists, organisations and policy makers should take responsibility for advocating for funding, support and building partnerships with community sport or recreation providers to support fitness and activity programmes for youth with disabilities [58]. The BIP programme is built on collaboration between municipal services and specialist health services, and therapists, teachers and assistants from municipalities are invited to BHC during each period to learn more about how to optimise participation through adapted physical activities offered in the local community.

The participants in the current study described both fears and hopes for the future. Many of them hoped for a life comparable to their peers and to be as independent as possible. To fulfil these hopes, interventions must be implemented to impact sustained changes in attendance and involvement for youth with CP throughout their lifespans. The optimal dose and content of interventions for optimising participation over time remains relatively unknown. The conclusion from the current study is that intensive rehabilitation periods given over a longer time have been a positive experience for youths with CP. It seems to be important that the interventions are goal-directed, enjoyable, facilitate interactions between the participants and offer adequate support. Further, adaptation of environmental factors and action across the ecological levels including collaboration across service sectors and capacity building in young people within their preferred life situations appear to be essential [59]. A network of children, families, health professionals, peers, mentors and services in the community may support children and young people with disabilities to achieve their participation goals. The main intervention at BHC is adapted physical activity, which involves group-based training towards self-determined goals in a safe and competent context. Adapted physical activities in groups with enough time to explore and the supportive environment, including the competent staff and peer learning resulted in new self-insight in the participants, both strengths and limitations. The increased consciousness about the interaction between personal and environmental factors, enhanced the ability to prioritise between activities in daily life, thus facilitating the finding of balance between activity and rest which could be sustainable in the future. This was considered as crucial by the participants, because, even if they had worries, they had just as many plans for the future as any young person

Limitations

The current study's sample size was relatively small. However, as a first follow-up study among young people with CP who have participated in a periodical intensive rehabilitation programme for more than 10 years, our conclusion indicates long-term self-reported outcomes of intensive rehabilitation. Selection of the most appropriate sample size is important for ensuring the credibility of content analysis study [60]. It has been suggested that saturation of data may indicate the optimal sample size. In the current study similar experiences of the participants were described, and the data facilitated categorization and abstraction, indicating that data were well-saturated [60]. The current study was conducted in Norway, and as health services differ between countries, different opportunities for residential rehabilitation will exist in different countries. This study also contains some methodological limitations. Since the study excluded youth who had low cognitive and or communicative abilities, it may not be representative, and future studies need to explore the special needs of these groups. However, the design, which used interviews, enabled us to attain a broader understanding of the participants' experiences of participation in daily life and in intensive rehabilitation and what this periodical intervention meant for them. Importantly, the descriptions of these experiences from the participants' points of view may guide how new knowledge generated from this research can be implemented into clinical practice.

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