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Karin Sandström, Kersti Samuelsson and Birgitta Öberg

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Prerequisites for carrying out physiotherapy and physical activity
- experiences from adults with cerebral palsy

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- experiences from adults with cerebral palsy

Karin Sandström, RPT, MSc

Department of
Medical and Health Sciences/Physiotherapy
Linköping university
Linköping, Sweden

Kersti Samuelsson, OT, PhD

Department of Rehabilitation Medicine
Linköping University Hospital
Linköping, Sweden

Birgitta Öberg, RPT, Professor

Department of
Medical and Health Sciences/Physiotherapy
Linköping university
Linköping, Sweden

Author for correspondence:

Karin Sandström

Department of Medical and Health Sciences/Physiotherapy

Faculty of Health Sciences

Linköping University

SE-58183 Linköping

Sweden

e-mail: karin.sandstrom@ihs.liu.se

telephone: +4613227834

fax number: +4613227834

Abstract

Purpose: The aim of this study was to get a deeper understanding in how adults with cerebral palsy (CP) experience physiotherapy and physical activity in a perspective from childhood to adulthood; and how personal and environmental factors influence possibilities for physiotherapy and physical activity

Method: Data was collected through interviews with 22 community-living adults (35-68 years) with CP, from five counties in Sweden. The questions were open-ended and the interviews were taped and transcribed to written language. The material was analysed through qualitative content analysis, a classification process resulting in different themes.

Results: The narratives from the 22 informants, based on experiences from childhood to adulthood, resulted in a description of prerequisites for carrying out physiotherapy and physical activity. Five different themes were identified: Being enjoyable, Giving effects, Being comprehensible, Being integrated in daily life, Supportive health-care with competent professionals.

Conclusion: The information from the interviews elucidates the importance of a lifelong support from health care professionals. Physiotherapists with attentiveness to different life situations in combination with good understanding and knowledge in CP could facilitate continuous physical activity in people growing up and ageing with CP.

Key words: ageing, cerebral palsy, health-care, physical training, well-being

Introduction

Cerebral palsy (CP), a lifelong disability, is a non-progressive disturbance in the immature brain that always includes a motor disorder and is often associated with other sensory and cognitive disabilities [1, 2]. Many adults with CP have deteriorated locomotion skills [3-6] and become more dependent on help in daily activities [7]. Secondary complications - such as pain, stiffness and fatigue - are also common in adults with CP [8-11]. Ageing in combination with overuse and/or immobilisation are considered as contributory factors to the deterioration [3, 5, 12]. Physical training may counteract the impairments, but only a few studies report from the effects of physical training in the adult population with CP [13, 14]. More studies shows that different kinds of physical activity are beneficial for children with CP [15, 16]. Today it is also “general knowledge” that physical activity is a health promoting factor and there are studies showing that it can reduce the progression of disability and cognitive decline in older adults [17, 18].

Adults with CP are a heterogeneous group with different experiences in living with a disabled body. It includes feelings of a body that functions and does not influence daily life, but there are also feelings of a dysfunctional body disturbing daily activities [19] The coping strategies in managing daily life varies and people with CP must find different ways to counteract the process of deterioration [19]. Physical activity and consumption of physiotherapy often decrease in adulthood compared to childhood [11, 20, 21] and some reported causes are no effects, lack of initiative and lack of motivation [20]. There is still insufficient knowledge about what motivates the individual to carry on with physical activities. How do the persons themselves perceive this? What experiences do they have of physical activity and what motivates them to continue? An “insight-perspective” of thoughts and experiences of physical activity can contribute to an understanding and knowledge that

will give physiotherapists and other professionals better ground for supporting individuals with meaningful physical activities.

The aim of this study was to get deeper understanding in how adults with CP experience physiotherapy/physical activity in a perspective from childhood to adulthood and how personal and environmental factors influence possibilities for physiotherapy/physical activity.

Method

Data collection

A qualitative interview study was conducted and adults with cerebral palsy were interviewed. The interviews were informal and the questions were open-ended, albeit based on an interview guide outlining topics to be covered. The interviews contained different areas about experiences of living with a disability and experiences of physiotherapy/physical activity. Each interview lasted between 45-90 minutes and the conversation was in a perspective from childhood to adulthood and techniques of rephrasing questions, follow-up questions and probing for additional examples were used [22]. Results from the analysis of the described experiences of living with a disability are presented in a previous study [19]. The informants' experiences of physiotherapy/physical activity are analysed and presented in this study.

Informants

Inclusion criteria for the study were adults with CP, 35 years or older. In total, 22 persons participated and mean age was 47 years (range 35-68 years). People with functional level II-IV according to Gross Motor Classification System (GMFCS) [23] were included. GMFCS consists of five levels and this means that people with very limited motor problems (level I) and with severe disabilities (level V) were excluded. All the participants had their own housing and six people received personal assistance. Seventeen people had a daily occupation

and two of these were on sick leave. Four people received pensions (because of disability or age) and one was searching for work. For further information, see table I.

Table I. Characteristics of the adults with CP (n=22)

GMFCS	Population n= 22	Men n=12	Women n=10	Mean age 46,5 years	Daily occupation* n=17
II	7	5	2	41,5	7
III	7	3	4	48.4	6
IV	8	4	4	49,4	4

* Includes people with paid and unpaid work

Procedure and ethical considerations

The study population was recruited from five counties in the middle and south part of Sweden and selected by rehabilitation professionals who had knowledge of the population.

The professionals contacted and informed each person about the study. If the person permitted, he/she received a letter with further information and later the interviewer contacted the person by telephone. The persons who participated also gave a written consent for the interview to be taped and transcribed. They were also informed that they could withdraw from the study at any time. Nineteen interviews took place in the informants' home and three in a rehabilitation setting. The interviewer (the first author) had no therapeutic relation with the informants. An ethics committee approved the study.

Analysis

All interviews were tape-recorded and transcribed to written language word for word. The data was analysed using qualitative content analysis [24, 25], a method aimed to describe a phenomenon, including a systematic classification process of coding to interpret the context and identify patterns or themes. First, the transcribed interviews were read several times to obtain a sense of the overall data. Second, meaning units were derived from the text by

reading the text word for word. A 'meaning unit' is words and sentences from the text containing aspects that are related to a certain topic [25]; in this text experiences related to physiotherapy and physical activity. The meaning units were condensed, i.e. shortening the text, while still preserving the meaning of the text. The condensed meaning units were coded and the transcribed interviews were read again to test the relevance of the coded units. A pattern emerged and the next step was to gain an understanding of the underlying meaning and group the codes in categories containing different aspects of experiences of physiotherapy/physical activity. The last step was to find relevant themes based on the latent content of the text. A theme represents the condensed meaning units, codes and categories on an interpretative level [25]. Together with the second author different interpretations were compared and developed, resulting in five themes.

As a validation, a physiotherapist experienced in rehabilitation read the interviews and compared her perceptions of the interviews with the interpretation made by the authors. The preliminary result was also presented to nine of the informants. Their feedback supported that the interpretation of the interview texts agreed with their narratives.

Results

The narratives from the 22 informants were based on experiences from childhood to adulthood. The analysis of the informants' experiences resulted in a description of important prerequisites for carrying out physiotherapy and physical activity. The prerequisites were summarized into five themes (Figure 1) containing both negative and positive experiences of physiotherapy and physical activity.

The themes are illustrated by quotations, where "....." indicate a pause and () indicate removed information because of irrelevance. An explanation to a quotation is presented in brackets. The number in brackets after a quotation is a specified subject.

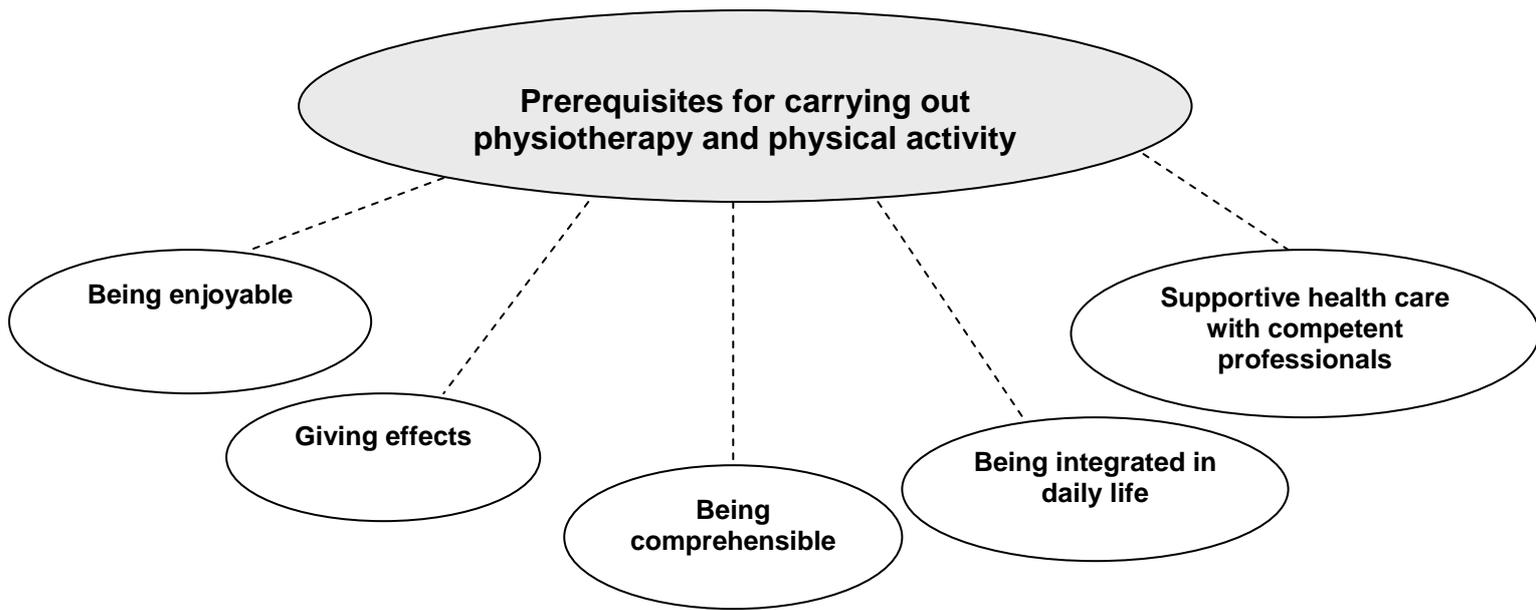


Figure I. Prerequisites for carrying out physiotherapy and physical activity

Being enjoyable

In childhood, physiotherapy was sometimes experienced as a duty imposed by an authority system of experts and parents. The training was just something that they had to do and the parents often nagged their children and cooperated as trainers. There were many experiences of dreariness, monotony, stretching, bending and above all pain. Many of the informants had gone through orthopaedic surgery and painful training in connection with that. Feelings of discomfort could also occur when physical training was carried out together with non-disabled children as sometimes happened in school situations. Many of the training sessions with the physiotherapist were also uncomfortable, highlighting the body as dysfunctional, and they often struggled to perform tasks:

... and then just doing things you're really bad at. Well you go out of your way () those mirrors on wheels are dreadful gadgets, and you have to do various movements ... () You only have to look in that mirror and you see how crooked things are ... /10/

Also in adulthood training can be boring or cause pain and many of the informants feel a sense of duty to carry through the training in spite of that. The informants related to the “training stress” in society and some informants also feel that they train too much, as they become tired and get pain; however they continue with training:

When I back off it drives me mad well I have to. /5/

Some of the informants avoid places that make them feel “out of place”, such as a fitness centre. It can also be the contrary; it is unpleasant to go to a rehabilitation setting and have to meet many other people with physical disabilities.

Swimming, horse-riding, and other activities that were combined with leisure activities were often experienced as enjoyment in childhood. These activities were not experienced as physical training as the focus was on the activity and not on the body:

(About riding)... you'd sit and wave your arms about, and now I understand that it's balance ...
but you didn't understand that then /8/

Children often enjoyed situations where the physiotherapist made training sessions playful and interactive with other children. As an adult, joy experience is similar to those experienced as a child and the informants highlighted the importance of doing activities that combine training and own interests and that it is important to do something you are good at. Some of the informants stressed that going away to another place for some weeks to train with others is valuable as that means a break from usual daily activities such as work, children and other duties. They can concentrate on training and togetherness, which is an enjoyment and motivates to continued physical activity:

You get away from everything around you at home, so you can totally focus your energy on just training. () And you get away from phones and a lot of mobility service and driving to and fro – you are simply there. /12/

Enjoyment was thus expressed as an important prerequisite to be motivated to do physical activity both in childhood and adulthood and the balance in enjoyment and hard work could be expressed like this:

...and preferably enjoyable!... it has to be enjoyable and not so laborious, but it's laborious nevertheless. /18/

Giving effects

The experienced effects of physical activity could vary. Pain and fatigue were sometimes experienced, especially after intensive training, and when starting up after a longer break:

But I found out, as I was at one of those rehabilitation centres (), that if you do too much then things backfire. ()...you find that you get better, but that's up to a certain level ()... and then things turn around. /3/

Some informants expressed uncertainty about the effects. For example, a physiotherapist may indicate a positive result, while the person itself may not notice the same improvement:

Well I don't know ... I don't feel it helps or anything but ... people round about me say I'm walking more steadily and am not flapping my arms about ...but I don't know. /6/

The informants also expressed improvement and maintained functions related to different kind of physical activities. There were different thoughts about what kinds of activities and what intensity that is needed in order to produce a positive effect. Some thought that they must have intensive training periods and others thought that daily activities in small doses would have an effect. Some informants feel that they need higher doses and intensity to get functional effects as an adult and they also note that they lose function very quickly if they stop training. There were also experiences related to life perspective and some were convinced that the received physiotherapy in childhood had contributed to today's condition:

But at the same time I can see that it's probably all this physiotherapy I've had that means I can have this life today. /22/

An often- mentioned positive effect is the relation between physical activity and a feeling of well-being, often described as reduced pain, stiffness, and fatigue. When they have a break in training these problems often increase. The well-being effects are important prerequisites for carrying on physical activity and sometimes they were expressed as finding a balance in rest and activity:

I get pains (from training) – I really do. But if you train too little it also hurts. /12/

Being comprehensible

As children many informants felt that they did not understand why physiotherapy or other physical activities were important. The given explanations were often in relation to their future, or that continuing training would make them better; however, for a child the words “future” and “better” were abstract:

Do they mean I'll be like my brother ...I'll be able to jump and walk () and then you realise things will never really be like that. /3/

Some informants expressed that as a child they did not want explanations at all, but instead they wanted meaningful goals where the child participates in goal setting. Other informants stressed the enjoyment in training situations as a factor for meaningfulness as it was difficult as a child to understand even if there were explanations and goal settings. Being born with a disability, performing training that one did not understand the point of as a child, sometimes resulted in the decision to stop training during adolescence:

Yes, but then, when I was 16 and got to decide something for myself, I immediately stopped the physiotherapy. /11/

As a young person they were often fed-up with physiotherapy and they were not focused on getting problems in the future and did not want, or did not accept, “depressing” future perspectives about functioning.

In adulthood there is an underlying comprehension of the importance of physical activity; however, some informants have doubts. Many informants have come to an understanding based on deterioration of function and increased knowledge about the importance of physical activity. The knowledge often comes from media and general health information, and less often from physiotherapists. The own responsibility to be physically active was stressed, but it can be hard to be self-motivated:

I'll do that tomorrow, I'll do it tomorrow. I just keep putting it off. I need it to happen.

() Something's got to happen. Something's got to really grab me. /4/

Understanding the disability and relations to deterioration were main topics in the interviews; what is cerebral palsy and what will happen as you age? Some of the elderly informants looked back wishing that they had had a better understanding, especially as young adults. Further knowledge of this process was highlighted as an important factor leading to motivation. A 35-year old man expressed it in this way:

I'm more motivated because I know why I'm doing it. I want to try and avoid future problems, so to speak. /15/

Being integrated in daily life

To integrate physical activities into school, leisure and other activities was sometimes experienced as problematic during childhood especially during the teenage years when it was hard to incorporate training among a lot of other interests. In adulthood, the relation between time-consuming daily living and physical training can be difficult and many hindrances must be limited:

Well, it's the time; I mean you can't just leave work maybe one afternoon a week, or whatever. You just can't, because then you get into a tight spot with your job and ultimately you get into a tight spot in terms of work – things just don't work that way.

/21/

One way to get more time for physical activity is to work part-time and some informants also stressed that they use the daily activities as a way of training and through that they can integrate physical activity into daily life:

To be honest, I don't need to do training because I feel my body copes I get enough exercise and I do a lot in my everyday life ... so I get the exercise I need. /8/

Some of the informants practise sports and consider sport as their way of physical training, but sometimes it focuses on rather narrow activities and they expressed that it is hard to find leisure activities that include physical activities adapted to the disability. To get continuous training in settings outside health care can also be restricted on account of limitations in accessibility and high costs. Some informants also need personal assistance to visit training settings, but they experience that it is difficult to get help from assistants just for training. Even physiotherapy environments in primary health care are often too small; there is no hoist and the training equipment is difficult to use when you have severe activity limitations. To integrate physical training in daily life can be solved in different ways, but training at home is not always the best alternative:

And then it's hard to do things yourself. Managing movements and so on ... and at home, with my husband for example, he's so tall and () Where can you go to train? You can't do it in bed. He'd break his back. /17/

The informants expressed that physical activity must be integrated into daily life, but they also expressed that there are many obstacles that must be eliminated to facilitate this integration.

Supportive health care with competent professionals

Barriers and support can be related to the structure in health care and rehabilitation. In childhood, there was often a supportive organisation, which was accessible and had competent professionals. For an adult who wants support and physical training, it

is not obvious where to turn. The experience of a vacuum after leaving the paediatric rehabilitation was managed in different ways. For some it was a relief to stop training and others found a way to continue training and being physical active, but it was often their initiative and not always with the help from a rehabilitation setting. The biggest problem, expressed by many of the respondents, is to know where to turn when they need competent support and treatment. Often primary health care is a starting point if the problem is pain and/or musculoskeletal problems. However, they often feel that they have to convince the professionals that they need help.

Experiences of unprofessional treatment with no time for discussion, referring to other health care units were common:

.... nobody has the time to find out how the body feels and what kind of incorrect load it is. /4/

Even in the special settings aimed for people with disabilities they often only get advice and support but no possibilities to physical training and sometimes they feel that they are in-between to the possibilities in health care:

The difficult thing I've felt, it's having been too well to get help and not well enough to manage completely on my own, so you sort of end up between two stools. /17/

Even though the informants want to have continuity in their contacts with health-care, they are most often offered insufficient or no follow-up in adulthood. They regularly want to meet professionals from a unit that has knowledge about cerebral palsy; a unit that will be easy to contact if any problems related to the disability should occur, such as help with physical therapy:

Well, you need someone giving you a jog. It's like going to the dentist. It's easier for the dentist to send out a bit of paper and contact me about a new appointment than for me to ring them, because you receive a bit of paper ... and you have to do it. () ...and you get appointments ... so you don't get forgotten /4/.

It is easier to take initiative to contact health care if the respondents have a “common” disease, but with problems related to the disability it is not that obvious and they do not get help easily:

If I get an acute infection of the urinary tract it's not a worry. I don't find that worrying, but if it's something specific to my disability, then it is ... /5/

To be a competent professional can include many aspects, but the overall meaning for the informants is based on the ability to be attentive to the person's needs in combination with knowledge of cerebral palsy and different treatment possibilities:

But you have to try and put yourself in someone's place, putting yourself in that particular person's shoes in some way, because if you just go by the diagnosis ...that's valueless, because I've not met anyone who's the same, even though people say "Well you're so alike". /10/

Many of the informants had met incompetence, especially as adults, when meeting physiotherapists and other health care professionals and they thought that there is a lack of specialists, who can explain and help them live with their disability. The informants stressed a competence about cerebral palsy and ageing in relation to physical activity. They expressed that physiotherapists must support the balance in rest and activity and possess knowledge in prevention and contribute with special treatment based on competence.

The informants emphasized that physiotherapists must listen to the patient and understand contexts of importance for the patient. The attentiveness, in seeing the whole patient and having knowledge about the life situation, was highlighted. For example, some informants stressed that physiotherapists must visit homes and workplaces to get an overall picture of a person. Another competence that was emphasized is the ability to inspire as well as explain and motivate. The informants experienced a limited competence in physiotherapists and other

professionals when they have met them as adults and as a consequence they stressed the importance of a unified supportive organisation with competent professionals.

Discussion

The aim of this study was to get a deeper understanding in how adults with CP experience physiotherapy/physical activity in a perspective from childhood to adulthood. There were many differences in experiences, but there was a more homogeneous view on prerequisites necessary for carrying out physical activity throughout one's life.

One important factor for performing physical activity was enjoyment. There were many experiences, especially from childhood, which were contrary to enjoyment. Perceptions of physiotherapy as a duty containing pain and "stretching and bending" were common and this is also described in other studies [20, 26]. Highlighting of physical deformities also focused on the disabled body and sometimes this created discomfort. When physiotherapy was perceived as pleasant, it often was when it included activities that were enjoyable and when the focus was on something else than the body. An interview study among adults with CP [27] showed that nine of ten participants in a strength training programme experienced the programme as enjoyable. The main factor making it enjoyable was that the programme was run as a group and the experience of social support provided by other members of the group. However, the 22 informants in the present study showed that the experiences of group training was divergent and it must be important to have attentiveness in helping people to find an enjoyable activity in agreement with the person's own interest.

The informants had different experiences of the effects of physiotherapy and physical activity and some expressed that as an adult they need a higher dose and intensity to achieve positive effects. Only a few studies dealing with physical activity in adults were found, and they focused on strength training [13, 14]. The training increased strength and improved

performances in activities. However, an increased knowledge about what gives functional effects in adulthood is still lacking and needed.

Studies have shown that problems such as pain, stiffness and fatigue are common in the adult population [6, 8-11, 19] and one effect that the informants sometimes perceived through physical activity was the disappearance of those complications, which can be expressed as an aspect of well-being. Well-being was an important prerequisite to continue with different physical activities, a finding also described in other studies [20, 28]. Therefore, it is important to find activities that can promote this sense of well-being. As a consequence of this, when measuring effects of physical activity, it must include well-being factors.

In childhood there was a lack of understanding about the meaning of physiotherapy and meaningfulness was related to the existing situation and not to future perspectives. The explanations from professionals were often in relation to adulthood, which often was abstract for the child. In childhood, small achievable goals and doing enjoyable activities that promote physical activity can be a strategy instead of “complicated” explanations. In adolescence, perhaps another approach is necessary, that focuses on understanding of physical activity in a life perspective. Jahnsen et al. [20] showed that a significant predictor for continuing physical activity was that the adolescents had learned how to take personal responsibility for their own health. This is a significant challenge for rehabilitation professionals; we need to find better ways to promote an understanding of physical activity in life-long caretaking. Many of the informants told that they were fed-up with physical therapy in adolescence and did not want to think in a longer perspective. Transition planning in adolescence are proposed to include decision making and problem solving to facilitate ongoing physical activity based on their own motivation [29] and that was also stressed by the informants in the interviews. The informants of course had another understanding as adults, but still there were many questions about CP, ageing and health promoting issues. A paradox is that the informants expressed that

when they were children they often got explanations, but did not always understand or did not want to “take it in”. As adults, when they wanted more knowledge and explanations, they did not always know where to find it.

To integrate physical activity into daily life was not always described as easy, especially in adulthood. The informants often referred to time-consuming daily activities. There were many barriers that they had to overcome if they wanted to carry on activities in a special setting, as transportation time, accessibility and costs. Those environmental barriers are also described in other studies [30-32]. It is also argued that there is a need to establish links between rehabilitation facilities and community-based fitness centres and to educate experts in adapted physical activity [28, 31, 33] in order to help disabled people to participate in continuous training. However, different severity of the disability and different personal needs must be guidelines in finding solutions to integrate physical activities in daily life. An important task for physiotherapists must be to support coping strategies in order for the individual to adapt to environmental factors, but also influence to environmental adjustments.

A common experience among the informants was a lack of supportive health care and rehabilitation in adulthood, compared to the care-taking paediatric organisation in childhood. They expressed insecurity in where to turn when they wanted to meet a physiotherapist and the meeting with health care could sometimes also be a disappointment and there often was a lack of specific disability competence. They felt misunderstood and insulted, which caused feelings of frustration. The interviews in this study were carried out in five counties in a Swedish context and, of course, the organisation of different society contributions differs both in Sweden and in other countries. However, this problem is also described in other studies [30, 32, 34] and stresses the importance of structured follow-up programmes for adults with CP. There is a need of rehabilitation settings with knowledge about CP and health promoting physical activity.

Methodological considerations

The interviews in this study were performed by a physiotherapist. Being a physiotherapist means that you have a special knowledge about this topic and that can be both an advantage and disadvantage. A limitation is that the interviews were mainly analysed by the first author, however the second author was involved in the last phase of the analysis and also read the interviews. Another physiotherapist read the transcribed interviews and the result was presented to a group of the informants. Validity in this study was thus confirmed through “peer debriefing” and “member checking” [35]. It is important to remember that this sample is from a specific context in terms of culture and health care system, but on the other hand it is of great interest and importance to get the perspective from this specific group not frequently investigated.

Conclusion

This exploratory study provides “insight perspectives” of physiotherapy and physical activity from childhood to adulthood. It shows that childhood memories focus on the training situation in itself and not on effects and future perspectives. In adulthood, well-being effects, daily-life situation and competent support were important prerequisites. It is a challenge for physiotherapists to give support with attentiveness to different life situations and to empower and motivate people with CP to continue being physically active in a life perspective.

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