Linköping University Post Print

Parents' conceptions of intensive group training. The case of cerebral palsy

Pia Ödman, Bengt Richt and Birgitta Öberg

N.B.: When citing this work, cite the original article.

This is an electronic version of an article published in:

Pia Ödman, Bengt Richt and Birgitta Öberg, Parents' conceptions of intensive group training. The case of cerebral palsy, 2009, DISABILITY AND REHABILITATION, (31), 4, 293-301. Disability and rehabilitation is available online at informaworld:

<http://dx.doi.org/10.1080/09638280801945709>

Copyright: Taylor Francis

<http://www.informaworld.com/>

Postprint available at: Linköping University Electronic Press

<http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-17159>

Parents' conceptions of intensive group training. The case of Cerebral Palsy.

Ödman P, Richt B, Öberg B.

Department of Medicine and Health Sciences, Faculty of Health and Sciences, Linköping University

Purpose: The aim was to explore what wants and needs intensive group training (IGT) fulfil for parents to children with CP and what problems that may arise due to participation.

Methods: A phenomenographical approach was used. Semi-structured interviews were conducted to elicit information about what participation means to parents. **Results:** Five overarching categories expressing positive functions of IGT were identified: IGT as knowledge promotion, as a complementary training resource, as a bracket to ordinary life, as a means to promote relations with therapists, and as a leisure-activity. One category: IGT as risk for ill-being expresses perceived problems. Each category is in turn divided into a number of subconceptions – 13 conceptions of this kind were identified. **Conclusions:** The conceptions express positive and negative functions of IGT as perceived by parents. These functions in turn can be considered as reflections of basic wants and needs. The results demonstrate that IGT have a potential to contribute to feelings of enhanced care competence among parents, of being supported and of increased strength and vitality. All parents didn't have needs of participation in IGT for themselves. There is also a risk that IGT is experienced as an additional burden and may have negative effects on family-functioning.

Key words: Cerebral Palsy, Therapeutics, Qualitative research, Conductive Education, Intensive group training

In family-centered child and youth habilitation it is believed that the functioning of the child is enhanced in a supportive family and in an ordinary life context [1, 2]. Different functional therapy approaches, based on theories of motor control and learning, have evolved within this framework. These approaches do not rule out training in segregated settings adapted for training activities, but commonly advocate that habilitation should take place in the ordinary environment of the child [3-5]. Goals should be set in collaboration with the child and family and accomplishment of tasks should be reached by identifying resources and changing constraints in the child, task, or the environment [5-7].

Within the Swedish child and youth habilitation intensive group training (IGT) is offered to children with Cerebral Palsy (CP) and their parents. IGT is pursued in segregated contexts and is considered to be a complement to interventions done in the ordinary life environment. Such training is also offered by private caregivers working with conductive education (CE). Typically, IGT help children exercise functional skills or prerequisites for functional skills over a 3-4 week period, with reiteration of movements and activities day after day. The groups are organized according to the child's level of function and age. Participation of parents, close relatives, and/or assistants is desirable or required and is seen as a means to improve their skills in supporting the child in ordinary life. An important target with interventions is to enhance parents' well-being [8] and feelings of competence in supporting the child [5, 9].

The close involvement of parents in the family-centered approach as well as in IGT give rise to many questions regarding the outcome of different interventions for participating parents/assistants and family. To improve intervention strategies more knowledge is needed about parents' (and children's) experiences and perceptions of different approaches regarding e.g.

intensity of training, parent-participation (11) and the environment of intervention (12). Only a few studies have evaluated interventions for children with CP using parental-outcome and these studies are inconclusive. No difference in maternal stress have been reported between CE-approaches and neurodevelopmental treatment (NDT) [10] or mainstream special schools [11]. After 6 months of intensive physiotherapy training parents felt a sense of relief [12]. Wright et al. reported increased parental stress after a second year of CE in an educational setting [13]. Reddighough et al. reported a better outcome of parents' perception of coping for the CE- than the NDT- approach [10]. Parents and assistants perceived enhanced competence following two community-based functional approaches [5, 9].

Based on the results of a previous evaluation of two intensive training groups – one alternative within the child and youth habilitation and the other a short-term CE-approach – it was suggested that other needs of participation in IGT than improvements in functioning needed to be explored. The results of the previous study showed that parents perceived a high service-quality despite small achievements in functioning, regardless training-approach. Fulfilment of expectations of the two intensive training groups were rather associated with fulfilment of needs (such as time for communication, considerate and appropriate treatment, and understanding of the child's needs and problems) than functional improvements of the child [14]. Parents' satisfaction with treatment/training programmes are generally high with small differences between them [10-12, 15]. An interest was raised to gain more knowledge about parents' thoughts and experiences from participation in IGT. A qualitative study was undertaken to identify and describe different meanings of participation in IGT to parents from a parent-perspective. The aim was to explore what wants and needs IGT fulfil in the lives of parents to children with CP and what problems that may arise.

Methods:

Wants and needs could in principle be explored simply by asking people, but may be difficult to pinpoint and express especially when an answer is requested and in a somewhat artificial situation such as an interview. In an effort to circumvent potential problems of reporting, a combination of a narrative approach to interviewing and phenomenographically oriented analysis was used. Phenomenographical studies contribute to increased knowledge about patients' ways of understanding central phenomena in health care and has been recommended for health care sciences by several researchers as a path to improved professional competence and quality improvements in health care [16-18]. The aim of phenomenography is to describe and explore different ways of experiencing and understanding various aspects of everyday reality. Different categories of understanding (conceptions) constitute the essential outcome of the analysis and describe how the phenomenon is apprehended, thought about, or perceived [19].

It was assumed that wants and needs can be inferred from conceptions in such a way that positive conceptions of IGT are direct expressions of underlying wants/needs, and that negative conceptions also express wants/needs but in an inverted order. (For example, if someone states that a certain place is too crowded, this can be taken as an expression of a need for privacy.)

Participants and training-settings

Information was collected with interviews. To optimize the chances of finding a number of different conceptions, a strategic selection of parents to children with different types of CP, various ages, and functional (gross motor classification system – GMFCS) [20] and cognitive levels were invited. Both male and female children were included Table 1. displays

background data of the 15 children. Parents and children had previous experiences of IGT that were completed or they were in a process of participating in repeated periods of IGT.

Table I. Background data for the 15 children and settings that form a basis for parents' lived experiences of intensive group training.

		number	
Male:female ratio	11:4	15	
Ages	4-6	4	
	7-12	4	
	13-17	7	
Type of Cerebral palsy	spastic	hemiplegia	6
		diplegia	2
		tetraplegi	2
	dyskinetic	4	
	ospecificerad	1	
Level of gross motor function (GMFCS)	I	6	
	II	2	
	III	3	
	IV	2	
	V	2	
Learning disabilities	yes	5	
	no	7	
	unspecified	3	
Experiences of IGT	Lemo	6	
	ITG	1	
	CE	2	
	Lemo+ CE	5	
	ITG+CE	1	

Gross Motor Function Classification System (GMFCS) [14]. LEMO is an acronym for “Learning and motorfunction” and ITG is an abbreviation of “intensive training group”. They represent two intensive training programmes within the child and youth rehabilitation. Parents had experiences of four different private settings delivering conductive education (CE).

Eleven mothers, two fathers, and in two cases both parents participated in the interview. In six cases, parents had experience of IGT with both a child and youth habilitation approach and with a conductive education approach (CE). In seven cases, parents had experience of IGT with child and youth habilitation approaches in two different settings in middle and southeastern Sweden. In two cases, parents had experience with CE. CE-approaches were delivered in four different settings in the middle and southern Sweden (Table I).

The different IGT approaches offered training in a segregated group setting 2 - 4 hours/day, 3 - 5 days/week during 3 - 4 weeks. There were some approaches, but not all, offering accommodation for the family during the training-period. The child and youth habilitation approaches were led by physiotherapists, special educational needs teachers, occupational therapists or other team members. The conductive education approaches were led by conductors educated in Hungary. Parents, close relatives, and/or assistants participated together with the child in the training. The group should have included a minimum of three children. The contents of training had previously been described and categorized as goals for improved functioning of neuromusculoskeletal and movement related functions, mobility, self-care or communicative activities according to the International Classification of Functioning and Health (ICF) (child and youth version) [21] and was found to be similar between one of the child and youth habilitation approaches (Lemo) and one of the CE-approaches (Move&Walk) [22].

Data collection

The interviews were tape-recorded and lasted from 39 to 120 minutes. Questions were open-ended. All interviews started by asking parents what IGT meant to the child and to them; they

were asked to include positive and negative aspects. If needed, further probing was performed to elucidate parents' thoughts or perception of the group setting, the environment, intensity and parent-participation as these were considered to be characterizing aspects IGT. Since previous studies had shown similar outcome on functioning and parents' perception of the service-quality between two IGT in these settings [14, 22, 23], no difference was made whether training was performed within a child and youth habilitation approach or with the conductive education (CE) approach. The sequence of asking questions varied and parents' answers to the basic questions were followed-up with further questions. Rephrasing and probing were used to get a deeper understanding [24] (p.162). The interviewer was not involved in delivering any of the IGT but had experience working with disabled children and evaluating intensive training for children with CP [14, 22, 23].

Analysis

All interviews were transcribed verbatim, but, since the intended focus was on conceptions and not on conversational aspects of the situation, without consideration of things like pauses, intonations and emotional expressions [24]. The interviews provided rich and varied information, not only about conceptions but also parents' thoughts, feelings, beliefs, interactions and actions/reactions. The researchers listened to each interview, and transcripts were read several times to extract different conceptions and nothing else. In the next step, conceptions were sorted into different categories. These are formed on the basis of an analysis of similarities and differences between singular conceptions and contain conceptions with what we have considered as having some common traits. The categories and conceptions were labelled and relabelled in an effort to find the best possible labels to reflect their essence [17, 25]. To increase credibility, analysis was also performed by the second author. In the final step quotations from the interviews were selected and included in the text. These are

neither selected on the basis of considerations of representativeness, nor intended as “proofs” of the truth value of our analysis, but only serve as illustrations/clarifications of the conceptions and categories.

The study was approved by the ethics committee at the Faculty of Health and Sciences, Linköping University, Sweden, date 20 06 06 Dnr 65/06.

Results

Five overarching categories describing what wants and needs IGT may fulfil were identified: IGT as knowledge promotion, as a complementary training resource, as a bracket to ordinary life, as building up relations with therapists, and as a leisure-activity. An additional category – “IGT as risk for ill-being” – subsumes different kinds of problems that may arise. Each category is in turn subdivided into a number of conceptions, ranging from one to four. The categories “building up relations with therapists” and “leisure activity” are the least differentiated and only contain one conception each. Sometimes quotations in the presentation were slightly edited to increase readability, but great care has been taken not to change the essential meaning. Numbers in brackets in connection to quotations refer to page in the transcription.

IGT as knowledge promotion

This category can be interpreted as a reflection of wants and needs for knowledge concerning the present and future functioning of the child, but also concerning ways of coping with the situation.

A means to explore the present functioning of the child

According to this conception, IGT is a means for parents to improve knowledge of their child's present functioning. In the quotation below, knowledge is gained through explorations of the child's upper limit of functioning:

IP 6: Mother: You throw a ring onto a stick and pick it up from a standing position, and bend down.

Father: Without any support.

Mother: On his knees, and puts it on and takes a new one, and . . .

Father: He's never done anything like this at home. (p. 9)

In the following quotation, knowledge of the child's functioning is achieved by comparisons with other children in the group:

IP 2: Yes, you also get the experience of seeing how other children are doing and the problems they have. (p. 9)

In the example below, increased knowledge is attained by symbolic means – listening to the therapist's explanations of why particular tasks may be difficult to perform:

IP 12: ITG helped us realise how hard it is. It's not just that he finds it hard to move his foot – his entire balance and his whole body are affected. (p. 2)

A means to improved anticipation

According to this conception, IGT is a means to insights regarding changes in functioning to be expected in the close or distant future. Similar to the conception above, this can either be reached through personal experiences or it can be reached by listening to other's experiences, especially the opinions and experiences of therapists:

IP 4: Yes, you see a lot during a period like this when you go there for four hours a day. You can't do much more training. I think it's a period during which you realise this is somewhere you can go to.
(p. 9)

IP 7: She [the therapist] had another child with similar disabilities, so we got onto the subject of his future development - she thought he might be able to go on his own in a few years, and that seems really positive. (p. 5)

A means to learn how to support the functioning of the child

According to this conception, IGT is a means to improve knowledge about how to support the child's functioning. This can be accomplished in different ways. In the quotation below, a parent's need for knowledge about how to use her hands while assisting the child is expressed:

IP 6: Your attitude, how are you to handle this child, what do you do with a child that's lying, and crawling or jerking around and who can't sit – how should you hold them? (p. 33)

According to the second quotation, parents learn a way of thinking and behaving that is meant to encourage the child's own activity in favour of assisting the child with their hands:

IP 7: ... and minor details such as how to sit ... it's enough to say "put your feet down, or think about how you're sitting" so he'll then sort that out. It's little things like that you've learnt at ITG that you then take with you into your everyday life. (p. 3)

According to the third quotation, parents learn how to modify tasks to enhance functioning:

IP 15: We had a big tray that she couldn't easily carry. I've now bought a small tray with two handles, and I say to her "can you carry it to daddy in the room?" Then she'll perhaps carry it with one hand, but then I put the plate on it and yes ... (p. 7).

In the fourth quotation, knowledge about technical aids as a means to support functioning is exemplified:

IP 2: It was the first time he tried out the food machine. Yes, he's still doing that. He has a food machine at school too, so now he basically eats unaided. (p. 17)

A means to share experiences with other parents

According to this conception, IGT is a means to share experiences with other parents who have a child with similar needs. Experiences and feelings about parenting a child with CP is an important topic for exchange:

IP 8: Here they sat together – a group of children with similar disabilities – so we have similar experiences, even about what happens, going over why things turned out the way they did, when did they get their injury and things like that, and all those things you need to process, so you can really speak to someone who understands about all the weeks you've been in hospital and the operations that have been done – things other people can't understand or cope with listening to. (p. 8)

Other topics for exchange cover everything from social rights to issues in daily life, such as choices of practical clothes:

IP 11: We've received a great deal of help from other parents about where you can get in touch; like we didn't even have a parking permit until we found out through a parent ... and then we had one within a week. Home adaptations: you go and see how people do things. I'd never have known that if I hadn't met parents through the intensive training. (p. 10)

IGT as a complementary training resource

This category can be interpreted as a reflection of wants and needs for relief from ordinary training-responsibilities, through temporary personal discharge but also by mobilization of others.

A means to get relief from the training-responsibilities

According to this conception, IGT may serve as a means to get relief from the child's training:

IP 3: It's ... a bit of a holiday (embarrassed laughter) ... when she's doing the training. Well the therapist doesn't want me there, because Mia can do things on her own, and she does her training really well when I'm not there. I get a bit of free time ... and that gives me the opportunity to breathe out. (p. 30)

A means to mobilize others in training

According to this conception, IGT is a means of exchanging knowledge with close relatives, assistants, or staff in school about the functioning of the child and how to support the child in daily life:

IP 3: ... and the assistant is there with Mia instead of us for the other hours of the day, you also learn something and realise her legs can be used, and she can stretch, she doesn't need to be fed, she maybe should sit at a square table instead of a round one, to provide support for her arms ... you get a bit of a 'Eureka!' realisation to transfer to your everyday life, to life at school and other situations. (p. 34)

A means to get the child motivated in the training

According to this conception, IGT can help parents stimulate the child's involvement in the training-activities. IGT were described as doing training with playfulness, songs, joy, competitiveness, and togetherness in a group and in a room prepared for training. Parents holding this conception believe that the group and the environment facilitate concentration and motivation:

IP 6: Well, you don't need to go, though you can get it anyway, but you have to find the commitment – you have to find the things our lad likes, and there have to be several of them.
(p. 9)

IGT as a bracket in ordinary life

This category can be seen as a reflection of wants and needs for relational, social, personal and physical “normalisation”.

A means to get time together with the child

According to this conception, IGT is a means to leave daily life demands and to get time to focus on the child. The first quotation simply states that participation has given this kind of opportunity; the second illustrates some of the barriers that may exist in ordinary life:

IP 8: That meant an awful lot, because ... focusing all your time and energy on her. (p. 3)

IP 4: Well if I put it like this to clarify things, when you're back home it's not just Fia – the phone rings, siblings and friends come home, and you can always be interrupted – you might have a headache and you can't manage to do any training. (p. 8)

A means for temporary “normalisation”

According to this conception, IGT offers an environment knowledgeable and understanding toward disabled children where the child is met as a person without being stigmatized. IGT becomes a way for parents to relax and experience a temporary normalisation:

IP 10: Everyone was aware that these children have special needs, they maybe don't behave quite like other children, but that's quite OK, you could be normal, I can feel that. (p. 10)

A means to get a widened perspective

According to this conception, IGT is a means to widen one's perspective on the disabilities of the child in comparison with other children in the group. This conception includes feelings of ease and comfort:

IP 8: An awfully important aspect (laughter) of this is maybe seeing what other children have, being able to sigh with relief that things have turned out so well, though you might find it dreadfully hard, but you can also see how terrible it can be or what it's like for them. (p. 6)

A means to gain increased vitality and strength

According to this conception, participation in IGT leads to a feeling of increased vitality and strength. The quotations below illustrate that this is to be taken in a psychological sense:

IP 11. It strengthens you so much and you feel so strong after a period like this when you've met other parents – there's such an exchange between us it's just incredible. (p. 9)

IP 7: I think it's been a boost nearly every time we've been, if I might say so – you feel you get a kick out of it, so to speak. (p. 5)

IGT as leisure activity

This category/conception can also be seen as indicating needs for “normalisation” but now in a more cultural sense. Many people in late modern societies arrange their existence according to a more or less sharp divide between work and leisure time, and quite a lot of people are engaged in sports and training on part of their leisure time. According to this conception, IGT is a way for parents to arrange spare time for their child. IGT compensates for difficulties to find leisure activities adapted to the child's training and social needs in daily life:

IP 1: I think it's good when something happens, so they're not just at home, because our young people have nowhere to go ... and the other children have friends, they have this and that training – Pelle has nothing like that, and you have to create things for him to do, so the intensive training has fulfilled a function. (p. 17)

IGT as building up relations with therapists

This category/conception expresses wants to transgress the therapist/parent divide. According to this conception, IGT is a way to establish a better relationship with therapists. A more personal relationship is attained through participation in the group-activities:

IP 2: ... and the fact that you also experience somewhat closer contact with those working with Anders. That's important too. You perhaps experience more personal contact if you're involved in the actual work. (p. 8)

IGT as a risk for ill-being

This category indirectly expresses wants and needs for integrity and self-respect, perceived to be threatened by IGT.

A contributor to feelings of insufficiency

According to this conception, IGT contributes to feelings of insufficiency, of not living up to the role of being a good parent. Two main problems were described. In the first quotation, feelings of insufficiency seem to have emerged in the encounter with other parents and patients:

IP 1: The negative things I've experienced over the years, but not now – how should I put it here so I don't say the wrong thing – the fact that you know other parents, that you feel you're not doing the maximum for your child. (p. 27)

In the quotation below feelings of unease and insufficiency are reported to have occurred due to the therapist's expectations of parent-participation:

IP 3: ... and then when we met, the therapist was cross about the homework, saying "you shouldn't let things drop, you have to maintain the level, the level will fall if you can't cope with working hard as a parent" – what are we to do now. (p. 18)

An intruder in ordinary life

According to this conception, IGT interferes with ordinary life and places extra burdens on the family. It requires extra work to plan for the training-period both at home and at work. In the quotation below, the family is described as suffering from one parent being absent from home:

IP 1: To start with he didn't have an assistant and I was there, granny too and dad, and we busied ourselves with times etc. – it drained a lot of energy from the family. (p. 6)

Discussion

Methodological considerations

A single phenomenographic study may not capture all the possible conceptions about the phenomena under investigation. It is, however, believed that the present study has given a fairly good picture of a variety of subjective (and to a certain extent shared) conceptions of IGT and beyond that about the kinds of more or less unacknowledged needs that IGT may fill. A methodological limitation is that parents with no experiences of participation in IGT were interviewed. They may as well have conceptions about IGT. It may have reduced the number of different conceptions. The imbalance between positive and negative aspects of IGT may reflect parents' eagerness to communicate positive aspects because improved support with the child's training was requested. Parents who participated in the interview were consumers of IGT and may have more positive expectations of the interventions than parents choosing not to let their child participate. Another limitation was that sociodemographic data was not among the inclusion criteria. Only one parent raised the child as a single parent. Single parents might have different experiences or possibilities to participate in IGT, especially if it necessitates accommodation. More studies are needed to test these findings critically. Several interviews were also performed after the interviewer had experienced saturation.

Result discussion

To ask parents about the meaning of IGT is not the same thing as asking them how important they consider IGT to be. It is basically to ask them what aspects of IGT they like, dislike or are more or less indifferent to. And as they answer they simultaneously make a kind of assessment of regular care and provide information about their wants and needs. A mother who is saying : "It strengthens you so much and you feel so strong after a period like this when you've met other parents" is obviously not only expressing a positive attitude towards

IGT but is also saying that she has a need to meet other parents in a similar situation and, implicitly, that this need is not sufficiently met in regular care or everyday life. The results from this study show that IGT have a potential to meet many wants and needs among parents. Wants and needs for relational, social, personal, “normalisation”, for relief from ordinary training responsibilities, for mobilization of others in training, but also for improved knowledge concerning present and future functioning of the child and about ways of coming to terms with problems in everyday life and in training. Wants and needs have, directly or indirectly, been reported to be met, although not necessarily “satisfied”, by participation in the IGT. Wants and needs for knowledge, for example, could be considered to be endless [26-28] and some of the needs for “normalisation” are only temporarily being met.

Are these wants and needs also central concerns for the habilitation services? Since parent participation is part of the family centred approach and since knowledgeable parents are important for successful involvement in caregiving [2, 29], it is unlikely that anyone would deny that transference of knowledge and a sense of actual involvement among parents are central goals for the enterprise. Increased parent involvement has also been suggested to improve prerequisites for a better fit between practical difficulties in ordinary life, services delivered, family strengths, and family limitations [30]. Since good knowledge is insufficient unless parents also trust their own agency, development of feelings of competence among parents is another almost self-evident goal [5, 9] and so is actually enhancement of different aspects of parents’ well-being [8]. Deficient well-being arising from overload of responsibilities, perceived lack of support from professionals, lack of self-confidence and actual or perceived marginalisation is not only a problem for parents themselves but also reduce their abilities and motivation as caregivers.

The knowledge theme, including a sense of increased competence, is of course most salient in the category IGT as knowledge promotion and in the specific conceptions belonging to that category, but also linger about in conceptions like IGT as building up relations with therapists, as a means to get a widened perspective, as a contributor to feelings of insufficiency and as a means to mobilize others. Results show that participation in IGT may contribute to increased knowledge through direct experiences and verbal exchange between parents, personal assistants and professionals. The formal and informal activities in the group setting may help parents to widen their understanding of the present functioning of the child, to make better predictions of the future, to get additional knowledge of ways of supporting the child's functioning and to share experiences and practical knowledge with parents in a similar situation. Despite the fact that many activities in the IGT approaches were simulated and carried out in a segregated setting, parents gave many examples of how they learned to support their child in his/her daily activities. The results also suggest that parents value therapists being models by showing how to afford learning opportunities by different means such as using hands, verbal instructions, structuring physical spaces, and use of materials to promote child participation. Opportunities for observation and imitation of therapists have previously been reported an effective [31] and valued [32] method for parents' learning. The results from the present study also support previous findings stating that selected activities which are easy to integrate into daily routines are doable and reasonable demands for parents in the home-environment [31, 32].

Well-being is a theme that appears most distinctly in the category IGT as a bracket in ordinary life. This category includes conceptions that together illustrate that IGT may contribute to comfort, feelings of being supported, sense of belonging, strength and vitality. The results also reveal experiences of the child being met with respect, appreciation, and encouragement.

Behaviour problems of the child have been found to be a source of stress (ill-being) for parents with disabled children [8, 33]. The conception IGT as a temporary normalisation illustrates that a relatively short stay in an environment of peers and knowledgeable and understanding professionals may serve as a platform which bolsters against strains in everyday life.

In categories and conceptions such as IGT as a means to; get relief from the training responsibilities, increased vitality and strength, getting time together with the child, it is obviously a parent's own wants and needs and the satisfaction of these that are in focus and may result in improved well-being. In categories and conceptions such as IGT as a means to get the child motivated in training, temporary normalisation and IGT as a leisure activity it is instead the supposed needs of the child and the perceived accommodation to these that are in focus and serve as a source for increased well-being for parents.

Judging from the results participation in IGT as a means to get relief from the training responsibilities may also positively contribute to parents' present well-being. Activities, where the child can independently participate and the child's special needs are met, might also support parents and children in their role transitions during child development. Disabled children have been found to participate in informal activities to a higher extent than formal activities and the overall participation in activities besides school decreased for children older than 12 years because of less participation in informal recreational activities [34]. This suggests a need for formal activities for older children with disabilities and for physiotherapists to take on a role in finding sports and activities that fulfil the needs of older children with CP [35] .

The results show that IGT may yield a good return for parents to children with CP, but also that it often is something of a mixed blessing. Some parents did not feel it necessary for themselves or for the sake of the child to participate, and it has been suggested in previous studies that participation is less important and may even be counterproductive for parents who already feel competent in handling the child [36]. It has also been shown that previous experiences of IGT decrease the need to participate [14]. Other parents, including persons who were predominantly positive, felt overwhelmed by demands to stimulate the child's development or to protect functioning from further deterioration, and experienced a growing conflict between the family's needs and the child's needs. Yet others reported that the interaction with therapists and other parents, as well as unrealistic demands on training at home, had given rise to feelings of insufficiency.

Expectations of professionals can be overwhelming for parents [32, 37]. Some parents perceive every day as a big exercise [30] and decreased caregiver demands have been shown to be associated with increased physical and psychological well-being [8]. Caution has therefore to be taken not to press unnecessary, unrealistic and at worst even destructive demands on parents who already have a very high caregiver burden compared to parents with non-disabled children. This calls for sensitivity to and awareness of parents' different expectations and needs and for an improved dialogue between parents and therapists [31]. The results of the present study may help parents and professionals discuss pros and cons of IGT in relation to different available interventions strategies in order to choose the best compromise between the child's and family's needs.

Acknowledgements

We are grateful for the parents sharing their experiences as participants in intensive training groups with their children.

References

1. King S, Teplicky R, King G, Rosenbaum P. Family-centered service for children with cerebral palsy and their families: a review of the literature. *Seminars in Pediatric Neurology* 2004;11 (1): 78-86.
2. Rosenbaum P, King S, Law M, King G, Evans J. Family-Centred Service: A conceptional Framework and Research Review. *Physical and Occupational therapy in Pediatrics* 1998; 18: 1-20.
3. Damiano DL. Activity, activity, activity: rethinking our physical therapy approach to cerebral palsy. *Physical Therapy* 2006; 86: 1534-40.
4. Helders PJM, Engelbert RHH, Custers JWH, Gorter Jw, Takken T, Van Der Net J. Creating and being created: the changing panorama of paediatric rehabilitation. *Pediatric Rehabilitation* 2003, 6: 5-12.
5. Ketelaar M, Vermeer A, Hart H, van Petegem-van Beek, Helders PJM. Effects of a functional therapy program on motor abilities of children with cerebral palsy. *Physical Therapy* 2001; 81: 1534-45.
6. Law M, Darrah J, Pollock N, King G, Rosenbaum P, Russell D, Palisano R, Harris S, Armstrong R, Watt J. Family-Centred Functional Therapy for Children with Cerebral Palsy. *Physical and Occupational Therapy in Pediatrics* 1998; 18: 83-102.
7. Darrah J, Law M, Pollock, N. Family-centered Functional Therapy- a choice for children with motor dysfunction. *Infants and young children* 2001; 13: 79-87.
8. Raina P, O'Donnell M, Rosenbaum P, Brehaut J., Walter SD, Russel D, Swinton M, Wood E. The health and well-being of children with Cerebral Palsy. *Pediatrics* 2005; 115:626-636.
9. Ekstöm-Ahl L, Johansson E, Granat T, Brogren Carberg E. Functional therapy for children with cerebral palsy: an ecological approach. *Developmental Medicine and Child Neurology* 2005; 47: 613-9.
10. Reddihough DS King J, Coleman G, Catanese T. Efficacy of programmes based on Conductive Education for young children with cerebral palsy. *Developmental Medicine and Child Neurology* 1998; 40: 763-70.
11. Hur JJ, Cochrane R. Maternal Stress and Level of Satisfaction with Treatment for children Undergoing Conductive Education. *International Journal of Special Education*, 1995; 10: 54-62.
12. Bower E, Michell D, Burnett M, Campbell MJ, mC Lellan DL. Randomized controlled trial of physiotherapy in 56 children with cerebral palsy followed for 18 months. *Developmental Medicine and Child Neurology* 2001; 43: 4-15.

13. Wright FV, Boschen K, Jutai J. Exploring the comparative responsiveness of a core set of outcome measures in a school-based conductive education programme. *Child Care Health and Development* 2005; 31: 291-302.
14. Ödman P, Krevers B, Öberg B. Parents' perceptions of the quality of two intensive training programmes for children with Cerebral Palsy. *Developmental Medicine and Child Neurology* 2007; 49: 93-100.
15. Catanese AA, Coleman GJ, King JA, Reddighough DS. Evaluation of an early childhood programme based on principles of conductive education: the yooralla project. *Journal of Paediatrics and Child Health* 1995; 31: 418-422.
16. Barnard A, McCosker H, Gerber R. Phenomenography: a qualitative research approach for exploring understanding in health care. *Qualitative Health Research* 1999; 9: 212-26.
17. Dahlgren L., Fallsberg M. Phenomenography as a Qualitative Approach in Social Pharmacy Research. *Journal of Social and Administrative Pharmacy* 1991; 8: 10-156.
18. Lymer UB, Richt B. Patients' conceptions of quality care and barrier care. *Journal of Evaluation in Clinical Practice* 2006; 12: 682-691.
19. Marton F. Cognosco ergo sum-reflections on reflections. In: Dall'Alba G, Hasselgren B, editors. *Reflections on phenomenography : toward a methodology?* Gothenburg: Acta Universitatis Gothoburgensis; 1996 p. 163-187.
20. Wood E, Rosenbaum P. The gross motor function classification system for cerebral palsy: a study of reliability and stability over time. *Developmental Medicine and Child Neurology* 2000; 42: 292-6.
21. World Health Organization (WHO). *International Classification of Functioning and Health (ICF) - child and youth version*. 2004 WHO library cataloguing-in-publication data. Geneva.
22. Ödman P, Öberg B. Effectiveness and expectations of intensive training: A comparison between child and youth rehabilitation and conductive education. *Disability and Rehabilitation* 2005; 28: 561-5
23. Ödman P, Öberg B. Effectiveness of intensive training for children with Cerebral Palsy - a comparison between child and youth rehabilitation and conductive education. *Journal of Rehabilitation Medicine* 2005; 37: 1-10.
24. Kvale S. *Den kvalitativa forskningsintervjun*. Vol. 1. Lund: Studentlitteratur. 1997.
25. Starrin B, Svensson PG. *Kvalitativ metod och vetenskapsteori*. Lund: Studentlitteratur. 1994.
26. King G, Law M, King S, Rosenbaum P. Parents' and Service Providers' Perceptions of the Family-Centredness of Children's Rehabilitation Services. *Physical and Occupational Therapy in Paediatrics* 1998; 18: 21-40.

27. Darrah J, Magil-Evans J, Adkins R. How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery. *Disability and Rehabilitation* 2002; 24: 542-9.
28. Garwick AW, Pattersson JM, Bennett FC, Blum RW. Parents' perceptions of helpful vs unhelpful types of support in managing the care of preadolescents with chronic conditions. *Arch Pediatr Adolesc Med* 1998; 152: 665-71.
29. Dunst CJ, Trivette CM. Empowerment, effective helpgiving practices and family-centered care. *Pediatr Nurs* 1996; 22: 334-7, 343.
30. Siebes RC, Wijnroks L, Ketelaar M, van Shie PEM, Gorter JW, Vermeer A. Parent participation in paediatric rehabilitation treatment centres in the Netherlands: a parents' viewpoint. *Child: Care Health and Dev* 2007; 33:196-205.
31. Hinojosa J, Anderson J. Mothers' perceptions of home treatment programs for their preschool children with cerebral palsy. *American Journal of Occupational Therapy* 1991; 45: 273-9.
32. Leiter V. Dilemmas in sharing care: maternal provision of professionally driven therapy for children with disabilities. *Social Science Medicine* 2004; 58: 837-49.
33. King G, King S, Rosenbaum P, Goffin R. Family-Centered Caregiving and Well-being of Parents of Children With Disabilities: Linking Process With Outcome. *Journal of Pediatric Psychology* 1999; 24: 41-53.
34. Law M, King G, King S, Kertoy M, Hurley P, Rosenbaum P, Young N, Hanna S. Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine and Child Neurology* 2006; 48: 337-42.
35. Ekenberg L. The meaning of physiotherapy: experiences of parents of young adults with impairment, in *Human Work Sciences*. (dissertation) Luleå: Luleå University of technology; 2000. p.84.
36. Jansen LM, Ketelaar M, Vermeer A. Parental experience of participation in physical therapy for children with physical disabilities. *Developmental Medicine and Child Neurology* 2003; 45: 58-69.
37. Ekenberg L. The meaning of physiotherapy: experiences of fathers and mothers of young adults with impairment. *Advances in physiotherapy* 2001; 3: 76-85.