

Parental effects from participation in an intensified multimodal programme of habilitation for children with cerebral palsy

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(Received 20 September 2009; accepted 1 July 2010)

Objective: To evaluate the effect on parents of participating in an intensified multimodal programme of habilitation for preschool children with cerebral palsy (CP). **Methods:** Thirteen pre-school children with CP, and their parents attended four in-patient sessions during the programme period of one-and-a-half years. During each group session, the parents were given lessons in coping strategies and positive adaptation. A group of six CP children receiving traditional follow-up habilitation services and their parents were used as controls. Parental effects were evaluated with Parental Stress Index (PSI) and Life Orientation Test (LOT). **Results:** Mothers in the intervention group had reduced scores below clinical level on both domains of PSI and an increase in LOT score after the intervention period. No changes in scores were seen for fathers or parents in the control group. **Conclusions:** The intervention programme seemed to reduce stress and increase optimism among mothers of participating CP children.

Keywords: CP; child; habilitation; intensified training; Parental Stress Index; life optimism

Introduction

It has been found that parents of children with cerebral palsy (CP) experience high levels of stress (Ketelaar et al. 2008). There is no obvious explanation as to why some parents deal with this added stress better than others (Raina et al. 2005) but the answer probably lies in how several reciprocal and dynamic relationships between stressors and strengths in the family system influence each other (Rentinck et al. 2007).

The importance of stress levels in the family is demonstrated in studies showing that level of parenting stress is positively correlated with level of depression among parents of children with CP (Wanamaker and Glenwick 1998). Often, behaviour problems are an additional source of difficulties and stress in families with children with CP (McDermott et al. 1996). Studies show that the incidence of behaviour problems in offspring is the single most important predictor of parents' psychological and somatic health (Raina et al. 2005).

A meta-analysis by Singer, Ethridge and Aldana (2007) concludes that stress management interventions for parents of children with disabilities have an effect in reducing psychological distress, at least for mothers. King, King, Rosenbaum and

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Goffin (1999) also find that parents of children with CP with a low degree of stress and depression experience better family functioning and more satisfying social support. The findings in this study clearly demonstrate the need for service providers to assist families in developing good problem solving and coping skills.

As a contrast to reducing parental stress, increasing parental optimism is a way of supporting everyday coping. The optimistic way of thinking about and explaining everyday life and the world in general, holds that there are solutions to the challenges of life. The optimistic way of thinking has been shown to be a good predictor of parents' positive attitudes and experiences of their child's capabilities and potential. Optimism has also been shown to be a central predictor in mastering larger life crises and challenges in a constructive way (Baker, Blacher, and Olsson 2005). Health services of good quality, and especially early intervention, are related to the degree of optimism parents have about the future, and consequently to hope for the future, which is central to family adaptation (Bailey et al. 2007).

In Norway the diagnostic process of cerebral palsy (CP) is provided by the specialized health care services, while treatment is given by professionals in the child's home community. The intensified habilitation programme (PIH) is a specialized multidisciplinary pilot programme of intensified training and stimulation of functional abilities for pre-school children with cerebral palsy (CP), their parents and local professionals that is offered to families in the southern part of Norway (Vestheim et al. 2007). The PIH programme represents a supplement to the ordinary habilitation services. The focus of the intervention in the PIH programme includes stimulation of functional activity, communication and executive functions, combined with counselling sessions by a trained psychologist for the parents. A central issue in the PIH is also to identify and deal with the stressors in the family system, to help the family system cope better with stress, and prevent possible stressors to develop further and impact the whole family system.

Aim of study

The aim of this pilot study was to evaluate the parental effects of participation in a specialized multidisciplinary programme of intensified habilitation for CP children. We wanted to know whether participation in this programme had an effect on the parents' experienced stress and feeling of optimism. Our hypothesis was that participation in the programme would result in lower degrees of stress and increased optimism. We did not expect any changes of stress and optimism among parents in the control group during the same time interval.

Method

Design

This was a non-randomized controlled trial where a group of CP children and their parents were followed prospectively for one-and-a-half years during participation in a Programme of Intensified Habilitation (Figure 1). Their results on standardized function tests and effects on parents were evaluated before and after the training period, and compared with the results of a control group of CP children and parents receiving traditional habilitation services during the same time period.

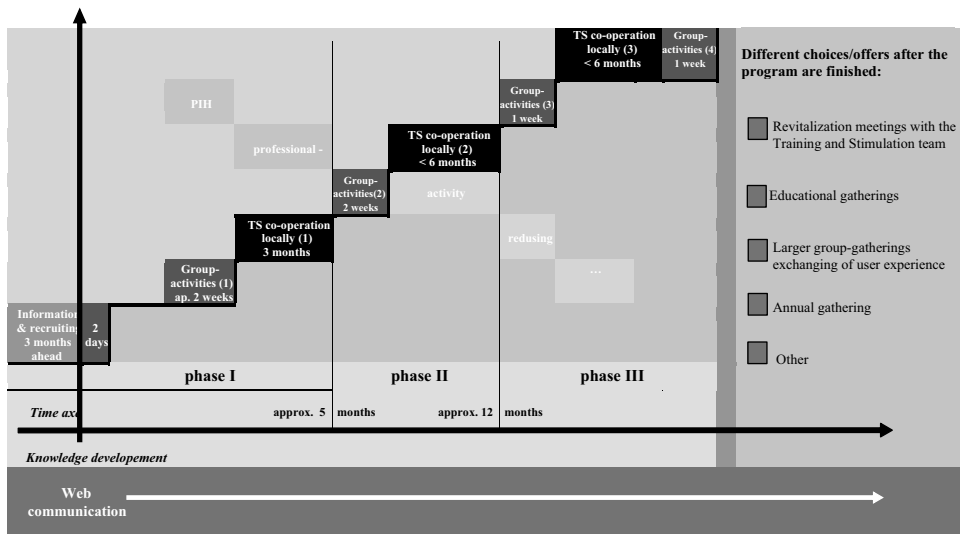


Figure 1. An illustration of the Programme of Intensified Habilitation (PIH).

The PIH – Programme of Intensified Habilitation

The PIH is a multidimensional programme, focusing on family-centred cooperation, improving knowledge about the child, goal-setting and goal-directed working, training and stimulation. PIH was developed based on clinical experience in working with groups of CP children. In addition, elements from other training programmes (Bower et al. 2001; Ketelaar 1999; Jansen, Ketelaar, and Vermeer 2003), central principles of learning (Hadders-Algra 2000), and the CanChild family-centred concept (Canchild 2010) formed the basis for this programme.

During the inpatient group sessions of one to two weeks professionals in the specialist health care arrange the daily training as individually-based goal-directed playing sessions. During the periods in between, when the children are in their home settings, parents and local professionals arrange the training. Services to the parents consist of a combination of parent group sessions in coping strategies and positive adaptation, and couple counselling on stress handling during the time their child attend the in-patient group activities. The counselling sessions are managed by a clinical psychologist working in the PIH programme.

Inclusion criteria for the participation in this pilot study were: age (two–four years), CP as the main diagnosis, and motivated parents for participation in the programme. CP children with different cognitive levels were included. Exclusion criteria were: genetic syndromes, autism spectrum disorder, extensive visual and hearing impairments, and receptive language disorders.

Participants

Experimental group

Thirteen CP children aged two–five years with Gross Motor Function Classification Scale (GMFCS) (Russell et al. 2002) levels 1–5, participating in the PIH were recruited from the specialized child habilitation services in Southern Norway. Twenty three parents participated in the evaluation process, 11 women and 12 men. Some of

the parents did not fill out all of the questionnaires after the programme period, causing some minor variations in the number of parents included in the statistical analyses.

Controls

Six CP children and their parents in the control group were recruited from a specialized child habilitation centre in another region of Norway (Sør-Trøndelag). The families received traditional habilitation services and follow-up in the same time period as the duration of the PIH programme. From our experience, the traditional habilitation services in this other specific region of Norway is quite similar to the services offered in our own health region, where the PIH programme is offered as a supplement, and not an alternative, to the traditional habilitation service. Some characteristics of the children in the study are summarized in Table 1.

Instruments

Parenting Stress Index (PSI)

The degree of parental stress was evaluated with the Parenting Stress Index (PSI) (Abidin and Wilfong 1989). The PSI is designed to identify stressful areas in parent-child interactions, and the results from the PSI indicate whether parents experience distress to a clinically disturbing degree.

The Life Orientation Test (LOT)

The Life Orientation Test (LOT) (Scheier and Carver 1987) was designed to measure an individual's optimistic orientation; that is, generalized expectations that good

Table 1. Clinical data for all the children in PIH (n = 13), divided into groups (Group A, B and C) and for controls (n = 6).

	PIH children (n = 13)	Group A (n = 4)	Group B (n = 5)	Group C (n = 4)	Controls (n = 6)
Boy : girl ratio	8 : 5	2 : 2	4 : 1	2 : 2	3 : 3
CP type					
– bilateral spastic type	8	4	0	4	5 (6)
– unilateral spastic type	5	0	5	0	0
GMFCS					
– level I	4	0	4	0	0
– level III	1	0	1	0	1
– level IV	3	2	0	1	3
– level V	5	2	0	3	2
Age (months) at pretest – mean (SD)	37.5 (8.9)**	30.6 (1.9)*	46.2 (8.6)*	33.5 (1.2)*	52.4 (11.2)
Age at last evaluation	56.2 (9.0)**	48.7 (2.5)*	64.4 (8.3)*	51.6 (1.1)*	71.4 (11.3)

**p < .01 (PIH children versus controls), *p ≤ .05 (group A, B and C versus controls).

Abbreviations: PIH: Programme of Intensified Habilitation; GMFCS: Gross Motor Function Classification Scale; SD: standard deviation.

things will happen. LOT is able to assess individual differences in generalized optimism versus pessimism.

Statistics

SPSS version 15.0 for Windows was used for data analysis of the clinical data. Mean values from cases and controls before and after the project period were compared using the Mann-Whitney U test. The Wilcoxon's signed rank test was used for evaluating paired data and changes with time.

Ethics

The Regional Committee of Medical Ethics and the Data Inspectorate in Southern Norway approved the study protocol. Written informed consent was obtained from the participating parents.

Results

Parental Stress Index (PSI)

Mothers participating in the PIH programme had the highest levels of reported stress prior to and showed the greatest decrease in stress levels after the intervention period based on the PSI. A significant reduction was found both on the Child Domain Total score and the Parent Domain Total score (Table 2). No significant changes were seen in fathers in the PIH programme during the study (Figure 2). Among the control parents, no significant changes were seen (data not shown).

The horizontal lines in Figure 2 represent the clinical border levels for Child Domain Total score (CDT – dotted line), Parent Domain Total score (PDT – broken line) and Total Stress Index (TSI – solid line). This means that values above each line represent stress of clinical significance. As seen from Figure 2, mothers' levels of stress seemed to decrease during the time period from pre to post test. Fathers' levels did not decrease. Mothers levels' at pre test were above clinical levels on both child and parent domains, and below clinical levels at post test on both child and parent domains.

Life Orientation Test (LOT)

There was a significant increase in LOT scores for mothers participating in the PIH programme, but no change for the fathers during the training period (Figure 3). No changes in LOT scores of control parents were found (data not shown).

Table 2. PSI – Subtest scores – Mean values (SD) of pre-test and post-test scores for mothers participating in the PIH (n = 9).

	Pre-test	Post-test
<i>Mother's report</i>		
Child Domain Total score	120.3 (23.0)	104.6 (28.1)**
Parent Domain Total score	144.2 (20.5)	125.4 (14.7)**
Total Stress Index	264.6 (39.2)	230.0 (38.9)**

**p ≤ .01, (Post-test versus pre-test score).

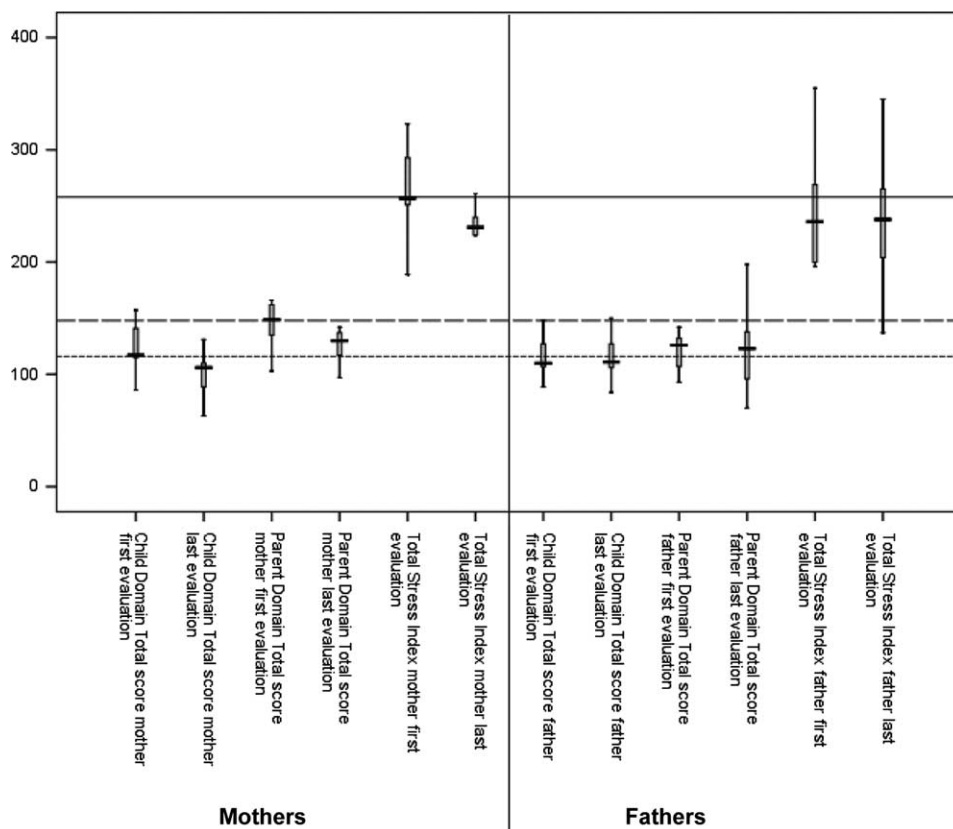


Figure 2. Mother's and fathers's PSI scores before and after the programme period. Horizontal lines represent the clinical border level (t-scores) for Child Domain Total score (dotted line), Parental Domain Total score (broken line) and Total Stress Index (solid line).

Discussion

The results of this study suggest that mothers with increased stress levels can achieve stress reduction and increased feelings of optimism through participation in an intensified habilitation programme including a limited number of group and couple counselling sessions. The fathers in this study did not show a reduction in stress levels or increased feelings of optimism.

The PIH project's ideological background is based on a belief that children with disabilities have the best opportunities if their parents cope with their disability and if the parents are able to manage the stress they experience. The link between stress management and family functioning is also well established in research (Raina et al. 2004; King et al. 1999).

The intensified habilitation programme in this study had a focus on optimism and the possibilities of each child. The strengths of the child and the individual family members were given much attention, as were the ways in which these individual potentials could help the whole family system work as optimally as possible. At the first meeting with the psychologist in the PIH programme, the participating parents started a dialog about how to find a good organization and structure of daily living, dilemma concerning overprotection and control, disclosure

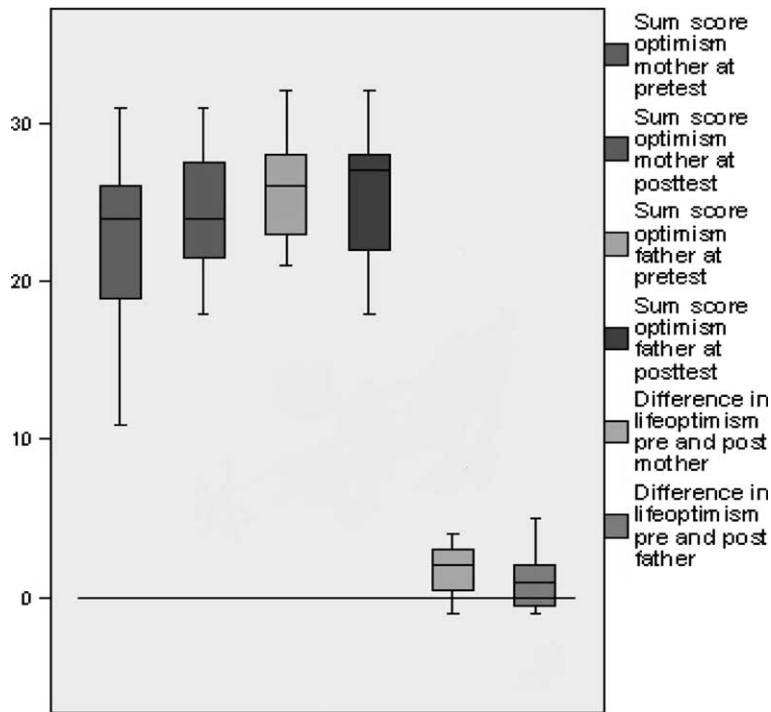


Figure 3. Life orientation test (LOT) scores at pre-test and post-test in mothers and fathers in the PIH programme. For mothers there is a significant increase in score (Wilcoxon's signed ranks test $p < .05$).

of diagnoses and other challenges in their family life. Parents reported meeting other parents, although belonging to different socioeconomic classes and cultures, as being central, and weighted focus on coping in the families as giving them security and competence.

Stress

Mothers in the PIH programme had the highest levels of reported stress prior to the intervention and showed a significant decrease in stress levels after the intervention period. Whether the training of the children in the PIH programme itself leads to a decrease in stress levels, or the counselling sessions have made the mothers more capable of handling stress is not controlled for in this study. The premises of the research programme in the PIH have not yet made us capable of evaluating the parental effects of the children's training programme or the stress management intervention, independently of each other. The programme consists of both aspects for all participants and separating the two aspects of the programme for research purposes would require a thorough ethical and medical debate within PIH. Nevertheless, these results strengthen the assumption that intensified habilitation combined with counselling sessions for the parents are of great value for these families.

The fathers in the PIH programme did not reduce their stress levels. Several factors might underlie this finding. One might assume that the stress management

intervention sessions are more suitable for women, the intention to fully participate and explore the mechanisms behind the psychological distress in the family system might differ based on gender or the overall participation in the PIH might be more stressful to men than women. An alternative explanation to the apparent gender difference is that parents experiencing stress to a clinically disturbing degree in general are the ones most likely to benefit from this type of intervention. Focusing the intervention at parents with a heightened stress level instead of explaining the difference in effect in terms of gender might be a more suitable way of addressing this. Nevertheless, at this point the findings direct our attention to a serious issue, in that approximately half of the parents participating in the PIH do not seem to experience the effect that we would like from the stress management intervention. In the following research programme within the PIH these considerations will be of particular interest to pursue further.

Parents in the control group

The parents in the control group reported less stress than the intervention group at both pre- and post-test. Their stress levels based on PSI closely resembled those of mothers of cases with mild CP, although the controls had moderate to severe CP. An explanation may be that parents in the intervention group, who actively have sought a supplement to the traditional follow-up habilitation, do not find the traditional habilitation services satisfying. Being dissatisfied with the offer from their traditional habilitation service might also lead to elevated levels of stress. The possibility of selection bias must also be kept in mind; the parents in the control group might already be coping within a well-functioning family system, therefore displaying lower levels of stress. Parents with low levels of stress could be more inclined to participate as a control group in a study like this.

Optimism

As for experienced stress, the same, although reversed, tendency was found regarding optimism among mothers in the intervention group. Mothers' reports indicated a greater general optimism towards life after participating in the PIH programme. An explanation for this might be that parents have experienced the PIH programme to be a health service of good quality and contributing to a more predictable and controllable future for their child and the family system. The increase in reported optimism also suggests that these mothers might be more attuned to their child's capabilities and potential after participating in the PIH programme (Baker, Blatcher, and Olsson 2005).

Limitations of study

This pilot study has some methodological limitations. The selection of children and parents to the intervention group was based on their voluntary participation in the programme. This may have created selection bias of either especially motivated families or families that were not satisfied with their present services and wanted something new. There was also a non-randomized selection of controls belonging to another health region and they were asked to join because they had children with CP

at about the same age. This may also have created selection bias in the control group. Another limitation is the rather low number of participants and the functional variation in CP severity within the intervention group, and between groups. This resulted in few children at each GMFCS level. It is therefore not possible to interpret differences in effect of the programme based on different GMFCS levels.

Conclusions and further developments

Parents are essential in a preschool child's life, and need knowledge about important factors for improving their child's qualifications for participation. The child achieves optimal function within a supportive, low-stressing and well-coping family context (Lerdal and Sørensen 2008; Rentinck et al. 2007). As children with disabilities often have needs that are different from other children, and sometimes also difficult to fulfil, it is essential to offer parents of these children assistance and support in reducing stress and promoting good adaptation and coping.

Parental effects of this multimodal programme, with intensified training programme for CP children and counselling focusing on family coping and stress handling for the parents, seems to be reduced stress and increased optimism in mothers, with no changes seen in fathers. Whether this is a true gender difference or if the effect is based on pre-intervention stress levels is a question for further research. Nevertheless, helping parents in coping and stress handling is difficult, but important.

The PIH programme will be continued as a supplement to the traditional child habilitation services at Sørlandet hospital, in Kristiansand, in southern Norway. A follow-up research programme is in progress, partly aiming to reduce the methodological problems from the pilot study.

Acknowledgements

This project was supported with grants from the Department of Health Services, The Norwegian Ministry of Health and Care Services, the Health South Region administration in Norway, and the Competence Development Fund of Southern Norway.

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