

Optimism and sense of coherence in mothers and fathers of children with cerebral palsy (CP) participating in an intensified habilitation program.

Authors:

Randi Damgård

Lillesand kommune and University of Agder, Faculty of Sport and Health Sciences,
Kristiansand, Norway.

E-mail randi.damgard@lillesand.kommune.no

Telephone + 47 48101176

Kristian Sørensen

Child Habilitation Unit, Department Pediatrics, Sørlandet Hospital Kristiansand, Post Box
416, 4604 Kristiansand, Norway

E-mail: kristian.sorensen@sshf.no

Telephone + 47 38033978

Ida Eline Vestrheim

Child Habilitation Unit, Department Pediatrics, Sørlandet Hospital Kristiansand, Post Box
416, 4604 Kristiansand, Norway

E-mail: ida.vestrheim@sshf.no

Telephone + 47 38034389

Bjørn Lerdal

Child Habilitation Unit, Department Pediatrics, Sørlandet Hospital Kristiansand, Post Box
416, 4604 Kristiansand, Norway

E-mail: bjorn.lerdal@sshf.no

Telephone + 47 38074396

Jon Skranes

Dept. of Laboratory Medicine, Children's and Women's Health, Medical Faculty, Norwegian
University of Science and Technology (NTNU), 7491 Trondheim, Norway

E-mail: jon.skranes@ntnu.no

Telephone + 47993985

Child Habilitation Unit, Department Pediatrics, Sørlandet Hospital Kristiansand, Post Box 416, 4604 Kristiansand, Norway

Gudrun Rohde

Faculty of Health and Sport sciences, University of Agder, Servicebox 422, 4604 Kristiansand, Norway

Department of Clinical Research, Sorlandet Hospital, Kristiansand, Servicebox 416, 4604 Kristiansand, Norway

E-mail: Gudrun.e.rohde@uia.no

Telephone: +47 3814 1846

Conflict of interest statement

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Abstract:

Background: To describe optimism and sense of coherence in mothers and fathers of preschool children with cerebral palsy (CP), before and after participation in an intensified habilitation program (PIH). **Methods:** Forty-five parents of preschool children with CP answered the Life Orientation Test (LOT) and Sense of Coherence questionnaire (SOC) twice during one year. **Results:** Parents of the youngest CP children and those with high stress levels reported reduced optimism and sense of coherence at baseline. No statistically significant changes in LOT and SOC scores were found during the program period. However, among mothers who reported clinically significant change, 67% reported more optimism after PIH. There was a strong negative correlation between parental stress and LOT and SOC in mothers at baseline and the fathers results changed to a similar correlation after intervention. **Conclusions:** PIH seems to induce a more reality-oriented view of the situation among fathers and more optimism among about half of the mothers.

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Key words: CP, child, habilitation, optimism, sense of coherence.

Introduction.

Having a child with a disability can be described as a fundamental transformation and adaptation process for parents, and implications of the child's disability may influence every sphere of family life (Pelchat, Levert, and Bourgeois-Guérin 2009). Cerebral palsy (CP) is the most common neurological disability in childhood with a prevalence of 2.1 per 1000 live births (Andersen et al. 2008). Cerebral palsy (CP) is caused by damage to or abnormal development of the infant brain and affects the development of movement and posture, causing activity limitation and motor disability. Concomitant disturbances of sensation, perception, cognition, and communication are common and behavior problems and seizure disorder may occur (Bax et al. 2005). Most often CP is diagnosed within the child's second year of life (Andersen et al. 2012).

Parents of children with CP experience elevated levels of stress compared with the general population (Glenn et al. 2009). Lerdal et al (2013) found levels of stress above normative clinical level in 37.5% of mothers and 23.5% of fathers of preschool children with CP. The stress factors were partly due to the condition of the child, but parental factors such as feeling of incompetence, symptoms of depression and lack of support from spouse also increased the level of stress.

Optimism has been found to increase resilience to stress in parents (Fayed et al. 2011) and is described as a personal trait, a general expectation that positive outcome will occur (Scheier and Carver 1985). Optimism may function as a moderator and predictor between child problems and parental adjustments (Baker, Blacher, and Olsson 2005; Heinonen et al. 2006). Lowered optimism has been found in parents of children with impairments (Ekas, Lickenbrock, and Whitmann 2010; Fotiadou et al. 2008; Labbé et al. 2002). However, participation in an intensive habilitation program has been reported to increase optimism among mothers of preschool children with CP (Lerdal et al. 2011).

Optimism is positively associated with caregivers' psychosocial functioning and is found to be a predictor of coping with life challenges in a constructive way (Labbé et al. 2002; Thuen and Rise 2006; Carver, Scheier, and Segerstrom 2010). Sense of coherence (SOC) also seems related to parental coping as the capability to activate and increase resources. SOC is described as an individual global orientation and a relatively stable individual factor developing during adolescence and early adulthood (Antonovsky 2000). The overall issue is the personal capability to view the world as comprehensible, manageable and meaningful – focusing the “salutogenic” issues in health promotion (Lindstrøm and Eriksson 2006). SOC is also influenced by the surroundings and the society in general (Antonovsky 2000). Norwegian research on macrosocial processes shows that mothers and fathers of children with disabilities take on additional parental roles (Tøssebro et al. 2014). They have to be administrators and therapists and at the same time maintain a family situation that is as normal as possible. Our clinical experience is that parents feel overwhelmed by complex health and support systems. A lot of time and energy is spent trying to navigate, understand and make use of these systems. In addition they have to relate to and cooperate with a number of health and support professionals.

Sense of coherence is strongly related to perceived mental health and is described as a predictor of good health, a mediator in parental well-being (Olsson, Larsman, and Hwang 2008) and a negative predictor of stress (Margalit and Kleitmann 2006). Furthermore, SOC can be seen as a health promoting resource, which strengthens resilience and leads to a positive subjective state of health (Eriksson and Lindstrøm 2006). Low SOC is found in parents of children with different impairments (Olsson and Hwang 2002; Margalit and Kleitmann 2006; Grøholt, Nordhagen, and Heiberg 2007; Olsson, Larsman, and Hwang 2008; Pisula and Kossakowska 2010; Bergh and Bjørk 2012; Schubert et al. 2012) and is associated with avoidance, wishful thinking, distraction and resignation (Pisula and Kossakowska 2010).

Parents of children being treated for cancer show a decrease in parental SOC during the time course of treatment. These changes in SOC vary between mothers and fathers (Bergh and Bjørk 2012).

There is a lack in descriptions of caregivers' characteristics for identification of optimistic parents who cope well and those that are at risk (Guyard et al. 2011; Raina et al. 2005; Krstic and Oros 2012). Little is known about how mothers and fathers of preschool children with CP experience optimism and sense of coherence over time. Thus, the aim of the present study was to describe optimism and sense of coherence in mothers and fathers of preschool children with CP, before and after participation in an intensified habilitation program. We hypothesized increased optimism and sense of coherence in parents after attending the intensified habilitation program.

Material and methods.

Design.

To describe change in parental experienced optimism and sense of coherence, we applied a prospective design in mothers and fathers of CP children participating in a multidimensional, intensified habilitation program. The parents were followed for one year. Data were collected during the period 2007-2011.

The parents completed the questionnaires measuring optimism (LOT) and sense of coherence (SOC) before and after participation in the Program Intensified Habilitation (PIH). Data regarding parental stress were collected at baseline and post-test, i.e. after finishing the program. In describing data, baseline data were numbered 1 (LOT₁, SOC₁), and post-test data 2 (LOT₂, SOC₂).

Program Intensified Habilitation (PIH).

The intervention was a one-year, intensified, habilitation program (PIH) for preschool children with CP, their parents and local professionals, given from a multi professional team in a child habilitation unit in a hospital- in the Health Region of South-Eastern Norway (Sørensen et al, 2011). It addresses parents who want to learn more and take a more active role in training and stimulating their child. It is a supplement to the ordinary habilitation services. The intervention (PIH) has a multimodal approach (Fig1); i.e. several interventions are simultaneously applied. During the year in PIH, parents and their child spend four periods of one or two weeks in a hospital setting. In these periods parents and their child receive intensified habilitation interventions for about six hours each day, this includes services from physical therapists, occupational therapists, special educated teachers, pediatricians and psychologists. In the time in between hospital periods, the interventions are being implemented by local professionals in preschool or by parents at home. The families attend a group but the interventions are individually adjusted. The concept is based on a Family-centered service model (King et al, 2004) as children are addressed through their parents, in addition to being treated directly.

Figure 1 near here

Participants.

Parental data in the study were gender and clinical stress. Inclusion criteria for children were a CP diagnosis and age between 2-4 years. The children represented all Gross Motor Function Classification System (GMFCS) levels from I to V (Palisano et al. 2008). Exclusion criteria were comorbid autism spectrum disorders, extensive visual and/or hearing impairments and receptive language disorder. At baseline sixteen parents had children from 2 years to 2 years

and 11 months (2-3 years), sixteen parents represented children from 3 years to 3 years and 11 months (3-4 years), while thirteen parents participated with children aged 4 years to 4 years and 11 months (4-5 years).

Clinical data for children and parents are presented in Table 1.

Due to variation in fulfilling the questionnaires across time, number and characteristics of parents and children differed somewhat in the analyses.

Table 1 near here.

Instruments.

Life Orientation Test (LOT).

LOT is designed to measure individual optimism or optimism as a general expectation that positive outcomes will occur (Scheier and Carver 1985). Previous studies have found acceptable construct- and criterion validity, and test-retest reliability (Andersson 1996; Scheier and Carver 1985). LOT includes 8 items; 4 positively and 4 negatively loaded, the positive items' scores were reversed. A four point Likert-type scale was used (1 = strongly agree - 4 = strongly disagree). Higher scores indicate higher optimism and a total sum score is ranged from 8-32 points. Cronbach's alpha in our study reached 0.81.

Sense of Coherence questionnaire (SOC).

SOC is designed to measure individual global orientation to view the world as comprehensible, manageable and meaningful (Antonovsky 2000). More than 15 different versions of the instrument have been described (Eriksson and Lindstrøm 2005). The instrument used in our study contained 3 items; 2 positively and 1 negatively loaded, the positive items' score were reversed. The total score was based on a 3 point Likert-type scale (1 = yes, 2 = yes sometimes, 3 = no) with sum score ranged from 3-9 points. Higher score

indicated higher sense of coherence. Validity and reliability of the three-item version of SOC is proved acceptable and fairly good (Eriksson and Lindstrøm 2005), but is also found not encouraging (Schumann et al. 2003). Cronbach's alpha in our study reached 0.36.

Parenting Stress Index (PSI).

The degree of parental stress was evaluated with the Parenting Stress Index (PSI) (Abidin and Wilfong 1989). Parenting Stress Index (PSI) is a commonly used questionnaire to identify areas of stress and burdens in the parent-child relationship. The total score is based on a 5 point Likert-type scale (1 = strongly disagree - 5 = strongly agree) with sum score ranging from 101-502 points. Clinical stress level is defined at the 85th percentile. Scores above the 85th percentile are associated with lower parental quality of life and reduced parent-child interaction skills. The standardized scores and clinical stress level are based on an American sample from the original development of the PSI (Abidin and Wilfong 1989). The Norwegian version of the questionnaire was used. This version has been approved by developers of the original questionnaire and has in previous studies shown satisfactory reliability and validity (Glavin et al. 2010).

Statistics.

Statistical analyses were carried out using the IBM SPSS Statistical Package for Social Science for Windows (version 18). Descriptive statistics were calculated for parent and child characteristics. Independent samples t-tests and One way ANOVA were used to compare mean values in LOT and SOC between sub-groups, while paired sample t-test was used to compare mean values in LOT and SOC at baseline and post-test. Multiple linear regression analyses were used to assess adjusted (parental gender and age group) changes in LOT and SOC. Furthermore effect sizes of mean change in LOT and SOC across time were calculated by subtracting the mean LOT and SOC scores at baseline from the mean scores of post-test,

and then dividing by the SD at baseline. The effect size allows for comparison across dependent variables and was interpreted according to Cohen`s effect size index, with 0.2 indicating a small difference, 0.5 a moderate difference, and 0.8 or more a large difference (Cohen et al1988). Correlations were used to identify any possible relationships between optimism, sense of coherence and stress. The strength of relationships were estimated as weak ($r = .1 - .3$), moderate ($r = .4 - .6$) and strong ($r = .7 - .9$) (Dancey and Reidy 2011). To describe within-person change across time and estimate the proportions of parents in the intervention group with clinical changes; we described minimal clinical important difference (improvement or worsening) in LOT and SOC. We identified the parents with modest- (5-10%), moderate- (10-20%) and substantial change (>20%) (Fayers and Machin 2007) from baseline to post-test. Internal consistency in the two scales was estimated by Cronbachs´ alpha at baseline. The level of significance was set at 0.05.

Ethics.

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

The study is registered at the Clinical Trails nr. NCT00202761 (Skranes 2005).

Results.

Baseline characteristics of the mothers and fathers and children are presented in table 1.

Thirteen out of 29 parents (nearly 45%) reported clinical stress above the 85th percentile at baseline (Abidin and Wilfong 1989). The percentage of mothers above clinical stress level was twice the percentage of fathers.

Optimism, sense of coherence and stress at baseline.

Mean parental response on LOT was 24.4 (3.9) and on SOC 7.0 (1.3) at baseline. No differences in mean LOT and SOC scores at baseline were found, regarding parents' gender, children's gender, GMFCS levels or subgroups of CP diagnosis. However, parents of children with CP in age group 2-3 years experienced lower LOT and SOC mean scores at baseline compared with parents of children between 3-4 years (Figure 2). For age group 2-3 years, parental mean LOT score was 22.8 (4.7) while for age group 3-4 years mean LOT score was 26.4 (2.4) ($p=0.021$). Parents of age group 2-3 years reported SOC mean score of 6.5 (1.2) while reported mean SOC score was 7.7 (1.1) for parents of age group 3-4 ($p=0.022$). No differences in parental mean LOT and SOC scores were found between age group 4-5 years and the two other age groups.

Figure 2 near here.

Parents with PSI scores above clinical stress level reported lower mean LOT scores 21.1 (3.8) versus 25.7 (3.1), ($p= 0.001$) and lower mean SOC scores 6.1 (1.1) versus 7.3 (1.1), ($p= 0.005$) than parents with PSI scores below clinical stress level at baseline (Figure 3).

Figure 3 near here.

Change in optimism and sense of coherence.

No significant changes in LOT and SOC mean scores were found between baseline and post-test (Table 2). This was also the case when controlling for parental gender and the age group of the children.

Table 2 near here.

Minimal clinical important difference.

A total of 25 parents reported clinically significant change in LOT score at post-test (14 positively and 11 negatively changes) and 16 parents reported clinically significant change in SOC score at post-test (10 positively and 6 negatively changes) (Table 3).

Table 3 also shows that ten (67%) of fifteen mothers who reported clinically significant change in LOT, changed in a positive direction. In the group of fathers, four (40%) of a total of ten changed in a positive direction.

Table 4 near here.

Correlation between parental experienced optimism, sense of coherence and stress.

Strong correlations between scores on SOC, LOT and parental stress were found for mothers before attending PIH (Table 4). High scores on the LOT and SOC were associated with low scores on the PSI. The same strong correlation was seen for LOT and PSI after PIH participation. Fathers' scores indicated the same relationship, but changed from moderate correlations at pretest to strong correlations, at post-test (Table 5).

Table 4 and Table 5 near here.

Discussion.

Parents of children aged 2-3 years with CP and those with high stress levels reported reduced optimism and sense of coherence. No statistically significant changes in LOT and SOC scores

were found between baseline and post-test. However, among mothers who reported clinical significant changes, 67% reported more optimism after participation in PIH. There was a strong negative correlation between parental stress and LOT and SOC in mothers at baseline and in fathers at post-test.

We found lowest optimism and sense of coherence in parents of the youngest children with CP. The level of optimism in parents of 2-3 year old children with CP in our study was comparable to that reported in a study of mothers to autistic children (Ekas, Lickenbrock, and Whitmann 2010) and parents of children with cancer (Fotiadou et al. 2008). The confirmation of the CP diagnosis may indicate a crucial time in parental adaptation. The prognosis and consequences of the development of a child with CP is often unknown at the time of diagnosis. This first period after diagnosis, may affect parents' vulnerability, their expectations and coping (Olsson and Hwang 2002). The unclear and changing situation may give parents increased difficulties in choosing among coping strategies and efforts (Lin 2000; Rentinck et al. 2007; Rentinck et al. 2010). Parents of children with CP may experience greater personal burdens and higher levels of stress, in particular in the child's infancy, and this may be more pronounced in mothers than in fathers (Rentinck et al. 2007). Our findings support the comprehension of excessive parental challenges in this stage of the family life (Rentinck et al. 2010) and the importance of early intervention to support these parents.

In this study, we found no differences in optimism and sense of coherence between the groups of parents of children with CP participating in PIH, neither at baseline nor at post-test. However, lower sense of coherence was found in parents when compared to a German population study (Schumann et al. 2003). Also sense of coherence among mothers and among parents of 2-3-year old children with CP, were lower than comparable groups in this German population study (Schumann et al. 2003). Our findings are supported by previous studies that have found lower sense of coherence among parents of children with cognitive disabilities

(Grøholt, Nordhagen, and Heiberg 2007; Olsson, Larsman, and Hwang 2008), among parents of children with autism (Olsson and Hwang 2002; Pisula and Kossakowska 2010) and among parents of children with different type of chronic diseases (Schubert et al. 2012). Some studies have found a gender difference in sense of coherence between parents (Olsson and Hwang 2002; Olsson, Larsman, and Hwang 2008; Cheshire, Barlow, and Powell 2010), while others found no such difference (Pisula and Kossakowska 2010). Low sense of coherence supports the comprehension that parents caring for a child with neuroimpairments are at greater risk than parents of healthy children. These lower levels may make parents even more vulnerable to experiencing stress (Olsson and Hwang 2002), and stress could worsen the situation further creating a negative circle. It is of importance to find intervention strategies that will contribute to better coping for the families.

Although mean scores on LOT and SOC did not change statistically significant during the intervention period, clinically significant changes were reported in a high proportion of the parents. This may indicate that participation in PIH does affect parents on this dimension. Mothers more than fathers, reported improved optimism after PIH. Mothers may be more open to such intensified habilitation programs (Pelchat et al. 2009), or the PIH intervention may be more suitable for mothers than fathers (Lerdal et al. 2011, Lerdal et al. 2013).

There was a correlation between optimism, sense of coherence and parenting stress. Strong correlations were found in mothers' scores, before attending PIH. At this point the same correlations for fathers' scores were moderate. After attending PIH, strong correlations between optimism, sense of coherence and stress were found in fathers' scores as well. The weaker correlations in fathers' compared to mothers' scores prior to the intervention, maintain the comprehension of the traditional family roles (Raina et al. 2005) and in particular the comprehension that the mother still is the main caregiver of the child (Lerdal et al. 2013). After attending PIH, fathers' results resembled those of the mothers' to a greater degree.

Earlier studies have shown that the fathers' levels of stress are not altered during participation (Lerdal et al 2011), but our results indicate that parents at least experience the stress and realities of the situation in a more similar way after attending PIH. It is our clinically experience that parents after participation in the program view their child and the challenges associated with CP in a more similar way. Generally the roles of administrator and home fall on the mother (Tøssebro 2013), but in PIH both parents participate and the traditional family roles are set aside. Receiving the same information, experiences and counselling provide parents with a much more similar basis of understanding their child. It is therefore tempting to assume that the parents through participation in PIH have reached a more similar understanding of the realities of caring for their child.

Our results indicate strong correlation between optimism and stress in mothers. Therefore, we suggest that LOT might be used as a clinical instrument, to find parents in need of intervention to improve their coping with the situation. Optimism may be seen as a more generic factor (Carver, Scheier, and Segerstrom 2010), and more directly connected to change in stress (Lerdal et al. 2011) than sense of coherence (Eriksson and Lindstrøm 2005).

Methodological considerations.

Participation in PIH is voluntary and this may have created selection bias. There were also some drop-outs (variation in fulfilling) from baseline to post-test. This might limit the possibility to generalize from our results. The lack of control group including parents of children with CP and identical functional level is another weakness of our study. The main reason for not including such a control group is because it is difficult to identify controls that match both the characteristics of the children with CP and their parents. However, a control group would make our results more reliable. The election of the three-item version of SOC may be criticized and the rather low Cronbach's alpha may be of concern (Schumann et al.

2003). The low Chronbach`s alpha underlines results from a previous study finding the three-item version not encouraging (Schumann et al. 2003). The results in our study do not support the responsiveness in LOT and SOC questionnaire to detect changes in life orientation and sense of coherence during an intervention program. Considerations regarding internal and external validity in this design may also limit the generalization of our results.

Conclusion.

To our best knowledge this is the first study reporting optimism and sense of coherence in both mothers and fathers of preschool children with CP before and after attending a non-traditional multidisciplinary treatment program over a year. Mothers and fathers of children with CP seem to be at increased risk of lower optimism and reduced sense of coherence, especially those with children aged 2-3 years and those with high stress levels at baseline. Our findings may indicate that the PIH program influences parental experienced optimism and sense of coherence to some extent. Correlations between parental optimism, sense of coherence and stress suggest that stress reduction may be an approach in targeting optimism at least in mothers. Our findings also showed that fathers' experienced stress level before attending an intensified program is relatively low and that there is a stronger correlation between stress, optimism and sense of coherence in fathers after participation. This may be due to a more reality-oriented view of the situation after attending a program like PIH. Whether these findings also indicate a more permanent change in the parental adaptation processes and change in experienced spousal support was not within the aims of this study and has to be further examined.

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Table 1. Clinical data for children and parents

	N
Parents	45
Mother/father ratio	23/22
Clinical stress mothers/fathers	9/4
Children	26
Girl/boy ratio	11/15
Mean age of child (months)	39.4 (9.4)
GMFCS levels	
GMFCS level I+II	9
GMFCS level III+IV	11
GMFCS level V	6
Age group child	
2-3 years (2-2 years 11 months)	9
3-4 years (3-3 years 11 months)	8
4-5 years (4-4 years 11 months)	9

Data are given as numbers of parents and numbers of children.

Mean age child is given in months

Table 2. Scores on Optimism (LOT) and Sense of coherence (SOC) at baseline and post-test .

	N	Mean	SD	p	Effect size	Mean change (SD)
LOT						
LOT ₁	29	23.8	4.0			
LOT ₂	29	23.6	5.0	.640	-0.06	0.26 (2.95)
SOC						
SOC ₁	26	6.9	1.3			
SOC ₂	26	7.1	1.3	.327	0.14	-0.19 (0.98)

Data are given as means with standard deviation, effect size, and mean change with standard deviation. Paired samples t-tests were applied to detect significant differences between baseline and post-test.

LOT = Life Orientation Test (range 8-32). SOC = Sense of Coherence questionnaire (range 3-9). LOT₁/SOC₁= baseline, LOT₂/SOC₂= post-test.

Table 3. Minimal clinical important change in maternal- and paternal scores on Optimism (LOT) and Sense of coherence (SOC) from baseline to post-test.

	Negative minimal clinically difference			Positive minimal clinically difference		
	>20%.	10-20%	5-10%	5-10%	10-20%	>20%
Mothers						
LOT ₁ – LOT ₂ (N=17)	3	1	1	8	0	2
SOC ₁ – SOC ₂ (N=14)	2	0	0	0	0	5
Fathers						
LOT ₁ – LOT ₂ (N=12)	3	0	3	2	1	1
SOC ₁ – SOC ₂ (N=12)	2	2	0	0	1	4

Life Orientation Test baseline/post-test (LOT₁/LOT₂), Sense of coherence questionnaire (SOC₁/SOC₂)

Table 4. Correlations between Optimism (LOT), Sense of Coherence (SOC) and stress (PSI) in mothers.

	Baseline - r _(n)		Post-test - r _(n)	
	SOC1	PSI1	SOC2	PSI2
LOT1	.84 ₍₂₃₎ **	-.78 ₍₂₀₎ **		
SOC1		-.74 ₍₁₉₎ **		
LOT2			.78 ₍₁₄₎ **	-.69 ₍₁₅₎ **
SOC2				-.42 ₍₁₃₎ **

Optimism (LOT), Sense of Coherence (SOC), stress (PSI)

LOT₁,SOC₁, PSI₁ measured at baseline, LOT₂,SOC₂, PSI₂ measured at post-test

** p< 0.01, *p<0.05

Table 5. Correlations between optimism (LOT), Sense of Coherence (SOC) and stress (PSI) in fathers in the intervention group.

	Baseline - r _(n)		Post-test - r _(n)	
	SOC1	PSI1	SOC2	PSI2
LOT1	.48 ₍₁₉₎ *	-.54 ₍₁₉₎ *		
SOC1		-.55 ₍₂₁₎ *		
LOT2			.79 ₍₁₃₎ **	-.70 ₍₁₅₎ **
SOC2				-.81 ₍₁₃₎ **

Optimism (LOT), Sense of Coherence (SOC), stress (PSI)

LOT₁,SOC₁, PSI₁ measured at baseline, LOT₂,SOC₂, PSI₂ measured at post-test

** p< 0.01, *p<0.05



Figure 1. The intervention modules in the Program of Intensified Habilitation (PIH)

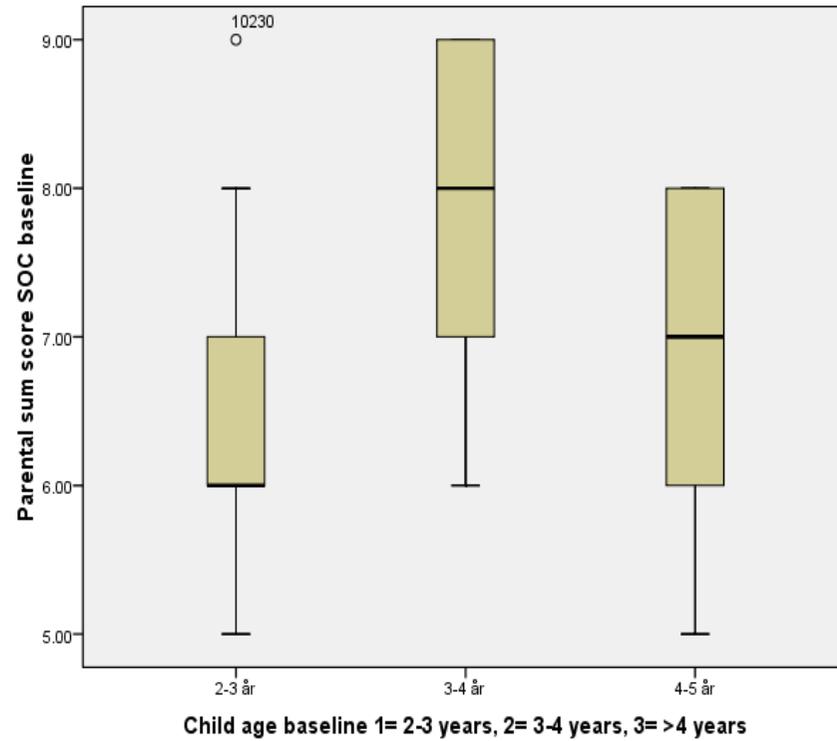
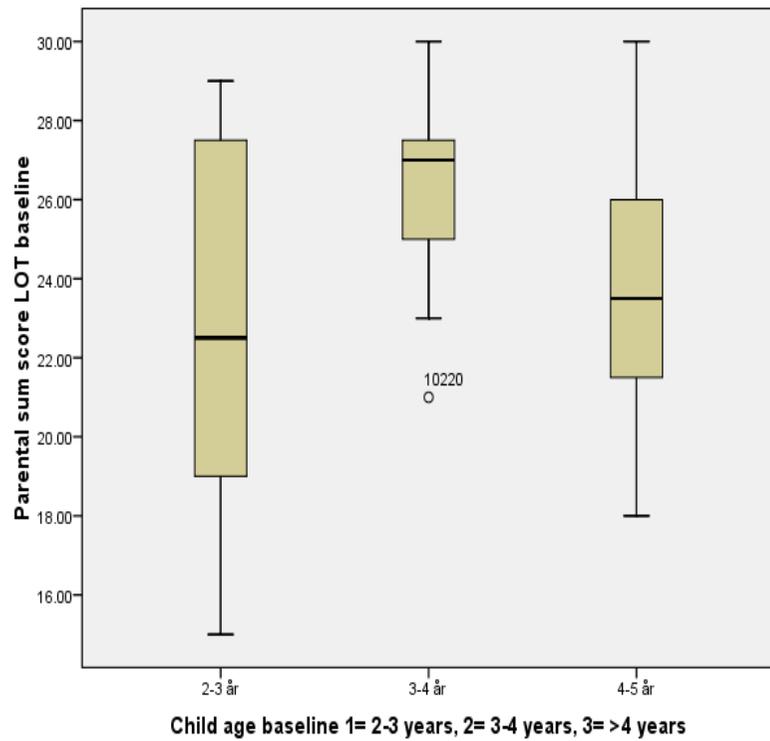


Figure 2. Parental sum scores of LOT and SOC, respectively at baseline divided in different age groups of children; 2-3 years, 3-4 years and 4-5 years. LOT = Life Orientation Test (range 8-32). SOC = Sense of Coherence questionnaire (range 3-9).

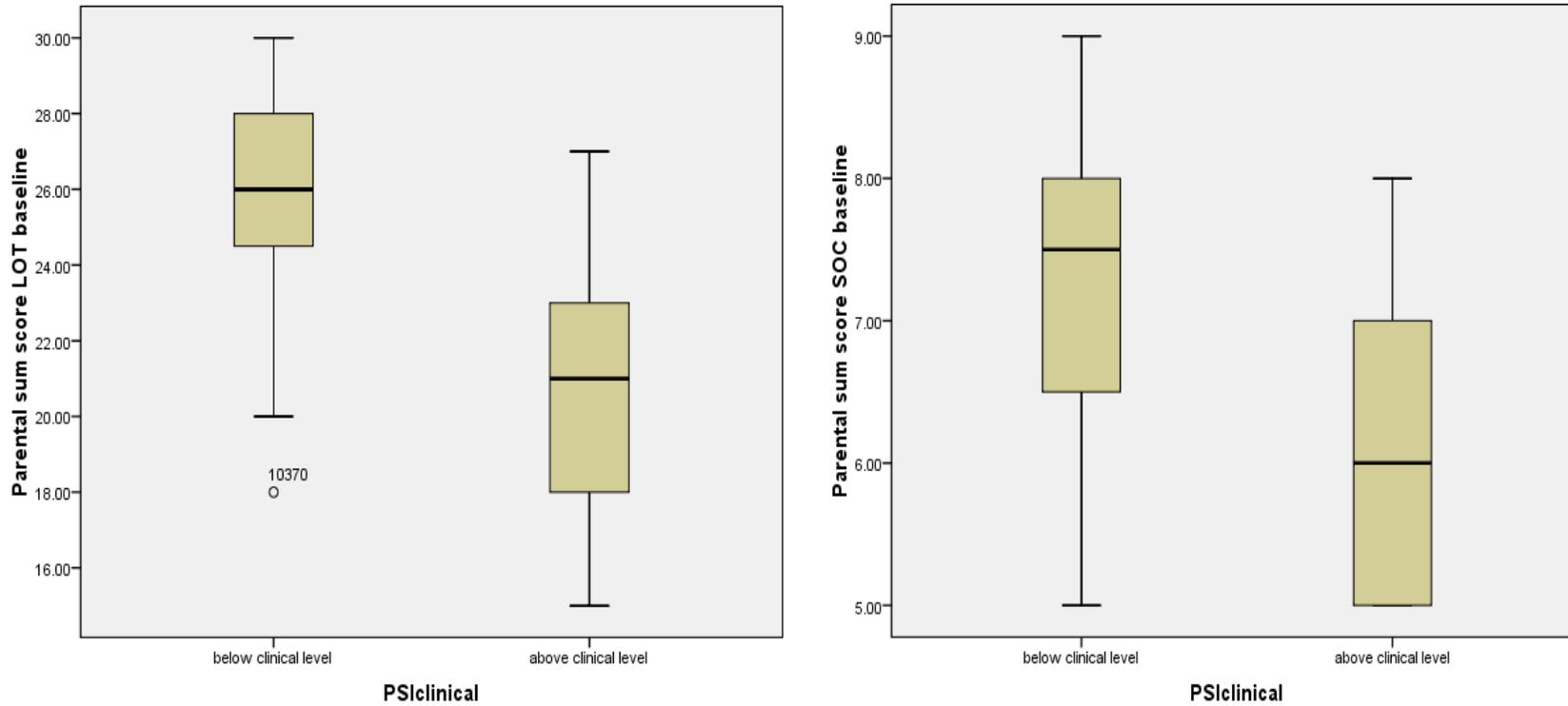


Figure 3. Parental sum scores LOT and SOC at baseline divided in groups with PSI score above or below clinical stress level (85th percentile). LOT = Life Orientation Test (range 8-32). SOC = Sense of Coherence questionnaire (range 3-9). PSI: Parenting Stress Index.