Outcomes of a group parent training procedure in families with autistic children

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Summary: The effects of a parental training program involving three one-day group parent training were evaluated. The training focused on (1) addressing issues of the nature, etiology, and treatment of autism, (2) teaching child management and education skills, (3) discussing family roles and family coping strategies. A total of 24 parents of 23 autistic children participated in the center-based training program, which was performed in three small groups in three different areas of Germany in 1998. The mean age of the children was 8.9 years. The outcome variables included: (a) group training assessments by parents; they evaluated quality of the curriculum, therapist variables, and group atmosphere, using a self-administered Likert-type-questionnaire format, (b) parental 3-month follow-up assessments of the effects of group training on parent-child interactions and family adaptation, using two self-administered Likert-type questionnaires and a semi-structured parent diary. The parent training resulted in (a) a high degree of parental satisfaction with the training format and (b) positive effects on daily parent-child interactions. These findings provide some evidence for the clinical and social validity of the family intervention method examined in this study.

INTRODUCTION

Child autism is defined as a pervasive developmental disorder. About 75 percent of all autistic children function at a retarded level of intelligence (DSM-IV, Diagnostic and Statistical Manual of Mental Disorders, 1994). Looking at parents and families of autistic children, there is strong evidence from the research literature that they face a high level of stress (Probst, 1996, 1998). This is mainly caused by the typical symptom pattern which pervades the child's cognitive, emotional, and social functioning. In addition, parents' stress is influenced by their children’s interactions with family, neighborhood, school, and community environments.

Many people react to autistic children and their parents in an unfriendly or even aggressive manner, because they are not able to recognize the children's disability. Consequently, they blame the children or their parents for misbehaving.

Thus, many parents of children with autism and related pervasive developmental disorders (Rett's Syndrome, Asperger's Syndrome, Atypical Autism, Childhood Disintegrative Disorder, cf. DSM-IV, 1994) are in urgent need of social support provided by professionals (Probst, 1997). In the international research literature, in particular from English-speaking countries, parent training methods - individual as well as group - have proven to be effective interventions in terms of outcome variables such as "child adaptive behaviors", "level of child development", "quality of parent-child interactions", "family adaptation", and "parental treatment satisfaction" (Probst, 2001). Unfortunately, almost no outcome studies have been reported from German-speaking countries, although a high proportion of parents of autistic children in Germany want to have a more active and reciprocal role within the parent-professional relationships than they experience in the present situation. This finding was reported in a three-nation comparative study performed by Häussler in Denmark, the USA, and Germany in 1998.

Based on empirical findings like those described above, the present pilot study was designed to assess whether the parent training method is a valid approach in the context of the German health care system. A group parent training program was developed and evaluated in cooperation with the National Association of Parents with Autistic Children (Bundesverband "Hilfe für das autistische Kind") and the regional branches of this German parent organization.

The key questions of the present pilot study are:

* Firstly, do parents of autistic children accept the group parent training approach
described in the present study? Do parents evaluate the goals and procedures of the parent training positively? In other words, does the type of family intervention used in this study have a high degree of social validity?

* Secondly, does parent training have a substantial effect on child behavior, parent-child interactions, and family adaptation in the view of the parents?

**Assessments of child symptoms and parent stress reactions**

Table 1: Selective findings from the 48-item Child Symptom Behaviors and Parental Stress Questionnaire (3-point rating scales on frequency of child behaviors and corresponding parental stress levels)

<table>
<thead>
<tr>
<th>My child:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FREQUENCY:</strong> sometimes or frequently (%)</td>
</tr>
<tr>
<td>lives in his or her own world</td>
</tr>
<tr>
<td>prefers to play alone instead of with other children</td>
</tr>
<tr>
<td>does not express his or her needs by using verbal language</td>
</tr>
<tr>
<td>becomes frustrated when he or she tries to communicate and then gives up</td>
</tr>
<tr>
<td>hurts him- or herself, e.g. by banging the head on the floor, biting him- or herself or hitting his or her head with the fists</td>
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<tr>
<td>has severe tantrums</td>
</tr>
<tr>
<td>becomes upset by changes in daily routines or by new activities</td>
</tr>
<tr>
<td>does not obey me and does not accept restrictions and limits</td>
</tr>
<tr>
<td>demonstrates deviant and strange behaviors in public</td>
</tr>
<tr>
<td>permanently puts high demands on me by his or her dependency (from Family Adaptation)</td>
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</table>
Table 1 reports selected findings from the 48-item *Child Behavior Symptom and Parent Stress Questionnaire*, used as a pre-training assessment instrument. Some behaviors that are particularly stressful for many parents are summarized in table 1. In the left hand column the frequencies of symptom behaviors are reported, in the right hand column the stress levels associated with the behaviors are presented:

* 85 percent of the parents report: "My child lives in his/her own world sometimes or frequently" (rating level = 2 or 3); 61 percent of these parents express the view that this child behavior is very stressful (rating level = 3).
* Similarly, "impairment in verbal communication", "tantrum behaviors", "self-injuring behaviors", and "strange behaviors in public" place high stress on parents as well.
* All parents from this sample report facing *permanent demands* caused by dependent and challenging behaviors of their child.

**Some remarks on the theoretical framework of the parent training approach**

* The parent group training developed in the present study is designed to function as a *component* within a more *comprehensive rehabilitation program*, which includes additional components of home-based or clinic-based individual parent training, broad spectrum parent counseling, and preschool/school counseling.
* Several concepts and techniques selected from a *broad-spectrum behavior modification* approach have been included in the curriculum, such as *discrete trial* format interventions (highly structured), *incidental-naturalistic* format interventions, and *antecedent behavioral* interventions, which put the focus on environmental changes (Probst, 2001). Furthermore, ideas selected from *developmental* theory, *family ecology* theory, and *client-centered* theory were taken into account.
* The main goal of the parent training approach was not the *recovery* of children from autism, as autism is a permanent, mostly life-long disorder or disability, which is strongly caused by genetic, prenatal, perinatal, and postnatal factors in-
fluencing the early brain development. Rather, the principal goal was the optimal integration of the autistic children and their families into societal life. Veilande & Bahmacova (2000) discussed Antonovsky's concept of *sense of coherence* at this conference. In fact, the principal goal was the enhancement of the *sense of coherence* in parents and children, that is strengthening the *meaningfulness, predictability, and manageability* of life.
METHODS

Table 2 summarizes the methodological characteristics of the present study:

Table 2: Overview: Methodological features of the present study

<table>
<thead>
<tr>
<th>Parent sample</th>
<th>24 parents (83% mothers), mean age = 41 yrs. (s= 9.1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child sample</td>
<td>23 children (61% boys), mean age= 8.9 yrs. (s= 3.6), No or very low language: 52%</td>
</tr>
<tr>
<td>Training procedure</td>
<td>3-one-day-training sessions (1 per month) in 3 small groups (3-13 participants)</td>
</tr>
<tr>
<td>Training methods</td>
<td>* Instruction by lecture, training manual, * model training by video and in-vivo-role-play-exercises (e.g. prompting, preparing a daily schedule) * homework assignments, * group discussion</td>
</tr>
<tr>
<td>Pre-training assessment measures</td>
<td>* Biographical 50-item-Questionnaire, * 48-item-Child-Symptoms-Questionnaire, * 25-item-Family-Adaptation-Questionnaire</td>
</tr>
<tr>
<td>Outcome measures</td>
<td>* 29-item Parental-Evaluation-of-Training-Sessions-Questionnaire, * 26-item Effects-on-Parent-Child-Interaction-Questionnaire for parents * (3-month follow-up)</td>
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Sample

- A sample of 24 volunteer parents of 23 autistic children participated in the study. The mean age of the children was 8.9 years.
- A percentage of 52% of the children were functioning at a very low level of language. They had no functional use of language.
Parent group training curriculum

The curriculum of the parent group training included six main topics as follows: (1) nature of autism, (2) etiology of autism, (3) treatment and rehabilitation, (4) family and child issues, (5) practical instructions on how to promote the child's cognitive-social functioning and to manage his or her behavior problems, (6) life-span development issues.

Didactic methods used in the parent training

The parent training included the following didactic methods:

* Oral and written instruction,
* Modeling by trainer and video demonstrations,
* Role playing exercises, which mainly consisted of the following five elements:
  (a) instructing, prompting and rewarding the child within the discrete trial format
  (b) instructing the child within the natural-incidental format,
  (c) breaking down a complex task to be done by the child into several small steps,
  (d) developing a daily schedule or activity schedule for the child,
  (e) or making materials for tasks which were given to the child later in order to promote his or her abilities; these tasks were designed to be motivating and meaningful to the child.
* Assignment of homework to parents: homework consisted of various planned activities with the child such as matching objects or playing with toys. Generally these activities were designed to last not longer than 10-20 minutes per day. Homework also included some informal documenting of the child's behavior in a parent diary.
Illustration of the parent training curriculum by examples

* Three examples (Figure 1, 2, 3) of materials produced by parents at home or within the three-day-parent group training are presented.

| Figure 1: Visual structure in the kitchen: Susanne's working and activity schedule for setting the table | This schedule tells the child: First find plate (*Teller*), then cup (*Tasse*), drinking glass (*Glas*), knife (*Messer*), fork (*Gabel*), and spoon (*Löffel*). |
* The first example (Figure 1) shows the kind of homework that parents did with their 16-year-old girl, who was mentally retarded, nonverbal, and autistic. They supported Susanne by a visual structure that told her what to do in the kitchen and where to find various objects necessary for setting the table, such as plates, cups or spoons.

* The second example (Figure 2) refers to visual support in the bathroom: The poster tells the boy pictorially how to do his dental hygiene, what to do first, and so on.

* In the third example (Figure 3), the boy is supported by a so-called *social story*, which reminds him pictorially: "No hitting!" "Don't hit other children on the playground!".

**Procedure**

The training was completed in 3 one-day sessions held on Saturdays, one session a month, in 3 different groups at different sites: in Potsdam (Brandenburg), Hamburg, and Ibbenbüren (North-Rhine Westphalia).
**Assessment variables**

The pre-training assessment measures included the following instruments:
the *Biographical Inventory*, the *Child Symptoms-Parent Stress Questionnaire* (described above), and the *Family Adaptation Questionnaire*.

**Outcome variables**

The outcome measures included: * a 29-item *Parental Evaluation of Training Sessions Questionnaire*, and a * 26-item *Parental-Evaluation-of-Training-Effects-Questionnaire*, administered 3 months after completion of the three training sessions.

**RESULTS**

Table 3 summarizes some main findings (a) from the parental evaluation of the training sessions and (b) from the follow-up evaluation by parents.

Table 3: Selective overview: Parental evaluation of training sessions and parental follow-up evaluation

<table>
<thead>
<tr>
<th>Description of items of the evaluation questionnaires</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)Looking at this Saturday's session, how satisfied were you with this session on the whole? (4-point-bipolar rating-scales for items (1) to (4), averaged over 3 sessions: Percentage of &quot;fully satisfied&quot; evaluations)</td>
<td>82%</td>
</tr>
<tr>
<td>(2) (…) with the clarity of presentation</td>
<td>92%</td>
</tr>
<tr>
<td>(3) (…) with the engagement of trainer and co-trainer</td>
<td>88%</td>
</tr>
<tr>
<td>(4) (…) with the emotional atmosphere in the group</td>
<td>95%</td>
</tr>
<tr>
<td>(5) (…) with the schedule of this session</td>
<td>68%</td>
</tr>
<tr>
<td>(a) On the whole, parent training has been effective in improving my child's daily management (4-point unipolar rating-scale for items (a) to (c): Percentage of moderate or strong agreements to the statements</td>
<td>89%</td>
</tr>
<tr>
<td>(b) Parent training enhanced our family atmosphere</td>
<td>68%</td>
</tr>
<tr>
<td>(c) Parent training reduced the daily demands and stresses of parents</td>
<td>74%</td>
</tr>
<tr>
<td>The other parents in the parent training group were significant teachers to me</td>
<td>95%</td>
</tr>
</tbody>
</table>
The findings shown in table 3 indicate:

(a) A high proportion of parents evaluated the format of the group parent training **positively** in terms of trainer variables, quality of instruction, and atmosphere in the group. In addition, the **mutual exchange of experiences** between parents was rated as very **helpful** by almost all parents.

(b) A high proportion of parents reported **positive effects** of group parent training on the daily **parent-child interaction** in the family, and on the **family stress level**. Some anecdotal reports from parent diaries are consistent with the findings described.

**DISCUSSION**

In discussing the findings reported in the preceding chapter, firstly we have to take into consideration the level of experimental validity, and secondly we have to interpret the findings against the background of their validity: Do the findings confirm the two key hypotheses of this study: (1) Is the parent training approach accepted by parents? (2) Does this method show some effects in the real life from the view of parents?

**Experimental validity of the study**

Looking at the methodological features reported for this study we have to focus on a number of restrictions and limitations that threaten experimental validity is threatened.

**Internal validity**: The following factors can be identified by that reduce **internal validity**: * the small **sample size**, * the lack of **control groups** such as treatment comparison groups, * and the **narrow scope of outcome measures** included in the present study. All outcome variables are based on **parent reports**. They do not measure child functioning, family functioning, and parent-child interactions on a **behavioral-observational** basis.

**External validity**: Factors by which the external validity is reduced are: * **sample selection**: a highly motivated **volunteer parent sample** was examined; this sample is not **representative** of the population of all parents having an autistic child; * the external validity might also be reduced by some features of the **training curriculum** focusing partly on dealing with theoretical topics and participating in group discussions; these tasks will possibly make high demands of those parents
who are not used to performing activities of that kind. Thus, some parents perhaps need some propaedeutic measures or some different type of training curriculum.

**Outcomes of the study**

The overall outcomes of the present study are consistent (a) with the two key hypotheses stated in the introductory chapter as well as (b) with findings from several previous studies performed by Harris at Rutgers University in the USA (see review: Probst, 2001) and by Bernard-Opitz & Kok (1992) at the “Structured Teaching Center” in Singapore. Positive outcomes in child behavior and parent-child interactions at significant levels have been reported there.

In conclusion, it can be stated - cautiously, in the light of some factors, through which the experimental validity was reduced - that there is some empirical evidence for the parent group training showing a substantial degree of social as well as clinical validity. Thus, the parent training approach can be recommended as an appropriate treatment option to parents who are motivated to take an active parental role. Further research is needed for better understanding of the interactions between child, parent, and treatment factors.

**REFERENCES**


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