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ABSTRACT

Twenty-one families participated as members of experimental or control groups in a study which investigated the effects of family-oriented intervention on the stress level of families with young handicapped children (average age 2 years) whose impairments were primarily developmental delay or cerebral palsy. Parents completed the Parenting Stress Index (PSI) upon entrance to the program and again after 6 months. Systematic family-oriented intervention provided to the experimental group included transdisciplinary assessment, development of an individualized education program for each child, free-play observation of parent and child, assessment of family needs, an individualized family plan, sessions with a family therapist, crisis counseling as needed, and optional participation in parent and sibling groups. Post-intervention PSI scores for the experimental group indicated a significant decrease in stress related to the child's adaptation and demandingness, while parental perception of child mood was significantly improved. PSI scores for the comparison group did not change over the 6-month period. (Author/JW)

EFFECTS OF FAMILY-ORIENTED INTERVENTION WITH YOUNG HANDICAPPED CHILDREN ON INDICATORS OF PARENTAL STRESS

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Running Head: Parental Stress Intervention

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Abstract

The purpose of this study was to investigate the effects of family-oriented intervention on the stress level of families with young handicapped children. The effect of family support services provided to families by the intervention team was measured on the Parenting Stress Index (PSI) (Abidin, 1983). Twenty-one families participated in the study. Parents in the experimental group filled out the PSI upon entrance to the program and again after six months. The systematic family-oriented intervention provided to the experimental group included: transdisciplinary assessment and IEP development, a free play observation of parent and child, an assessment of family needs, an Individualized Family Plan, sessions with a family therapist, and optional participation in various parent and sibling groups. The family therapist on staff provided counseling to experimental families in crisis. Also, staff members were trained in counseling techniques to provide support to families. Significant differences between the experimental and comparison group were evident in the analysis. Specifically, child domain scores for adaptation, demandingness and mood, were positively effected by intervention provided to the experimental group. Scores for the comparison group did not change over the six month period.

EFFECTS OF FAMILY-ORIENTED INTERVENTION WITH YOUNG HANDICAPPED CHILDREN ON INDICATORS OF PARENTAL STRESS

The whole family system is affected by the diagnosis of a handicapped child or the recognition of a developmental delay. Increased demands are placed on the family as they manage their feelings of disappointment, grief, and loss; cope with day to day situations such as special care or behavior problems; or simply try to understand the meaning and impact of their child's disability.

There is considerable clinical and empirical evidence that, in many important ways, the process of adjustment experienced by the family of a handicapped child is similar to that experienced by a family when a member dies (Schnell, 1982). This is understandable since, in order to accept a handicapped child, a parent must mourn the loss of the normal child that was hoped for and expected (Solnit and Stark, 1961; Kubler-Ross, 1969; Martin, 1975).

Following the diagnosis of disability, in the initial stage of denial, parents typically feel shock, numbness, and disorientation. They often refuse to recognize that certain characteristic behaviors are abnormal; and shop around for more optimistic second opinions. In response to intervention, parents may deny the need for treatment or believe that intervention will cure the child's disability. This period of shock and denial may last only a few days or may continue for many months.

In the second stage, when the fact of the disability becomes real, parents typically experience strong feelings of both guilt and anger. In their search for a reason for the child's disability, they often blame themselves, their spouse, or others (e.g. educational and/or health care professionals). They also may experience feelings of shame, and failure, or may have wishes or hopes that the child had not been born, or would die.

This is often followed by a period of despair and hopelessness, when the parent hopes for improvement with intervention, but fears the worst. During this stage, a parent often experiences the physical and emotional symptoms of depression; and may withdraw from previously supportive relationships. During this stage, parents often burn out friends and relatives.

Ultimately, many parents are able to view their handicapped child realistically, and achieve an emotional stability which allows the family to move on. Some clinicians feel, however, that the process of mourning may never be completed by some families who keep a severely handicapped child in the family. These families experience chronic sorrow, a non-pathological state of sadness which does not interfere with the parent desiring satisfaction from the child's growth and modest accomplishment (Olshansky, 1962).

Early intervention programs in the past have focused on the individual handicapped child. However, a more global view of the child's ecological environment and effect on the family is emerging. Stress levels in families with handicapped children have been compared to stress levels in families with non-handicapped children. Some instruments have been developed to measure stress and coping in these families.

Friedrich, Greenburg and Crnic (1983) developed an instrument designed to measure stress and coping of families, the Questionnaire on Resources and Stress (QRS). Results from studies comparing families with handicapped children and families with non-handicapped children showed significant differences on the QRS. Results indicated that families with handicapped children experience more stress, less marital satisfaction, less psychological well-being, less social support and less religiosity. (Friedrich and Friedrich, 1981; Crnic, Friedrich and Greenberg, 1983; Friedrich, Greenberg and Crnic, 1983).

The Parenting Stress Index (Abidin, 1983) has been used to measure stress in several studies of parents of handicapped children. Zimmerman (1979) found that 10 of the 20 scores on the PSI were significantly different between mother-child systems with cerebral palsy children matched with control children who had no psychological or physical differences. In another study, Greenberg (1983) studied parents of mentally retarded children. She reported that the PSI was sensitive to overall level of stress as well as the child's deviant characteristics. Realizing that the level of stress is high in families with handicapped children, this study attempted to provide family support services which were designed to alleviate some of the stress experienced by these families.

Method

The purpose of this research was to evaluate the effects of systematic, family-oriented intervention on the stress level of parents of young handicapped children. Twenty-three families participated in the study as part of the experimental or comparison group. Differences in stress variables were evaluated prior to and subsequent to participation in planned intervention environment. Family-oriented intervention involved the experimental group only. The comparison group was composed of children and families entering the program after being on the waiting list for 6 months. Scores on the PSI were compared between the experimental group subjects (who had received intervention for 6 months) and the comparison group subjects who were just entering the project.

Subjects

Six boys and six girls were participants in the experimental group. Four of the children were black and eight were white. Similar numbers of boys and girls (4 and 2 respectively) were distributed across both racial groups in the sample (phi = 0.0, $p > .01$). The average age of the children upon entering the program was 27 months (SD = 11 months) and the average gestation age was 34 weeks (SD = 6 weeks); six of the children were premature at birth. The children's parents were well-educated, using number of years of schooling as a criterion; however, approximately 60 percent of the families earned less than $10,000 a year.

The extent of impairments of the children participating in the project were developmentally delayed (43%) or cerebral palsy (33%). Half of the children performed in the 69 - 84 range of cognitive abilities and the performance of 42 percent of the children evidenced more than a six month delay in language abilities. Only one third displayed normal motor development. Most of the children had normal vision and hearing (75%, 92% respectively) but some (approximately 60%) exhibited mild to severe behavior problems.

Five boys and six girls were participants in the comparison group. Three of the children were black and eight were white. Similar numbers of boys and girls were distributed across both racial groups in the sample (phi = 0.47, $p > .01$). The children were younger than those participating during the initial project year, averaging 20 months chronological age (SD = 11 months) upon entering the project; however, the average gestation age (mean = 35 weeks, SD = 5 weeks) was similar to that of the experimental group. The children's parents were well-educated, using numbers of years of schooling as a criterion; however, more than two-thirds of the families earned less than $10,000 a year.

The extent of impairments of the comparison group children were similar to those in the experimental group. Most were classified as developmentally delayed (82%). About one third of the children performed in the 69 - 84 range of cognitive abilities and performance of 46 percent of those remaining was below 52. Forty-five percent of the children evidenced more than a six month delay in language abilities and 55% experienced motor impairments. Almost all of the children in the comparison group had no behavior problems, normal vision and normal hearing.

Procedures

During an initial interview each child was screened to determine if the basic criterion of acceptance into the project (i.e., three months delay in two skill areas) were present. The transdisciplinary team screened the child's development in cognitive, communication, motor, social, and self-help skills. The Denver Developmental Screening Test (DDST), Developmental Assessment Screening Inventory (DASI), Receptive-Expressive Emergent Language Scale (REEL), and informal testing by the Occupational Therapist and Speech-Language Pathologist were used for this screening. In addition to these tools, each child was observed in play with the staff and parent; and, the parent completed an interview administered by the Project Coordinator about the child's development and family needs.

Once the child was accepted into the project, he was formally assessed by the transdisciplinary team and consulting Educational Psychologist. Recognizing that different levels of delay and handicapping conditions exist in the population, a wide variety of assessment tools were used. Since a comprehensive intervention plan was formulated from the assessment results, it was important that an accurate profile of the child's strengths and weaknesses be obtained. Often the assessment procedure was completed over several sessions.

A case manager wrote a comprehensive Individualized Family Plan (IFP) for each experimental family. The goals of the IFP included the areas of social support, behavior management, parent training and/or parent support. Parents and professionals formed a partnership in working with the child on developmental goals. Parents participated in the intervention visit and carried over intervention at home between visits. Intervention was consistent over time and responsive to the child's needs. The child's needs were always considered in the context of the home environment and the parents' style of teaching.

Visits with the child and family were scheduled weekly. Case managers tried to make this the same day and time each week. A monthly calendar was given to the parent with appointments for the month. Consistent contact was very important to the child's progress. In some situations, contacts were scheduled more than once a week.

Each family was administered The Parenting Stress Index (PSI) which contains 101 items (with an optional 19 item Life Stress Scale) in two domains. High scores (i.d., 122+) in the Child Characteristics Domain are evident when it is difficult for parents to fulfill their parenting roles as a result of what their children do. High scores (i.e. 153+) in the parent Characteristics Domain are suggestive of parent functioning as a source of stress in a family system. The relationship between the domain scores is used as an indicator of targets for intervention (e.g. high Child Domain versus high Parent Domain places emphasis on child or parent interventions) and the total score is evaluated as a reflection of need for outside consultant (i.g., if greater than 260).

The validity of the PSI was established in a series of predictive and comparative studies. Significant correlations (above .10) between scores on the PSI and other stress/anxiety measures are indicated in the user's manual. Evidence is also presented indicating that "handicapped" and "control" groups generate different scores on the stress dimensions of the PSI. Internal consistency estimated (e.g., coefficient alpha reliabilities) reported in the manual for the subscales range from .55 to .80 and from .89 to .95 over three month time periods. There is ample evidence of use with families of handicapped children presented in the psychometric characteristics provided in the test manual.

Results

Means and standard deviations for PSI scores obtained from parents participating in the project are presented in Table 1. Higher scores (relative to "high score" standards reported in the manual) are evident on the Child Characteristics Domain than on the Parent Characteristics Domain. This suggests that characteristics of the child are the primary stress producing factors in the family system (this is a common pattern in families with a handicapped child). All but one of the subscores within the Child Domain are less than 2 points from high scores extablished as reflective of child-centered family problems and stress. The total PSI score is also above the cut-off indicative of need for outside consultation services.

Insert table 1 about here

Means and standard deviations for Parental Stress Index scores of families prior to and after participation in the STRETCH program are presented in Table 2. In general, parents reported less stress after being in the project for six months; their scores on the Child Domain items were influenced more than their Parent Domain scores. Relative to specific domains, stress related to adaptation and demandingness significantly ($p < .05$) decreased while the parents perception of child mood was significantly improved. No other significant finding were indicated; however, the directional differences for most other specific stress indicators supported the posttest scores.

Insert table 2 about here

Means and standard deviations for Parenting Stress Index scores of families not participating in the STRETCH program are presented in Table 3. In general, parents reported less stress upon reevaluation after six months time; scores on the Parent Domain items were more influenced than the Child Domain scores. Relative to specific scores, no significent ($p = .05$) changes were indicated. Stress related to the child reinforcing the parents and social isolation increased while stress related to all other specific domains increased.

Insert table 3 about here

In general, the outcome analyses favored those families who participated in the experimental group systematic sessions. Parents in the experimental group generally reported less stress upon re-evaluation after six months. Parents reported significantly fewer problems with their child's adaptability and demandingness. Parent perception or child mood was also significantly improved.

Discussion

When a handicapped child is born into a family, changes and adaptations have to be made. Utilizing a family systems approach, programs can maximize the child's development by helping the family cope with the child. When an intervention specialist works with a handicapped child or a child who has developmental delays, it is important to remember that the child is a part of a family system. Knowledge of family dynamics and how the family develops coping mechanisms is important for the child's progress. Monitoring of the family process is essential when the goal is to help the family augment and accept the developmental changes in the child and assist the family in functioning constructively. In this research, systematic, family-oriented interventions were provided for an experimental group of handicapped young children as well as support and training for family members. Parents needs were addressed in several ways. In order to maximize the parent's educational involvement with the child, immediate practical and emotional needs were recognized by professionals. To provide a responsive and comprehensive program for the families, Individualized Family Plans (IFP) were developed to target family needs. These plans addressed family needs in a step-by-step manner. The consulting Family Therapist trained the staff to effectively communicate and monitor family dynamics. The Family Therapist also served as a consultant for case analysis during weekly staffings. All families had direct contact with the Family Therapist over the course of intervention. The Family Therapist was present at the Clinical Case Conference in which a family progress review was conducted based on information gathered by the case manager and assessment team. At this time Individualized Family Plans began to be formulated.

Formal contact between Family Therapist and families occurred at the IEP/IFP meeting. At this time the Family Therapist worked with the family to prioritize needs. Often the family needed counseling to help them cope with the diagnosis of the child. The Family Therapist and team members developed Individualized Family Plans based on prioritized needs and observations of child and family. By continuous monitoring of the case manager's observations of family functions the Family Therapist remained available to members of the family throughout the intervention process for any special counseling needs. The Family Therapist also screened for more intense or long-term counseling needs.

Every six months the child was reassessed to measure progress and develop another IEP. At this time, The Family Therapist conducted a preassessment interview and a post assessment debriefing. The Family Therapist also ran two monthly Family Support groups for interested parents. Finally, as the families met their goals or became ready to move on to programs for older children, the Family Therapist helped to facilitate an effective therapeutic closure.

An assumption guiding the research was that helping parents develop coping strategies is helpful. Participation in individual family therapy sessions during the intervention period proved useful. Recognition of family needs and programming for those needs was an integral part of this study. Parent participation in parent support groups where parents could interact together also seemed to alleviate some stress.

To provide responsive programming for families of young handicapped children, individualized services are needed which assess family needs and provide intervention based on those needs. This study adds to the knowledge base of research about intervening with families of young handicapped children. Responsive, individualized intervention for families can significantly alter the stress level of parents of young handicapped children, particularly in regard to how the parent perceives the child.

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Table I

Project STRETCH
Means and Standard Deviations for Parenting Stress Index Scores of Experimental Group

		Experimental Group	Comparison Group
		N=12	N=11
Child Domain Score	(122)	x = 123	x = 123
		s = 19	s = 30
Adaptability	(31)	x = 30	x = 32
		s = 4	s = 7
Acceptance	(17)	x = 18	x = 19
		s = 5	s = 7
Demandingness	(24)	x = 24	x = 23
		s = 6	s = 6
Mood	(13)	x = 11	x = 11
		s = 4	s = 5
Distractibility/ Hyperactivity	(31)	x = 32	x = 27
		s = 4	s = 5
Reinforces Parent	(12)	x = 11	x = 11
		s = 3	s = 5
Parent Domain Score	(153)	x = 132	x = 141
		s = 33	s = 18
Depression	(27)	x = 21	x = 22
		x = 5	s = 6
Attachment	(16)	x = 15	x = 14
		s = 4	s = 2
Restrictions of Role	(26)	x = 20	x = 21
		s = 5	s = 6
Sense of Competence	(37)	x = 30	x = 35
		s = 7	s = 6
Social Isolation	(18)	x = 16	x = 16
		s = 6	s = 3
Relationship with Spouse	(23)	x = 18	x = 19
		s = 7	s = 5
Parent Health	(16)	x = 13	x = 13
		s = 4	s = 3
Total Parenting Stress Index		x = 262	x = 264
		s = 52	s = 42

Numbers in parentheses are high scores reported in the manual which indicate the need for consultation services.

Table 3

Means and Standard Deviations for Parental Stress Index Specific Scores (Comparison Group Subjects)

Stress Domain	Pretest	Posttest
Adaptation	M = 31.60	27.40
	SD = 7.44	4.34
Acceptance	M = 17.80	15.80
	SD = 6.83	4.32
Demandingness	M = 22.40	19.20
	SD = 6.31	4.32
Mood	M = 11.00	10.80
	SD = 5.05	3.70
Distractibility	M = 27.00	24.20
	SD = 5.43	3.27
Reinforces	M = 9.60	11.80
	SD = 4.10	5.36
Depression	M = 22.20	19.40
	SD = 6.91	4.67
Attachment	M = 14.20	13.80
	SD = 2.17	2.86
Role Restriction	M = 20.40	16.80
	SD = 5.68	2.17
Sense of Competence	M = 33.20	26.40
	SD = 4.15	4.52
Social Isolation	M = 14.60	15.40
	SD = 2.41	2.61
Relation for Spouse	M = 18.20	15.80
	SD = 4.92	3.70
Parental Health	M = 12.60	11.20
	SD = 3.05	1.92

Number of subjects in this analysis was 11.

Table 2

Means and Standard Deviations for
Parental Stress Index Specific Scores
(Experimental Group Subjects)

Stress Domain	Pretest	Posttest
Adaptation	M = 31.08	27.83*
	SD = 4.03	3.56
Acceptance	M = 17.50	16.50
	SD = 5.47	4.80
Demandingnes	M = 24.67	22.00*
	SD = 5.94	7.11
Mood	M = 10.75	12.92*
	SD = 3.57	4.64
Distractibility	M = 31.33	29.58
	SD = 4.56	8.28
Reinforces	M = 11.08	9.83
	SD = 2.88	2.73
Depression	M = 21.25	19.67
	SD = 5.33	6.23
Attachment	M = 14.83	15.75
	SD = 4.17	7.01
Role Restriction	M = 20.83	18.92
	SD = 5.47	4.40
Sense of Competence	M = 30.67	30.00
	SD = 8.28	4.73
Social Isolation	M = 15.75	15.67
	SD = 5.63	4.87
Relation for Spouse	M = 18.17	18.67
	SD = 6.73	3.96
Parental Health	M = 12.50	13.83
	SD = 4.40	4.65

*Difference between means is significant at 0.05 level of confidence.

Number of subjects in this analysis was 12.