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Psychological Characteristics of Mothers of Children with Disabilities

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The purpose of this study was to investigate the psychological characteristics of mothers of children with disabilities. This study was performed under the hypotheses that, at the initial diagnosis of the children's disabilities, (1) the mothers suffered from serious psychological distress; (2) the more severe the child's disability was, the more serious the mother's psychological distress was; and that (3) the mother's psychological distress might be resolved within 8 weeks of rehabilitational interventions. The results were as follows: 1) mothers of children with disabilities showed significant ($p<0.05$) somatization, depression, anxiety, hostility, and phobic anxiety more so than the control group; 2) there was no significant difference in T scores of 9 dimensions of the Symptom Checklist-90-Revision (SCL-90-R) of the mothers at the initial diagnosis of children's disabilities according to severity of child's disability; 3) there was no significant difference in T scores of 9 dimensions of SCL-90-R in mothers of children with disabilities between at initial evaluation and after 8 weeks of rehabilitational interventions. In conclusion, : 1) mothers of children with disabilities suffered from serious psychological distress at the initial diagnosis of their child's disability; 2) the severity of the child's disability had little influence on the degree of the mother's initial psychological distress; 3) this distress did not resolve with only 8 weeks of rehabilitational interventions. Therefore, effective rehabilitational programs should provide sufficient opportunities for repeated follow-up interviews which offer not only adequate information on the children's disabilities but also psychological support for the mothers.

Key Words: Delayed development, symptom checklist-90-revision, denver developmental screening test, mothers of disabled children

The process of telling parents about a diagnosis of physical or intellectual disability of their child creates a major burden on the family, especially on the mother who usually serves as the primary caretaker of the child. Several authors have described it as a traumatic event for parents, who may go through stages of shock, denial, anger, depression, acceptance or adjustment, in a similar process to that was described in the literature on bereavement (Sloper and Turner, 1993). If this psychological distress at the initial stage persists or is distorted, these emotionally distraught parents may lack the initiative to take proper care of their children (Smith *et al.* 1993); thus having a significant impact on the development of the children.

The purpose of this study was to investigate the psychological characteristics of the mothers of children with disabilities. This study was performed under the hypotheses that, at the initial diagnosis of the children's disabilities,: 1) the mothers suffered from seri-

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ous psychological distress; 2) the more severe the child's disability was, the more serious the mother's psychological distress was; and 3) that the mother's psychological distress may resolve within 8 weeks of rehabilitational interventions.

MATERIALS AND METHODS

The subjects of the experimental group were forty mothers of children with physical or intellectual disabilities. The inclusion criteria was that: ① their child had their first diagnostic evaluation for delayed development at the Department of Physical Medicine and Rehabilitation, Ajou University Medical Center; ② their child had never been evaluated for delayed development at other hospitals or clinics. The control group was composed of twenty normal healthy mothers. "Normal healthy mother" in this study meant that: ① their children had never been diagnosed or treated for any developmental problems or other major medico-surgical disorders; ② the mother did not have any history of psychiatric disorders.

The experimental group was evaluated with the Korean version of Symptom Checklist-90-Revision (SCL-90-R) at the initial diagnosis of their children's physical or intellectual disabilities and also after 8 weeks of rehabilitational interventions for the mothers. SCL-90-R can represent personality characteristics or impairment indirectly, but it mainly evaluates the present major psychological symptoms (Kim *et al.* 1978; Kim *et al.* 1984). Therefore, we chose SCL-90-R as the evaluation tool for measuring the psychological characteristics of the mothers in the initial diagnosis of the children's disabilities.

All children of the experimental group were evaluated with the standardized Korean Denver Developmental Screening Test (DDST). The performance on the DDST was rated 1,2, or 3. A rating of 1 denoted a normal performance and indicated that the child had no developmental delays on any of the test items, that is, he failed no items which were passed by more than 90 per cent of children of his age. A rating of 2 was given a child whose performance was questionable, meaning that he had a delay in one test item or failed to pass at least one item in each sector through which his chronological age line passed. A rating of 3, serious delay, was given if the child had two or more delays on items in any one sector (Frankenburg and Dodds, 1967; Frankenburg *et al.* 1981; Lee, 1987).

The subjects of the experimental group were divided into two groups according to children's performance on DDST. That is, group 1 was composed of twenty mothers whose children's performance on DDST was 2; and group 2 was composed of twenty mothers whose children's performance on DDST was 3.

The demographic characteristics of the subjects were presented in Table 1. Mean (±SD) age of mothers was 31.05±3.50 years (range 24 years to 38 years) in the experimental group and 31.55±4.87 years (range 24 years to 36

Table 1. Demographic characteristics of subjects

Characteristics	Control group	Experimental group
Number of subjects	20	40
Age(yrs)	31.55±4.87	31.05±3.50
Education level		
Middle school	2(10.0%)	8(20.0%)
High school	15(75.0%)	24(60.0%)
College	3(15.0%)	8(20.0%)
Total	20(100.0%)	40(100.0%)

Table 2. Child's primary disabling conditions

Child's primary disabling condition	Number of children(%)
Cerebral palsy	14(35.0)
Mental retardation	14(35.0)
Down syndrome	2(5.0)
Epilepsy	2(5.0)
Myopathy	2(5.0)
Others	6(15.0)
Total	40(100.0)

years) in the control group. There was no significant difference in both the age and education level between the experimental group and control group.

The children of the experimental group were 22 boys and 18 girls and their mean age at the initial evaluation was 23.44±13.94 months (range 3 months to 59 months). The children's primary disabling conditions included cerebral palsy, mental retardation, Down syndrome, epilepsy, myopathy, and others in order (Table 2). After the initial diagnostic procedures of children's disabilities, all children in the experimental group were treated with individualized physical therapy and occupational therapy three times a week by a pediatric-specialized physical and occupational therapists. Rehabilitational interventions were composed of neurodevelopmental therapy in physical therapy and sensory integrative therapy in occupational therapy (Ayres, 1989). Each therapy session was 40 minutes (physical therapy 20 minutes, occupational therapy 20 minutes) in total. Speech therapy was applied if it was indicated. All mothers of the experimental group had four interview sessions with the first author for sufficient medical information such as the possible causes of the child's disability, current developmental status, and prognosis (biweekly for 8 weeks). In addition, all mothers had four supportive psychological counselling sessions with the same rehabilitational psychologist (biweekly for 8 weeks). Each interview session was 20 minutes.

T-test was used for statistical evaluation of the demographic characteristics of the subjects and T scores in 9 dimensions of SCL-90-R between the experimental group and control group. Paired t-test was used for statistical evaluation of T scores in 9 dimensions of SCL-90-R between, at initial evaluation, and after 8 weeks for the experimental group.

RESULTS

T scores of 9 dimensions of SCL-90-R of mothers at initial diagnosis of the children's disabilities are presented in Table 3. T-test showed significant ($p<0.05$) somatization, depression, anxiety, hostility, and phobic anxiety items in mothers of children with disabilities more so than in the control group.

T scores of 9 dimensions of SCL-90-R of mothers at initial diagnosis of the children's disabilities according to the severity of the

Table 3. T scores of SCL-90-R of mothers at initial diagnosis of children's disabilities

Symptom dimension of SCL-90-R	Group	
	Control (n=20)	Experimental group(n=40)
Somatization	42.13±5.84	46.69± 9.01*
Obsessive-compulsive	46.00±7.31	47.38± 9.46
Interpersonal sensitivity	45.27±4.91	47.69±10.28
Depression	43.87±5.87	49.64±10.42*
Anxiety	40.93±4.92	48.74±10.54*
Hostility	43.60±4.12	50.87±10.72*
Phobic anxiety	41.00±1.46	46.79±10.06*
Paranoid ideation	44.73±6.24	47.23±10.23
Psychoticism	43.20±4.72	47.46± 8.73

Values are mean±SD.
*: $p<0.05$

Table 4. T scores of SCL-90-R of mothers at initial diagnosis of children's disabilities according to severity of child's disability

Symptom dimension of SCL-90-R	Group	
	Group 1[a] (n=20)	Group 2[b] (n=20)
Somatization	46.56± 8.40	46.81± 9.72
Obsessive-compulsive	45.33± 7.98	49.78±10.66
Interpersonal sensitivity	46.05± 9.91	49.61±10.66
Depression	48.43±10.46	51.06±10.50
Anxiety	47.94±11.21	49.43±10.16
Hostility	50.14± 8.55	51.72±13.02
Phobic anxiety	44.67± 6.27	49.28±12.96
Paranoid ideation	46.38± 7.65	48.22±12.77
Psychoticism	46.05± 7.36	49.11±10.07

Values are mean±SD.
a: mothers of children whose performance on DDST was 2
b: mothers of children whose performance on DDST was 3

Table 5. T scores of SCL-90-R at initial diagnosis and after 8 weeks in mothers of children with disabilities

Symptom dimension of SCL-90-R	Mothers of children with disabilities(n=40)	
	Initial diagnosis	After 8 weeks
Somatization	46.69± 9.01	43.12±5.31
Obsessive-compulsive	47.38± 9.46	46.00±4.25
Interpersonal sensitivity	47.69±10.28	46.65±7.54
Depression	49.64±10.42	47.55±6.23
Anxiety	48.74±10.54	47.87±6.50
Hostility	50.87±10.72	46.55±4.96
Phobic anxiety	46.79±10.06	44.60±3.30
Paranoid ideation	47.23±10.23	44.51±5.21
Psychoticism	47.46± 8.73	46.89±4.33

Values are mean±SD.

child's disability are presented in Table 4. T-test showed no significant difference in T scores of 9 dimensions of SCL-90-R 2 between group 1 and group 2.

T scores of 9 dimensions of SCL-90-R at initial diagnosis and after 8 weeks are presented in Table 5. Paired t-test showed no significant difference in T scores of 9 dimensions of SCL-90-R between the initial diagnosis and after 8 weeks. But, there were declining tendencies in T scores after 8 weeks when compared with T scores of initial diagnosis.

DISCUSSION

Studies of parental adaptation provide reasonably firm evidence that parents of children with disabilities, in general, are more likely to suffer from stress, anxiety, and depression than other parents. Not only must parents cope with a variety of painful and conflicting emotions, but they must also help their family cope with their reactions. The concept of adaptation to a child with disability is now seen as an ongoing process through out the child's life, rather than a difficulty overcome in the first months after the initial diagnosis (Sloper and Turner, 1993). Wikler (1981) suggested increased stress at certain transition points when there was discrepancy between normative expectations and actual events (Wikler, 1981). Such times include the diagnosis, start of school, adolescence, and graduation. In particular, the initial period after the diagnosis was highly stressful.

Our first hypothesis was that the mothers of children with physical or intellectual disabilities suffered from serious psychological distress at the initial diagnosis of the children's disabilities. Our study showed that mothers of children with disabilities suffered from serious psychological distress such as somatization, depression, anxiety, hostility, and phobic anxiety at the initial diagnosis of their child's disability.

Our second hypothesis was that the more severe the child's disability was, the more serious the mother's psychological distress at initial diagnosis was. But, in our study, there was no significant difference in T scores of 9 dimensions of SCL-90-R 2 between group 1 and group 2.

Our third hypothesis was that the mother's psychological distress at the initial diagnosis of the child's disability might be resolved in 8 weeks of rehabilitational interventions. Bruce *et al.* (1994) reported that the emotional resolution for parents of children with disabilities was unlikely to occur, since the source of grief remained and that the non-disabled children represented constant reminders of their child's loss which in turn triggered grief-like reactions (Bruce *et al.* 1994). On the other hand, Kennedy (1970) reported that parents' psychological distress at the initial diagnosis of their children's disabilities usually resolved in 6-8 weeks after diagnosis (Kennedy, 1970). In our study, there was no significant difference in T scores of 9 dimensions of SCL-90-R between the initial diagnosis and after 8 weeks. But, there were tendencies of decline in T scores after 8 weeks when compared with T scores at the initial diagnosis. One of the reasons for this might be that the follow-up duration of 8 weeks was too short to show any changes in the characteristics of mothers of children with disabilities. Therefore, long

term follow-up studies are required to evaluate changes in the characteristics of mothers of children with disabilities.

In conclusion: ① mothers of children with disabilities suffer from serious psychological distress at the initial diagnosis of their child's disability; ② the severity of the child's disability has little influence on the degree of the mother's initial psychological distress; ③ this distress did not resolved after only 8 weeks of rehabilitational interventions.

Therefore, effective rehabilitational programs should provide sufficient opportunities for repeated follow-up interviews which offer not only adequate information on the children's disabilities but also psychological support for the mothers (Ha *et al.* 1990). Such information could be useful to reduce or prevent problems in adaptation.

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