

ORIGINAL ARTICLE

Understanding Family Roles Perception of the Mothers Who Have Cochlear Implanted Child

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Introduction: The overarching goal of the present paper is to investigate how the mothers who have cochlear implanted children perceive their family roles, and to see whether some variants affect this perception or not.

Materials and Methods: This study includes mothers of 40 children with cochlear implant, whose ages are between 4 and 12 and who attend the auditory-verbal rehabilitation programs. "General Information Form" and "Family Assessment Device (FAD)" have been used as devices for collecting data, and the results have been evaluated statistically.

Results: It has been clarified that the variants such as age, education status, number of children, spending enough time with her child, social insurance of the mothers, have an influence on all the family roles in different terms. Although the difference between averages belonging to sub dimensions of family assessment scale according to age of mothers has proved to be insignificant ($p>0.05$), the averages of mothers according to education, number of children, spending enough time with her child and social insurance have been found significant ($p<0.05$).

Conclusion: Parents of the hearing impaired children; experts and trainers and official organizations and institutions should be advised on the subject, and consultancy should be done.

Key words: cochlear implant, child, mother, family roles

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Introduction

All relationships of a new born baby initiate with the mother. Meeting the basic needs of a baby periodically and in due time develops the baby's sense of trust, and enhances the relationship between the baby and mother. The father also joins this relationship later, thus, a new dimension is gained in the relationship. The fact that the child possesses the qualifications desired and attached importance by the society and the parents influences the attitudes of parents towards the child [1,2].

It is easy for the mother and father of a healthy child to bring up their child by adopting the parent roles which they observe in the society. The diagnosis of a hearing loss is a critical life event with profound effects on parents and the family system. An extensive body of literature has been published in recent years focusing on the stress of parents who have deaf or hearing impaired children [3,4].

On the other hand, when the child was born as a handicapped or having a permanent health problem,

this brings about changes in the roles of the parent. Mothers and fathers face changes in their private lives, social vicinity, expectations, plans, business lives and family responsibilities in a quite different way from what a healthy child can cause [5,6].

Also, findings from studies specific to stress levels reported by parents of children with hearing loss are inconsistent. Some evidences suggest that parents of children who are deaf/hard of hearing (hoh) feel more stress than parents of hearing children [7,8] while some studies report no difference in stress levels between the two groups of parents [9,10]. The types of stress reported by parents of children who are deaf/hoh may be different from that of parents of hearing children and specific to the child's hearing impairment, such as stress about degree of hearing loss, age of identification [11] language ability [10] and mode of communication [4].

The mother and father become nervous in their human relations, especially emotional ones like marriage; they have difficulty in meeting the daily responsibilities as

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well as they get stressed due to this situation hard to be accustomed. The inappropriate reactions to this trauma and the guilt feeling of the family drive the parent into depression. At the same time, the need for the extra time, money and energy for child care makes the mother and father stressed. The mother is being estranged from her husband and her environment and feels lonelier day by day, because she has more responsibilities than the father and she has to spend most of her time and energy with her handicapped child^[12,13]. As a result, the family stays more and more away from the environment and social activities, and experiences emotions such as loneliness, withdrawal, vulnerability and helplessness. These emotions weaken family relations, make the family feel lonely, and cause difficulty in accepting the handicap of the child^[14].

The mothers who are more responsible for the daily care of children with hearing loss may alienate to other members of the family and their social environment because of their limited leisure time activities and because they devote themselves to the handicapped child.

This situation can make spouses forget their roles as spouses. One of the most common feelings of parents with a handicapped child is putting blame on each other for the handicap. The parents accuse each other rather than sharing the responsibility. These accusations harm the soundness of marriage over time^[15-17].

When the researches on the marriage consistency of the mothers and fathers with a handicapped child are analyzed; in some studies we see that a handicapped child has a negative effect on marriage; in some studies no influence has been observed, and in the others it is demonstrated that a handicapped child refreshes the marriage^[13,18].

Materials and Methods

In this study, it is aimed to study family role perception of the mothers having a child with hearing loss and to see whether some variants affect the mothers' perception or not. This research includes mothers of 40 children with cochlear implant whose ages are between 4 and 12 and who attend the auditory-verbal rehabilitation programs in the Training Unit of Hearing and Speaking Abilities in Hacettepe University, Department of ENT, Audiology and Speech Pathology Section. The mothers involved in the research have no handicap, and they are volunteers. In the research, "General Information Form", which

has been prepared with the aim of collecting data about the family and "Family Assessment Device (FAD)" which has the aim of evaluating mothers' family role perceptions are used as the data collecting devices.

a. General Information Form: In this form there are common questions for the mothers whose children exhibit hearing loss, about their ages, education status, social insurance, number of children they have, whether they spend time with their children or not and ages and sexes of children. Besides, some other questions about when the child became handicapped, how and when the mother noticed the situation, what she felt and did at first take place in the form.

b. Family Assessment Device (FAD): The Family Assessment Device (FAD) has been developed to measure family problem areas based on the McMaster Model of Family Functioning. In its original version, there were 53 items in the FAD^[19]. In an attempt to improve the scale, a modified version, with 60 items, has been drawn up later^[20].

According to the McMaster Model of Family Functioning, there are six dimensions of family functioning. The first dimension, Problem Solving, refers to the family's ability to solve problems, which is conducive to effective family functioning. Communication is the second dimension, which refers to the effectiveness and content of information exchange among family members. The third dimension, Roles, addresses the issue of whether the family has recurrent patterns of behavior to handle family functions. The fourth dimension is Affective Responsiveness, which refers to the family members' ability to respond with appropriate effect to environmental stimuli. The fifth dimension, Affective Involvement, refers to the amount of affection family members place on each other. Behavioral Control is the final dimension, which assesses whether the family has norms or standards governing individual behavior and responses to emergency situations. In the Family Assessment Device, items assessing these dimensions include: Problem Solving: 6 items; Communication: 9 items; Roles: 11 items; Affective Responsiveness: 6 items; Affective Involvement: 7 items; Behavior Control: 9 items. In addition to the above six subscales, a 12-item General-Functioning Subscale, which "assesses the overall health/pathology of the family" is included in the FAD^[19]. Each item is rated on a 4-point continuum ranging from "strongly agree"^[1] to "strongly disagree"^{[4][20]}.

Data collecting devices have been conducted by interviewing with mothers both having and not having a child with hearing loss and/or the forms have been requested to be filled in, and the results have been analyzed statistically. During the study for statistical significance was $p < 0.05$ and SPSS 15.0 (for windows) software program was used. In this study, descriptive statistics for numerical variables, mean, standard deviation, median, minimum and maximum values were used. Qualifications for the variables were used in the number and percentage. Also, Chi-square test was used to determine the relationships between attribute variables.

Results

In the Table 1, distribution of demographic properties of mothers having a child with hearing loss is given. When the Table 1 is analyzed; it is seen that 42.5% of mothers age between 30 and 40, 20% of them age between 40 and 50; as for education status, 45% of them are literate or primary school graduates, 10% of them are university graduates, and mothers have generally two or three children. When we look at their social insurance distributions; we see that 70% of them have a social insurance from SSA (Social Security Authority), 15% have a green health card and %2.5 have no social insurance. Together with this, 72.5% of the mothers having children with hearing loss spend enough time for their children while 27.5% cannot spend enough time.

Table 1. Distribution of demographic properties of mothers having a child with hearing loss

Demographic properties of mothers (N: 40)		
The mothers of age	N	%
30 years and below	10	25
30–40 years	17	42,5
40–50 years	8	20
50 years and above	5	12,5
Education status		
Literate or primary school	18	45
Secondary school	8	20
High school	10	25
University	4	10
Numbers of children		
1 child	11	27,5
2–3 children	26	65
4 children and more	3	7,5
Social insurance		
Social Security Authority	28	70
Retirement fund	5	12,5
Green health card	6	15
No social insurance	1	2,5
Spend enough time for their children		
Yes	29	72,5
No	11	27,5

Distribution of demographic properties of children with cochlear implant is given in the Table 2. 37.5% of these children age between six and nine, 30% between three and six, 17.5 between nine and twelve, %15 between one and three; 60% are boys and 40% are girls. It is seen that the ratio of boys is higher.

Table 2. Distribution of demographic properties of children with hearing loss

Demographic properties of children (N: 40)		
The children of age	N	%
1–3 years	6	15
3–6 years	12	30
6–9 years	15	37,5
9–12 years	7	17,5
Gender of children		
Girl	16	40
Boy	24	60

In Table 3, we see the distribution of time periods when the mothers with cochlear implanted children notice that their children are hearing impaired; it is clear that 57.5% of mothers notice the situation when the child is between one and three, 20% notice it when the child is older than three, and 22.5% notice it before a year or when the child was born. 75% of these mothers noticed the situation in the hospital, 17.5% noticed it on their own, and 7.5% heard it from a family member. When we look at the distribution of the source of the first information relating to child's being hearing impaired; it is demonstrated that 85% of mothers having children with cochlear implant were informed by a doctor and 5% were informed by their husbands.

Upon learning that their children are impaired, %72.5 of mothers got shocked and 20% of them accused themselves for having a child with a hearing loss. 65% of the mothers tried to cooperate with the relative centers and persons, but 15% of them refused the diagnosis after they knew that their children were hearing impaired.

The average of mothers' family assessment device scores in the Table 4 shows us that mothers who are 30 or younger (2.05 ± 0.76) and mothers between 40 and 50 (2.08 ± 0.49) have the highest ratio, and mothers between 30 and 40 (1.98 ± 0.52) have the lowest ratio. The difference between averages belonging to sub

Table 3. Distribution of time periods and sensation when the mothers with hearing impaired children notice that their children are hearing impaired

Time periods and sensation (N: 40)		
When did she learn?	N	%
0–1 years	9	22,5
1–3 years	23	57,5
3 years and above	8	20
How did she learn?		
Herself	7	17,5
A family member	3	7,5
Hospital	30	75
Who did tell?		
Husband	2	5
Doctor	34	85
Relation	4	10
Neighbour	-	-
What did she feel?		
Shock	29	72,5
Accuse themselves	8	20
Affliction	2	5
Disappointment and discomfort	1	2,5
What did she do?		
Tried to cooperate with the relative centers and persons	26	65
Refused the diagnosis	6	15
Search the different cures	3	7,5
Take on heavy responsibility	5	12,5

dimensions of family assessment device according to age of mothers has proved to be insignificant ($p>0.05$). In the Table 4, we understand that the average of mothers' family assessment device scores is highest in the group of mothers who are literate or primary school graduates (2.13 ± 0.45), and it is lowest in the group of mothers who are university graduates (1.74 ± 0.37). Also, as the number of children increases, family functions are found to be unhealthier (4 children and more: 2.15 ± 0.46).

It is shown in the Table 4 that the mothers who have a green health card or no social insurance (2.12 ± 0.58 , 2.17 ± 0.53) have the highest average of mothers' family assessment device scores while the mothers who have social insurance from state retirement fund (1.84 ± 0.65) have the lowest one. When we analyzed the mothers' situation of spending or not spending time with their children; the average of mothers' family

assessment device scores of the mothers who cannot spare time for their children (2.07 ± 0.58) is higher than the average of mothers who can spend enough time with their children (1.90 ± 0.46).

Conclusion

The hard life of mothers and fathers begins with noticing the problem of their child and the diagnosis. In accordance with the results of our study, existence of a hearing impaired child influences all the family roles in different aspects. For examples, mothers who are 30 or younger and mothers between 40 and 50 have the highest ratio, and mothers between 30 and 40 have the lowest ratio. When we take the physiological changes coming together with the age of mother into account, we can find out that the hormonal disorders in the endocrine may cause some certain problems and these problems may have a negative effect on family roles accordingly. Also, mothers who have a green health card or no social insurance have the highest average of mothers' family assessment device scores while the mothers who have social insurance from state retirement fund have the lowest one. We can consider that the mothers having no social insurance do not have any insurance because some of them cannot comprehend the importance of social insurance for themselves, their children and their husbands; and they are of the opinion that the money spent for social insurance is an unnecessary expense, and the other ones live under bad economic conditions. It may be supposed that these mothers' educational, socioeconomic and cultural levels are low and they are poor in their family roles. In addition to these results, we have found that the average of mothers' family assessment device scores of the mothers who cannot spare time for their children is higher than the average of mothers who can spend enough time with their children. As the mothers' spending short time with their children may weaken the relationship between the child and mother, it can be guessed that these mothers behave poorly in the family roles.

With respect to these results; parents, experts and trainers, official organizations and institutions can be given some advices.

• Advices for parents;

Children with hearing loss may feel themselves lonely owing to the problems they face in their environment and to negative reactions of the people around. The

Table 4. The average of mothers' family assessment device scores

The mothers of age	N	Problem Solving	Commun.	Roles	Affective Responsiveness	Affective Involvement	Behavior Control	General Functions	Total Scores
30 years and below	10	1.83±0.77	1.95±0.62	2.25±0.58	2.12±0.98	2.31±0.75	2.01±0.59	1.74±0.56	2.05±0.76
30–40 years	17	1.86±0.54	2.01±0.54	2.06±0.73	1.79±0.53	2.14±0.64	1.94±0.53	1.81±0.61	1.98±0.52
40–50 years	8	2.09±0.76	1.79±0.50	2.16±0.58	2.03±0.67	2.10±0.42	2.02±0.45	1.96±0.74	2.08±0.49
50 years and above	5	1.60±0.86	1.83±0.49	2.32±0.72	2.13±0.54	2.40±0.62	2.11±0.51	1.73±0.61	2.01±0.50
Education status									
Literate/primary school	18	1.82±0.52	2.02±0.51	2.37±0.52	2.29±0.53	2.32±0.65	2.09±0.54	1.92±0.69	2.13±0.45
Secondary school	8	1.89±0.73	2.10±0.45	2.14±0.71	2.09±0.74	2.15±0.58	2.10±0.65	1.90±0.50	2.06±0.34
High school	10	1.67±0.68	1.66±0.48	1.90±0.56	1.59±0.54	2.20±0.63	1.89±0.58	1.56±0.46	1.78±0.43
University	4	2.08±0.27	1.74±0.28	1.94±0.74	1.63±0.68	1.72±0.34	1.77±0.56	1.70±0.56	1.74±0.37
Numbers of children									
1 child	11	1.94±0.56	2.08±0.59	2.05±0.66	1.76±0.64	2.10±0.37	2.05±0.53	1.93±0.64	1.94±0.36
2–3 children	26	1.81±0.63	1.85±0.46	2.24±0.78	2.06±0.66	2.31±0.64	1.99±0.64	1.82±0.56	2.01±0.55
4 children and more	3	1.70±0.80	1.83±0.52	2.27±0.66	2.26±0.68	2.46±0.55	2.19±0.59	1.78±0.54	2.15±0.46
Social insurance									
Social S.A.	28	1.86±0.56	2.01±0.64	2.26±0.45	2.14±0.64	2.22±0.76	2.00±0.57	1.85±0.77	2.05±0.63
Retirement fund	5	1.73±0.48	1.78±0.67	1.95±0.78	1.74±0.39	2.06±0.55	1.86±0.48	1.64±0.44	1.84±0.65
Green health card	6	2.02±0.72	1.96±0.56	2.34±0.53	2.22±0.60	2.40±0.43	2.18±0.52	1.85±0.57	2.12±0.58
No social insurance	1	1.98±0.58	1.96±0.35	2.37±0.45	2.24±0.88	2.40±0.67	2.19±0.59	1.87±0.98	2.17±0.53
Spend enough time for their children									
Yes	29	1.76±0.78	1.84±0.49	2.18±0.64	2.06±0.53	2.27±0.76	2.04±0.48	1.76±0.66	1.90±0.46
No	11	1.98±0.86	2.02±0.65	2.26±0.58	2.05±0.76	2.26±0.46	1.94±0.35	1.91±0.74	2.07±0.58

family should make the child feel supported and loved so that they can strengthen the self-confidence of the child. By organizing some social activities relating to their interests it can be ensured that the children participate in various social environments. The spouses may feel better by sharing sadness, fear and complaints with each other ^[21, 22].

The children might be given some simple responsibilities so as to make them feel themselves as individuals in the society. All their successes must be told them to support their self-confidence. An environment in which children are free in their behaviors, which is not too protective and which doesn't limit their movements, can be provided for them. Families can participate in the studies by following the child's development process with the help of programs prepared for their education and activities such as sport, music, art, drama and handicrafts which are supporting development ^[13, 23].

Negative reactions of close relatives and other people around may disturb the usual life of the family. Suggestions of experts must be applied rather than the information and advices of people around before problems caused by the environment turn into domestic problems.

Some information about the child's handicap can be obtained from experts and various books ^[21, 24].

• *Advices for researchers, experts and trainers;*

It can be ensured that families and children involve in education directly. Trainers and experts can visit the families so that they can observe the development level of child in other environments and so that the families won't feel lonely. By reaching more parents via the trainers, knowledge levels of the families on the training and state of their children can be controlled periodically in the schools. Family education programs on education of children and family relations can be made more common by the trainers especially for the mothers who have a low education level ^[21, 24, 25].

• *Advices for official organizations and institutions;*

Family education on the subject, consultancy services for the individuals and groups, and seminars can be organized for the families in the institutions where families take their children for treatment and training. Organizations and institutions where treatment and

training of handicapped children happen can be made widespread. Various social activities, amusement environments, programs and organizations in which parents can join with their spouses can be prepared in the institutions to lessen the burden and loneliness of the families ^[23].

Communion days on which the families come together with the families resembling them and share their problems can be organized in the relative organizations and institutions.

Necessary legal regulations can be realized on the economic issues which is one of the greatest problems of the families having a child with hearing loss and on the other matters. By preparing programs on hearing loss through the media, it can be enabled that the society thinks affirmatively about the handicapped children ^[21, 25-27].

References

1. Guttman, H.A. The epigenesis of the family system as a context for individual development. *Family Process*. 2002, 41, 533–545.
2. Türkoğlu, N. Assessment of the factors that affect the anxiety levels of parents and siblings of mentally retarded children. Master thesis. Hacettepe University. Ankara, 2001.
3. M. Hintermair. Sense of coherence: a relevant resource in the coping process of mothers of deaf and hard-of-hearing children? *J. Deaf Stud. Deaf Educ.* 2004, 15-26.
4. M.T. Greenberg. Family stress and child competence: the effects of early intervention for families with deaf infants. *Am. Ann. Deaf.* 1983, 407–417.
5. Aydoğan, A.A. Determination the level of hopelessness of parents of handicapped children. Doctorate thesis. Hacettepe University. Ankara, 1999.
6. Kampfe, C.M. Parental reaction to a child's hearing impairment. *American Annals of Deaf.* 1989; 134: 255–259.
7. A.R. Lederberg, T. Golbach. Parenting stress and social support in hearing mothers of deaf and hearing children: a longitudinal study. *J. Deaf Stud. Deaf Educ.* 2002, 330–345.
8. A.L. Quittner, J.T. Rouiller, R.L. Steck. Cochlear implants in children: a study of parental stress and adjustment. *Am. J. Otol.* 12 (Suppl.) 1991, 95–104.

9. K. Meadow-Orlans. Stress, support, and deafness: perceptions of infants' mothers and fathers. *J. Early Intervent.* 1994, 91–102.
10. S. Pipp-Siegel, A.L. Yoshinaga-Itano, C. Sedey. Predictors of parental stress in mothers of young children with hearing loss. *J. Deaf Stud. Deaf Educ.* 2002, 1–17.
11. M.M. Konstantareas, V. Lampropoulou. Stress in Greek mothers with deaf children. Effects of child characteristics, family resources and cognitive set. *Am. Ann. Deaf* 1995, 264–270.
12. Ersoy, Ö. The Effect of "supporting training programs" to acceptance situation and anxiety levels of the parents that have hearing impaired and mentally handicapped children. Doctorate thesis. Hacettepe University. Ankara, 1997.
13. Sarısoy, M. Marital adjustment of autistic and mentally retarded children parents. Master thesis. Ege University. İzmir, 2000.
14. Feher-Prout, T. Stress and coping in families with deaf children. *Journal of Deaf Studies and Deaf Education.* 1996; 1: 154–157.
15. Doğan, M. Evaluating the parents of hearing-impaired children in terms of some psychological variables. Master thesis. Ankara University. Ankara, 2001.
16. Kampfe, C.M. Parental reaction to a child's hearing impairment. *American Annals of Deaf.* 1989; 134: 255–259.
17. Stoneman, G. and Zolinda, P. Marital adjustment in families of young children with disabilities: Associations with daily hassles and problem-focused coping. *American Journal on Mental Retardation.* 2006; 111: 1–14.
18. Kazak, A.E. and Marvin, R.S. Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. *Family Relations,* 1984; 33: 67–77.
19. Epstein N.B, Baldwin L.M. and Bishop D.S. The McMaster family assesment device. *Journal of Marital and Family Therapy.* 1983; 9:171–180.
20. Epstein N.B, Baldwin L.M. and Bishop D.S. The McMaster Family Assessment Device (Version 3). Providence. Rhode Island: Butler Hospital Family Research Program. The Brown University, 1997.
21. Coots, J.J. Family resources and parent participation in schooling activities for their children with developmental delays. *The Journal of Special Education.* 1998; 31: 498–520.
22. Hornby, G. Working with parents of children with special needs. Cassell Academic, London, 1995, 30–45.
23. King, G. King, S. Rosenbaum, P. and Goffin, R. Family-centered caregiving and well-being of parents of children with disabilities: Linking process with outcome. *Journal of Pediatric Psychologys.* 1999; 24: 41–53.
24. Sarıhan Ö. A Study on perceptions about family functions and loneliness levels of mothers having and not having disabled children. Ankara University Graduate School of Natural and Applied Sciences, Department of Home Economics (Child Development and Education). Master Thesis. Ankara, 2007.
25. Gargiulo, R.M. Working with parents of exceptional children. Houghton Mifflin Company. Boston. 1985, p.231.
26. Floyd, F.J. and Gallagher, E.M. Parental stress, care demons and use of support services for school-age children with disabilities and behavior problems. *Family Realations.* 1997; 46: 359–372.
27. Frey, K.S. Greenberg, M.T. and Fewell, R. Stress and coping among parents of handicapped children: A multidimensional approach. *American Journal on Mental Retardation.* 1989; 94: 240–249.