

Problems of families with disabled children

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Abstract

Aims: The mental health of family members is influenced by the function of the family system and presence of a disabled child often leads to irretrievable damages to the family. Based in this issue, the aim of this study was to investigate the problems of families with disabled children and its indirect impact on their occupational function.

Methods: This descriptive analytical study was performed in year 2009. Study units were the families of *Sepah* personnel who had disabled children and lived in Tehran. 200 subjects were studied in two groups of families having disabled children and families without disabled children as the control group. Data was collected by family function questionnaire, Bell adaptation scale and researcher-made questionnaire. Data was analyzed by descriptive statistical methods and independent T-test using SPSS 15 software.

Results: Families with disabled children had statistically significant difference in family function ($p < 0.01$); in other words the control group families had better family function than those with disabled children. Considering adaptability, there was a significant difference between the two groups in total score and minor scales.

Conclusion Families with disabled children have weakness and trouble in terms of function and adaptability, therefore they need educational and consultation services and psychological supports

Keywords: Family Function, Adaptability, Disability, Children

Introduction

Two major courses of action are taken by societies in order to reduce the problems of the families with disabled children; first, the effort to prevent the disability and developing mental and physical defects, and second, creating the necessary welfare and rehabilitation facilities to serve the disabled individuals and their families [1]. Some people assume that disability is synonymous with limitation, individual and social limitations which isolate person and impose him/her on the family and society. But today's researches and science has proven that disability can be considered synonymous with ability-seeking and one can train individuals who are more prepared and dynamic even than the healthy [non-disabled] ones [2]. Physical, emotional and psychological needs of family members are satisfied in the family. On the other hand, communication ways between family members are also important. Function of the family system affects the mental health status of its members. Family function is positively correlated with problem-solving, social relations, roles, emotional control, psychiatric problems, physical complaints, social conflicts, anxiety and depression of its members. The poorer the family function, the more psychological problems of the family members will be [3].

Sociologists believe that there are two types of family, extended family, including man, woman and their children and the spouses' parents, and core families, including man, woman and their children [4]. Getting core and being more economically, families have been involved with some problems in terms of protecting the patient member, because caring for the these children require intensive care [5]. In the past, the responsibility for providing health and education of children were on the family, but now this role is by public clinics, hospitals, doctors and schools [4]. Disability of a family member has negative effects on all family members and its various functions, because the disability hurt the cohesion and structure of the family and the outcome is changing in the family function and adaptation [6].

Child's birth, at any age and condition, is a factor in creating mental stress. Now if the baby is born with a type of mental, physical and visceral disability, or a combination of them, the mental, social and economical pressure caused by the presence of such a child will increase several times [7]. The effects of this issue are not merely on the relationship between disabled children and others, but the family interaction will be deeply influenced [8]. The emphasis on the isolation of disabled child from the relatives, neighbors and close families cause the whole family isolation that, in turn, is followed by irretrievable

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mental disorders for the family [1]. Some families with disabled children, who are socially isolated, may be more vulnerable of post traumatic stress disorder [9]. In a research, it has been shown that the family personality problems and crises are the results of the reaction that others show towards the child. The increased attention to the inabilities of the child leads to parents' and children's more personality disorders [8]. Moreover, the social adaptation of mental-retarded girls differs significantly from that of normal-girls' mothers [10].

The purpose of this study was to investigate the problems of families with disabled children and its indirect effect on their occupational performance.

Methods

This is a descriptive-analytical study conducted in 1388. The study population was the family members of a military organization in Tehran that had children with disability. 200 families were studied in two groups of with and without disabled children [as control group]. They were selected by simple random sampling method. For sampling, first, the families of staffs with disabled children were identified. Then, families of the control group which were homogeneous in terms of degrees, occupational and economic status and also cultural level and age of the children were identified through a list of personnel. After the identification of individuals, the desired subjects were randomly selected from among them.

Data collection tool was the questionnaire of family function, Bell adaptation scale and a researcher-made questionnaire. The family function questionnaire includes 60 questions to measure family functioning according to the Mac Master pattern and with structural, job and interaction features of the family which shows the six dimensions of the family functioning. This questionnaire has the alpha coefficient of 0.72 to 0.92 and enjoys a high internal consistency.

Bell adaptation scale of which the adult-specialized form was used for the purpose of this study, consists of five adaptation dimension and has Iranian norms and the validity of the whole test is 0.94 [11].

The researcher-made questionnaire consisted of 24 questions and included demographic information of the family, information about the disabled child and some questions relating to the economic status, social communication, concern about the future and the desirability of the organization donated helps.

Data was analyzed using descriptive statistics and independent groups' T-test. Before using parametric

independent T-test, to determine the normality of the data and equality of the variances, the Kolmogorov - Smirnov test, and the test for the homogeneity of variances were used. Kolmogorov-Smirnov test's results showed the normal distribution of data and the Levine's test results illustrated the variance equality in both groups.

Results

Among the families of the staff who had disabled children, boys had the highest frequency (60%). Also 30% of disabled children had primary education, 54% of them were the first child of the family, 25% had mental disabilities and 31% had disabilities due to the genetic reasons.

Table 1- Comparing the staffs with disabled children and those without disabled children in terms of family function

Subscales	Groups	Mean±SD	T value	Df	Level Of Significance
Problem solving	Control	11.27±2.11	0.49	198	0.62
	Disabled	11.43±2.45			
Communication	Control	14.01±2.52	0.78	198	0.43
	Disabled	14.30±2.69			
Role	Control	19.60±3.08	3.52	198	0.001
	Disabled	21.11±2.96			
Emotional accompaniment	Control	17.64±2.73	1.02	198	0.30
	Disabled	18.03±2.63			
Control of the behavior	Control	18.48±3.07	2.61	198	0.01
	Disabled	19.68±3.40			
Emotional function	Control	16.21±3.41	2.68	198	0.008
	Disabled	17.56±3.67			
Overall function	Control	24.26±4.20	2.90	198	0.004
	Disabled	28.08±4.72			
Total score	Control	123.45±16.82	2.72	198	0.007
	Disabled	130.19±18.08			

In terms of performance within family, the differences between the groups of families with disabled children and control group was significant ($p < 0.01$). In other words, within-family function in the control group was considerably better than the group with disabled children. Family function in terms of role subscales, emotional functioning, behavior control, overall performance and the total score was much better in the control group in comparison with the case group and regarding the subscales of problem solving, communication, and emotional accompaniment, there was no significant relationship in comparison with the control group (Table 1).

In terms of adaptation status, there was significant difference between the two groups of families in the total score and the adaptation [tolerance] in home, health, job and emotional (99% confidence level) subscales. In other words, the adaptation rate in all items listed among families with disabled children was

lower than the families who didn't have a handicapped child. Concerning the social adaptation subscale, no significant difference was found between the two groups (Table 2).

Table 2- Comparing the staffs with disabled children and those without disabled children in terms of adaptability status

Subscales	Groups	Mean±SD	T value	Df	Level Of Significance
Home	Control	8.21±2.37	2.55	197	0.01
	Disabled	7.20±3.15			
Health	Control	9.993±2.15	5.38	197	0.001
	Disabled	7.99±2.86			
Society	Control	15.18±3.85	1.43	197	0.15
	Disabled	14.37±4.13			
Job	Control	10.55±2.71	2.09	196	0.03
	Disabled	9.57±3.77			
Emotional	Control	9.78±3.42	3.98	197	0.001
	Disabled	7.58±4.30			
Total score	Control	54.92±11.08	3.90	197	0.001
	Disabled	47.7±14.71			

In terms of economic status, families with disabled children with the income of less than 300 dollars and the rental housing status were of a high prevalence, representing the poor economic status of the families (Table 3).

Table 3- Economic status of families of children with disabilities

Housing status		Income rate (Tomans)				Total
		Less than 300	300-500	500-800	More than 800	
Owned	Number	21	18	10	1	50
	Percent	21.2	18.2	10.1	1.0	50.5
Rented	Number	22	5	1	1	29
	Percent	22.2	5.1	1.0	1.0	29.3
Organizational	Number	9	8	2	1	20
	Percent	9.1	8.1	2.0	1.0	20.2
Total	Number	52	31	13	3	99
	Percent	52.5	31.3	13.1	3.0	100

Discussion

The results of this study suggest that families with disabled children suffer several limitations in terms of family function, adaptation and economic status. In this regard, several points are notable; first, the families with disabled children suffer from weakness and deficiency in terms of role, in the areas of functional roles, behavior control, emotional function and overall performance. Therefore, according to the results of other studies in this field [9] it is probable that in the families with disabled children the members' role is changed and relationships are based more on emotions and the psychological needs of the family members are not fully satisfied. However, the

fact that no difference was observed between the two groups in terms of problem solving and communication aspects is probably because the whole families have some problems in these areas and these two types of problems are prevalent in the society.

The second point is that the adaptation status in families with disabled children is poorer than the families without disabled children. The presence of the handicapped child in the family is considered as a kind of crisis [12] and passing of the crisis requires reconstruction of family roles, structures and lifestyles in order to create an appropriate adaptation. For many families with disabled children, transition from crisis and achieving compatibility needs support and assistance, and with regard to the absence of such a supportive system, it is expected that this type of adaptation with problems is higher in families with disabled children [10].

Third is the low income and poor economic status of families with disabled children compared to families without disabled children. In families with low socioeconomic status, there is higher rate of disabled children and on the other hand, children with disabilities impose several economical problems on families. Thus, in spite of having higher routine and medical expenses, they have more inappropriate status compared to ordinary families.

With regard to the abovementioned points, it can be said that psychological and counseling support for families of children with disabilities is essential. In this regard, helping to improve the family performance and increasing the family members' adaptation are two pivotal issues. On the other hand the increased financial support directly or indirectly through providing care centers (at least daily) or therapeutic and educational services to the disabled children can reduce many problems of these families.

Conclusion

Families of children with disabilities suffer from several weaknesses and deficiencies in terms of function and adaptability, compared to the families without disabled children. In addition, families with disabled children do not enjoy a good economic condition. Thus, these families require educational and counseling services and psychological and financial supports.

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