DETERMINATION OF SOCIAL SUPPORT LEVELS OF THE PARENTS OF MENTALLY AND PHYSICALLY HANDICAPPED CHILDREN

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ABSTRACT

The aim of the present research was to determine social support levels of the parents of mentally and physically handicapped children. The research, which was descriptive model, was conducted with parents who had mentally and physically handicapped children in the city center of Kırşehir Province. The population of the research was consisted of parents whose children attended to five different educational institutions that provided service for the training of the mentally and physically handicapped children in Kırşehir city center and that belonged to Social Services and Child Protection Agency and Ministry of National Education (N= 111). No sampling was made and whole population was aimed with whole number method. As the data collection technique, a questionnaire form designed by the researchers after the literature scanning and Multi-dimensional Scale of Perceived Social Support (MSPSS) were used. It was found out according to the MSPSS scores that parents of the handicapped children received support from families most, then from friends and significant others. It was seen that 37.5 % of the parents had negative familial relations, 58.3 % had negative relations with friends and 50 % of them had negative relations with significant others due to having a handicapped child. As a result, it was explored that parents of the mentally and physically handicapped children had lower social support and the parents told that they received the biggest support from their own families.

Key Words: Mental and Physical Handicap, Child, Parents, Social Support.

* The summary of this study was presented as a poster in the tenth National & International Congress of Nursing Students Participated and took part in the summary book (28-30 April 2011,Gaziantep)

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Geliş Tarihi / Received: 04..03.2013
Kabul Tarihi / Accepted: 29.12.2013

ZİHİNSEL VE FİZİKSEL ENGELLİ ÇOCUĞA SAHİP EBEVEYNLERİN SOSYAL DESTEK DÜZEYLERİNİN BELİRLENMESİ

ÖZET

Bu çalışmanın amacı, zihinsel ve fiziksel engelli çocuğu olan ebeveynlerin sosyal destek düzeylerini belirlemektir. Tanımlayıcı tipte olan bu araştırma, Kırşehir il merkezinde fiziksel ve zihinsel engelli çocuğa sahip olan ebeveynler üzerinde yapılmıştır. Kırşehir il merkezinde Sosyal Hizmetler ve Çocuk Esirgeme Kurumuna ve Milli Eğitim Müdürlüğüne bağlı olarak, fiziksel ve zihinsel engelli çocukların eğitimine yönelik hizmet veren beş farklı kurumda kayıtlı çocukların ebeveynleri araştırmanın evrenini oluşturmuştur (N= 111). Araştırmada örneklem seçimine gidilmemiş, tam sayı metodu ile tüm evrene ulaşılmaya çalışılmıştır. Veri toplama tekniği olarak araştırmacılar tarafından ilgili literatür taranarak oluşturulmuş anket formu ve çok boyutlu algılanan sosyal destek ölçeği kullanılmıştır. Engelli çocuğa sahip ebeveynlerin kullanılan ÇBASD'den aldıkları puana göre en fazla aileden sonrasında arkadaş ve özel birinden destek aldıkları belirlenmiştir. Ebeveynlerin engelli çocuğa bağlı olarak %37.5'inin ailevi ilişkilerinin, %58.3'ünün arkadaş ilişkilerinin, % 50'sinin arkadaş ilişkilerinin olumsuz etkilendiğini belirtmişlerdir. Sonuç olarak zihinsel ve fiziksel engelliye sahip olan bireylerde algılanan sosyal destek düzeyinin çok düşük olduğu ve bireylerin en çok kendi ailelerinden destek aldığı saptanmıştır**.**

Anahtar Kelimeler: Zihinsel ve Mental Engel; Çocuk; Ebeveyn; Sosyal Destek.

INTRODUCTION

It is -without doubt- an exciting and hopeful experience to have a new member in the family for all mothers and fathers. However, when the baby –saying "hello" together with the mothers' and fathers' expectations, opinions and dreams of having a baby- cannot answer the demands of the families due to his / her mental or physical handicap; it is perceived as a huge disappointment in the family and creates a big resource of worry and anxiety in the family (1). The level of worry and anxiety undergone changes depending on the severity of the handicap or the disease, psychological maturity of the family members, their financial resources and how much the environment support them (2).

Having a handicapped child also accompanies some sort of specific difficulties whatever his or her handicap is. These difficulties lead to psychological, financial, educational and life-style-related problems and difficulties in the relations with family and social environment (3). Handicapped children meet many of their needs by receiving help. These needs are answered by those who are responsible for the care of the handicapped child. Parents of mentally and physically handicapped children are in need of help and social support in many aspects so that they can continue their daily livings, can bring up their children and can provide them with care during these compelling processes (4,5). In the general sense, social support –described as help given to the individual by the surrounding people- is explained as financial and spiritual help provided to the individuals who are under stress or in difficult situations by their social environments –such as spouses, families, friends- and professionals and social institutions (6). Socially supporting environments affect the behaviors and growth in many areas of the handicapped children and their parents and help them cope with the new roles created by the life changes and keep their identities (7). Supportive mechanisms of the family enable them to cope with the problems in an easier way, present them solutions for these problems by guiding them in the expected problems and thus decrease the stress of the family and facilitate their social adaptations by making connections between the individuals both in the daily lives and in the time of crisis and needs (6). It is reported in the literature that both physical and psychological health of the families of the mentally and physically handicapped children become better, their social adaptation is made in a more successful way, they can cope with their stress more easily and worry and hopelessness feelings are decreased when there are numerous people who give social support or when these families make close social relations (8-11). However; although studies

conducted in nursing are very limited in Turkey, it is emphasized in the studies made that social support mechanisms of the families of mentally and physically handicapped children are insufficient and there is a significant negative correlation between their social support and high level of depression, hopelessness, stress, worry (12-14).

Identifying social support as sufficient or insufficient should be determined according to whether or not it needs intervention. The role of the nurse in providing social support is important. Nurses should know the conditions that require social support, should understand whether or not social support is enough and should provide counseling when the social support is not sufficient (14). During the counseling for social support, nurses need first identify the difficulties undergone by the individual. Then, they need distinguish the most important problem of the individual and decide what kind of social support will be given. Individual-based obstacles or outside obstacles may decrease the effect of the social support. Determination of these obstacles that affect the individual is highly important in increasing the effect of social support. After all these factors have been identified, the nurse should try to increase the effect of the social support (15). Nurses can make crucial interventions in the primary, secondary and tertiary health services in order to prevent mental and physical handicap, to make an early diagnosis and to continue family-based care. Nurses who provide care for the mentally and physically handicapped children and their families at the clinics, rehabilitation centers and in the society should plan the care for the family by using their roles of trainer, counselor, advocator, decision-maker and care-giver (16,17). The aim of the present research was to determine social support levels of the parents of mentally and physically handicapped children.

MATERIALS AND METHODS

Official permissions from the Ethics Committee of Medical Faculty of Kayseri Erciyes University, written official permissions from the management of the institutions where the research was conducted (Vahide Hüseyin Karahan Training and Practice and Job Training Center School, Cumhuriyet Primary School and Hüsnü M. Özyiğin Primary School located in the Kırşehir city center) and oral consents of all parents were obtained.

The population of the research was consisted of parents whose children attended to five different educational institutions that provided service for the training of the mentally and physically handicapped children in Kırşehir city center and that belonged to Social Services

and Child Protection Agency and Ministry of National Education (N= 111). No sampling was made and whole population was aimed with whole number method. However, the research was conducted with 96 parents (86.48%) because 15 parents did not accept to participate in the research.

The parents who accepted to participate in the research, were older than 18, could communicate, had minimum primary school degree and whose children were registered to educational institutions that provided service for the training of the mentally and physically handicapped children in Kırşehir were included in the research.

The questionnaire form was designed by the researchers after the literature scanning in order to know the characteristics of the families and the handicapped children (1,2,9,17). The questionnaire contained 27 questions. The first 11 questions addressed at socio-demographic characteristics of the families, 4 questions targeted at the characteristics of the handicapped children and 12 questions aimed at the difficulties undergone by the families while they were giving care for the handicapped children and at the support resources used while they were coping with these difficulties.

Multidimensional Scale of Perceived Social Support-MSPSS was developed by Zimet et al. in 1988 (18). The scale is used to determine social support mechanisms that individuals perceive and its validity and reliability tests of MSPSS were performed by Eker et al. in 1995 in Turkey (19). In the present research, reliability for the subscales were α: 0.97 for family, α: 0.96 for friends and α: 0.98 for significant others and reliability of the total score was α: 0.87. MSPSS is consisted of 12 items and is a 7 point Likert-type scale. The points range from "absolutely no" to "absolutely yes". There are three subscales consisted of four items and the subscales determine family support, friend support and significant other support. The lowest score from the subscales is 4 whereas the highest score is 28. The lowest score from the whole scale is 12 whereas the highest score is 84. Higher scores mean higher social support perceived (18, 19).

The research, which was descriptive model, was conducted between the 1st of September, 2010 and the 1st of November, 2010. Written official permissions from the institutions which served for the training of the mentally and physically handicapped children were obtained before the interviews with the parents. Afterwards, telephone numbers of the parents of the children who were registered were asked and they were called and appointments were made. The data were collected using face to face interview with the

parents who took the children to the rehabilitation centers. All parents were informed of the purpose the study before the interviews and oral consents of the participants were obtained since they did not want to give written consents. Each interview lasted nearly 25 minutes.

The data gathered were assessed with computer environment. Percentages, Shapiro-Wilk normality test (to assess normality distribution of the data), independent two-sample t test (for the inter group comparisons), one way variance analysis, Kruskall Wallis variance analysis, Turkey HSD, Dunn's and Dunnet methods (for the comparison of the groups between which there was a difference) were used for the data analysis. Cronbach Alpha method was used to assess internal consistency of the MSPSS. Results were considered significant at $p<0.05$.

RESULTS

62.5 % of the participant parents were aged between 36 and 45, 70.9 % had primary school degree, 83.3 % were married, 70.8 % were housewives, 54.2 % lived in nuclear family and 87.5 % had social security coverage. It was found out that 27.1 % were married with cognate relatives and 8.3 % were married with uncles' sons (Table 1). 29.2 % of the parents had 3 healthy children and 75 % had one handicapped child. 45.8 % of the handicapped children belonged to ≤ 15 age group and 66.7 % were boys.

Parents told that they had problems in the care of the handicapped child "mostly related to dressing (33.3 %), bathing (33.3%), moving (31.2 %), feeding (18.8 %) and excretion (8.3 %) and they needed help about these issues most.

It was explored that mostly spouses (62.5 %) and healthy children (20.8 %) helped the parents in the care of the handicapped children and that they did not receive any social support from anybody else; except the family (83.3 %). Those who received state-aids (45.8 %) emphasized that they used state aids as care-payment.

According to the MSPSS scores of the parents of the handicapped children; it was noted that the parents received support mostly from families, from friends and significant others (Table 2).

Educational status, degree of the blood relation among the parents, professional status did not affect levels of social support of the parents significantly ($p>0.05$) whereas age, marital status, presence or absence of the social security coverage, family type, the number of

the healthy and handicapped children caused a significant difference in the perceived social support levels ($p<0.05$, $p<0.01$).

As the results of the advanced analyses performed among the groups between which there was a difference, the following findings were found (Table 1):

* Significant other social support levels (16.00±7.12), family social support levels (21.50±4.04), friend social support levels (22.50±7.01) and total social support levels (59.00 ±12.49) were significantly higher among the parents who were aged ≤ 35.

* Friends support levels were significantly higher (12.00 ± 7.48) among the married parents.

* Significant other social support levels (10.50±6.54), friend social support levels (12.00±7.58) and total social support levels (39.00±16.44) were significantly higher among those who had social security coverage (Table 1).

* Friend social support levels were significantly higher among the parents who had traditional extended family type (16.00±6.13).

* Significant other social support levels (16.20±6.30), family social support levels (22.30±5.33), friend social support levels (18.90±5.45) and perceived social support levels (57.40 ±10.81) were significantly higher among those who had one healthy child.

* Family social support levels (20.00±7.02) were significantly higher among those parents who had one handicapped child.

* Significant others social support levels were significantly higher among those who had care-payments from the State (16.00±6.44).

* Family support (20.00±6.38), friend support (16.00±7.39) and total social support levels (52.00±14.93) were significantly higher among those parents (16.00±6.76) whose social relations were not affected negatively by having a handicapped child (Table 1).

It was noted that having a handicapped child affected negatively the parents' familial relations (37.5 %), friend relations (58.3 %) and significant other relations (50 %). Family support scores, friend support scores, significant other support scores and mean total social support scores of the individuals whose social relations were negatively affected (N=68) were significantly lower compared to those whose social relations were not negatively affected (Table 1).

Table 1. The Average Scores Of Perceived Social Support Scale For Parents To Sociodemographic Characteristics

Sociodemographic Characteristics		n (%)	Special Somebody ($\bar{X}$ ±SD)	Family ($\bar{X}$ ±SD)	Friend ($\bar{X}$ ±SD)	Total ÇBASDÖ ($\bar{X}$ ±SD)
Age	35 and ↓	12 (12.5)	16.00±7.12	21.50±4.04	22.50±7.01	59.00±12.49
	36 – 45	60 (62.5)	10.00±6.49	17.00±6.89	11.00±7.04	39.00±16.00
	46-55	18 (18.8)	11.00±4.58	6.00±8.78	10.00±6.44	39.00±16.32
	56-65	4 (4.2)	7.00±3.46	21.00±8.08	18.50±10.96	46.50±15.58
	66 and ↑	2 (2.0)	8.00±0.00	20.00±0.00	4.00±0.00	32.00±0.00
KW /p		N= 96	10.00/0.033	12.19/0.047	12.51/0.038	12.65/0.040
Education Level	Primary school	68 (70.9)	10.50±6.14	17.00±7.01	11.00±7.44	39.00±16.17
	Secondary school	20 (20.7)	11.00±7.62	19.00±9.63	10.00±5.94	36.50±16.85
	High school	4 (4.2)	11.00±5.77	16.50±1.73	16.00±8.08	43.50±15.58
	University	4 (4.2)	7.00±3.46	24.00±4.61	18.00±4.61	49.50±12.12
KW /p		N= 96	4.08/0.447	5.15/0.802	3.91/0.996	1.43/0.203
Marital Status	Married	80 (83.3)	10.00±6.71	18.50±7.90	12.00±7.48	40.00±17.69
	Widowed	4 (4.2)	9.00±1.15	16.50±4.04	8.50±5.19	34.00±2.30
	Divorced	12 (12.5)	14.50±6.07	17.00±5.55	7.50±3.37	39.00±4.62
KW /p		N= 96	0.23/0.522	0.54/0.788	8.63/0.023	1.58/0.840
Blood Relationship by Partner						
	First cousin (Uncle)	8 (8.3)	14.50±2.65	18.00±3.77	22.50±4.49	57.00±9.88
	First cousin (Father's sister)	4 (4.2)	22.00±2.30	20.50±4.04	19.50±7.50	62.00±13.85
	First cousin (Maternal aunt)	4 (4.2)	12.50±6.35	21.00±2.30	12.50±4.04	46.00±12.70
	First cousin (Maternal uncle)	4 (4.2)	13.00±5.77	24.00±4.61	13.00±10.39	50.00±20.78
	Others	6 (6.2)	5.00±9.56	22.00±7.71	5.00±9.04	30.00±24.85
	Absent	70 (72.9)	10.00±6.29	17.00±8.06	10.00±7.13	39.00±15.70
KW /p		N= 96	8.87/0.709	4.21/0.493	8.69/0.505	3.99/0.325
Occupation	Housewife	68 (70.8)	10.00±6.42	17.50±6.34	11.00±7.79	39.00±16.86
	Civil servant	2 (2.1)	4.00±0.00	20.00±0.00	14.00±0.00	39.00±0.00
	Worker	2 (2.1)	13.00±0.00	23.00±0.00	22.00±0.00	58.00±0.00
	Nurse	2 (2.1)	10.00±0.00	28.00±0.00	22.00±0.00	60.00±0.00
	Others	22 (22.9)	10.00±7.24	14.00±1.03	10.00±6.22	39.00±16.39
KW /p		N= 96	4.56/0.518	6.64/0.448	5.49/0.269	3.63/0.609
Family Type	Living alone	4 (4.2)	12.50±5.19	19.50±0.57	10.00±6.92	42.00±11.54
	Large family	30 (31.2)	16.00±5.80	18.00±8.64	16.00±6.13	44.00±16.35
	Nuclear family	52 (54.2)	8.50±7.01	19.50±7.63	11.00±8.08	35.50±18.19
	Dicorved parents	10 (10.4)	10.00±6.49	17.50±7.49	11.00±7.39	39.00±16.49
KW /p		N= 96	5.83/0.419	2.46/0.403	10.64/0.027	1.42/0.682
Health Insurance	Present	84 (87.5)	10.50±6.54	18.00±7.46	12.00±7.58	39±16.44
	Not insurance	12 (12.5)	6.50±5.06	15.00±7.10	9.00±3.89	30.00±12.32
t/p		N= 96	-1.98/0.011	-1.64/0.431	-2.11/0.019	-3.17/0.036
Good health child	Absent	10 (10.4)	11.20±7.52	18.40±6.78	14.60±8.20	44.20±21.0
	1 child	20 (20.8)	16.20±6.30	22.30±5.33	18.90±5.45	57.40±10.81
	2 child	24 (25.0)	10.33±6.20	18.25±7.55	13.91±6.10	42.58±14.78
	3 child	28 (29.2)	11.35±6.29	16.64±8.32	11.71±8.85	39.71±16.57
	4 child and ↑	14 (14.6)	8.71±3.95	12.71±5.42	8.85±2.10	30.28±5.96
KW /p		N= 96	11.30/0.040	16.46/0.024	21.13/0.034	24.63/0.045
Having Obstacles Child	1 child	72 (75.0)	10.00±7.12	20.00±7.02	11.50±7.67	42.50±17.59
	2 child	16 (16.7)	17.00±2.31	17.00±3.24	5.00±3.24	39.00±2.31
	3 child	8 (8.3)	9.00±3.60	9.50±7.69	12.00±5.90	34.50±13.02
KW /p		N= 96	4.87/0.165	15.60/0.013	9.07/0.186	2.90/0.194
To be on Relief	To earn care salary	43 (45.8)	16.00±6.44	20.00±7.40	16.00±6.85	45.50±16.56
	Not to be on relief	53 (54.2)	8.00±6.00	16.50±7.63	10.00±7.58	34.50±15.79
t/p		N= 96	-2.95/0.048	-.75/0.214	-2.28/0.172	-2.01/0.265
The Negative Effects of Social Relations of Having Obstacles Child	Yes	68 (65.2)	7.50±2.60	15.00±7.52	9.50±6.68	31.00±12.59
	No	28 (34.8)	16.00±6.76	20.00±6.38	16.00±7.39	52.00±14.93
t/p		N= 96	4.67/0.017	-3.64/0.013	-2.96/0.010	-5.37/0.021

Table 2. The Average Scores Of Perceived Social Support Scale For Parents

Support of special somebody	10.00±6.49
Support of family	17.50±7.49
Support of friend	11.00±7.39
Total Scale of Perceived Social Support	39.00±16.49

DISCUSSION

Care of the mentally handicapped children is a fact that affects all members of the family and intra-familial and extra-familial relations and continues whole life long. In the present research, parents told that they had burdens in the care of the handicapped child mostly related to dressing, bathing, moving the child from somewhere to somewhere else, feeding and excretion and emphasized that they needed help about these issues most. Families experience physical difficulties due to their care responsibilities for the handicapped children (20). Erickson and Upshur pointed out that mothers perceived the care for the mentally handicapped children as a difficult situation (21).

The studies conducted reported that families underwent difficulties in preparing the meals, personal care, giving medicine, bathing, protecting against a danger, dressing, tooth care, toileting, feeding, changing diapers, temper tantrums, using stairs, using wheel-chairs and preventing the self damaging behaviors and the families told that they needed help for these situations (21, 22). Parents cannot spare time for themselves and for their social environments because they spend a lot of time for the care of the children.

In the present research, parents emphasized that familial relations (37.5 % of them), friend relations (58.3 % them) and significant others relations (50 % of them) were negatively affected due to having a handicapped child. It is highlighted in many researchers conducted with mentally and physically handicapped children that families experience social isolation; which may be the result of both numerous care responsibilities of the families or of social interaction (12, 12, 23, 24). There are studies that have proved that families feel discomfort due to the attitudes against themselves and against their handicapped children in the social lives (23). A mother speaking at the Panel of Our Handicapped Women and Mothers of Our Handicapped Children emphasized this situation as follows: “Their eyes are upon us. People

watch us like watching a film. We know that they do not do this to torture us but it is all the same anyway." (22). One of the mothers who participated in the study of Holroyd told that her mentally handicapped child was called as "idiot" in the social areas and felt sorry for it (24). Mothers reported in another study conducted by Sarı et al. that healthy children treated their adolescent Down syndrome children as "insane" and mothers may get angry in response to these reactions and experience insufficiency and shame feelings (25). Therefore they limit their social relations in order to protect themselves against the reactions and not to be affected from these reactions and to experience less damage. Rather, they may put emphasis on their intra-familial relations more (25). In the present research, individuals received the biggest social support from their spouses and children. Familial support helps coping with the multi-dimensional crisis faced and decreases psychological worry and pain, facilitates the adaptation to the current situation, increases quality of life, facilitates expression of the feelings and enhances the power to struggle against the obstacles and to live. According to the findings of our research, it was noted that the number of the handicapped children is one of the important factors that affect negatively family support. As the number of the handicapped children increases family support decreases; the reason behind which may be that care burden becomes more difficult as the number of the handicapped children increases. As a result of this, physical and psychological health of the individuals may be negatively affected. It was found out that not only family support levels but also friend support levels and total social support levels were significantly high for the parents who had one healthy child; which may be explained by the conclusion that parents are able to transfer their interests, time and energy not only to their handicapped children but also to social support systems such as family, friends and neighbors because decrease in the number of the handicapped children, functional limitations and long time dependency change care needs and the quality of parents' responsibility for the handicapped children.

Another remarkable finding of the research was that those who received care-payments from the state had higher perceived-significant-others-social-support scores, perceived-family-social-support scores, perceived-friend-social-support scores and mean total social-support-scores compared to those who did not receive care-payments from the state. Bringing up a normal healthy child creates economical burden for the family whereas bringing up mentally and physically handicapped child who has special needs creates much bigger economical burden for the family. Many of the studies conducted with the families of the

mentally and physically handicapped children reported that these families were in need of financial help due to economical burden of the family (24, 26). The study of Cunningham conducted with the families of the Down syndrome children indicated that intra-familial relations were negatively affected and stress increased more due to many economical problems (27). Floyd and Saitzyk detected that positive parental attitude and supportive family structure occurred when socio-economical status of the families of the mentally handicapped children was higher (28).

Although perceived – significant – others - social-support, perceived – family - social-support, perceived – friend - social-support and mean total social-support were significantly higher among those who told "My social relations were not affected due to the handicapped child."; -in the general sense- social support levels were found to be rather low among all of the parents. When the number of the supporters who provide the individuals with social support are big or when the individuals have close social relations outside the family, their adaptation to the present situation will be much easier (7). Socially supportive environments facilitate sharing of the values and feelings and fulfilling of the social roles by answering the needs; make contributions to coping with the new roles created by the life changes and to keeping their identities (1, 2). Besides, an enhanced social support affects the families' and children's behaviors and development in various areas and strengthens their sufficiency to cope with the problems (3). The outcomes of the extraordinary and difficult demands that occur in the family of the handicapped children may be decreased by internal and external supportive resources. Therefore, it is highly important to determine social support levels of the parents of mentally and physically handicapped children.

It is essential that services which will be given to the families of the handicapped children should be organized in way to be more supportive, to make the families more participatory in social lives and to make them more sensitive to the needs (17). Meetings and activities that allow the families to make relations with other families with handicapped children should be held at the state and private rehabilitation centers and family support groups should be organized and the participation of the relatives should be ensured. In addition to the financial support, the state may provide care-givers to the families of the handicapped children so that care burden of the families can be decreased and the opportunities to develop social relations can be provided (29-31). The number of the associations that facilitate the support mechanisms among the families and that affect social

support levels of the families of the handicapped children positively should be increased and the necessary efforts should be made in order to spread these associations across the country.

CONCLUSION

As a result, it was found out that the perceived social support levels of the individuals who had mentally and physically handicapped children were rather low and that they received support mostly from their own families. Therefore, programs to strengthen social support systems should be organized for the families.

RESOURCES

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