

Original Article

Having a Disabled Child

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e-mail: caglayigitbas@hotmail.com**Abstract****Aim:** The study was conducted as a descriptive study for the evaluation of the functions of family members with children with disabilities.**Method:** The descriptive cross-sectional study was conducted between 14 September-11 December 2018. In the universe of the research, parents (200 persons) with disabled children. 128 parents who were visited in their dynasties and voluntarily agreed to participate in the study constituted the sample group of the research. Participants have included the work in line with the Helsinki Criteria and voluntarily participated. The questionnaire used in the research was formed by the researchers in accordance with the literature knowledge. Permission has been obtained prior to the investigation. Descriptive variables were given as number and percentage, and chi-square analysis was performed for categorical data. $p < 0.05$ is the significance level.**Results:** The average age of the participants was 37.25 ± 6.25 (min: 25, max: 55) and the average age of the children was 10.56 ± 3.01 (min: 6, max: 17). 71.9% of children are mentally and 16.4% have more than one disability. The majority (70.3%) of those who are interested in children at home are mothers. 46.9% of the participants reported that postpartum family ties were affected. 31.3% of the participants reported that they blamed themselves for their child's handicap. Significant differences were found between participants' age ranges, sex, marital status, and self-blame status due to the child's disability ($p < 0.05$).**Conclusion:** Families with disabled children need to be strengthened and aware of the conditions in which they are able to change.**Key Words:** Disabled child, family, functions**Introduction**

Family is considered to be the union of the individuals who have a biological and psychological tie and historic, emotional and economic union between each other and who feel themselves to be members of the same house (Gladding, 2012). Family is the most natural environment with love, affection, close relation and care which are necessary for both physical and mental health (Kaytez et al., 2015; Cin et al., 2017).

Despite the natural difficulties of parenting, parents definitely have a plan, hope and imagination for their children (Aricioglu & Gultekin, 2017; Deniz & Goller, 2017). A family expecting a healthy child may have to change the plan, hope and dreams in the beginning when a disabled child joins the family. After that, the family starts to experience several changes including social circle and financial issues

(Akandere et al., 2009; Atila Demir & Keskin, 2018).

World Health Organization defines disability to be “the restriction or non-fulfilment of roles expected from a person depending on age, sex, social and cultural factors due to an inability or handicap” (Classification, 2018). According to UN, that defines disability to be a “handicap”, the disabled people are “who are not able to perform the works which need to be done by oneself in personal and social life due to a genetic or subsequent defect in their physical or mental abilities” (Universal Declaration of Human Rights, 2018). The disability definition of the Prime Ministry Directorate of Disabled People, that accepts disability as a "handicap" is as follows: "Handicapped persons are those who have various degree of loss in their physical, mental, spiritual, emotional and social due to any congenital or non-genital illness or accident and

who are not able to comply the requirements of normal life" (Turkish Statistical Institute, 2018).

Due to differences in care requirements and as may be a lifetime condition, the families of the disabled children face more problems caused by reasons including medical care, education, special physical arrangements and tools (Ayyildiz et al., 2012). Parents of a disabled child who have a positive self of sense immediately start to try coping strategies. Parents with negative thoughts find it difficult to comply and cope with a child with special requirements. These adversities turn to cognitive illusions and develop reactions to the social environment, themselves or the child such as having a tendency to put a distance (Avsaroglu and Gilik, 2017). The feeling of being disabled in the family of the disabled person manifests itself in problems affecting mental health including concern, depression, emotional trouble, low self-respect and stress (Canarslan & Ahmetoğlu, 2015; Duru & Duyan, 2017). Studies show that parents of a disabled child have low self-confidence and low marital accord, high levels of despair and that they need social support (Aricioglu & Gultekin, 2017). The concern of the families with a disabled individual is based on the question that who will take of the child in their absence.

This new condition increases negativities and causes shock, denial, excessive sorrow, guilt, embarrassment and lack of acceptance in the family. Families start to experience unexpected crises, avoiding from facing the attitude of the external world, feeling of guilt, disappointment, reduction of self-confidence and respect; they may have to search for a solution while trying to adapt to the new condition (Akandere & others, 2009; Atila Demir & Keskin, 2018).

According to a study conducted by the Turkish Statistical Institute, 25.1% of the children in the age group of between 0-6 years have language and speaking disabilities, 9.6% hearing disability, 7.4% mental disability, 3.7% orthopaedic disability, 3.7% multiple disabilities, 3.6% chronic diseases, 2% spiritual and emotional disabilities and 1.4% visual disability (Bilsin & Basbakkal, 2014).

The study was conducted as a descriptive study to evaluate the functions and emotional states of the members of families with disabled children living in a provincial centre located in the eastern black sea region of Turkey according to their socio-demographic qualities.

Material and Method

The population of the study consists of the families of the disabled children in the centre of the Giresun province. The sample group consists of the parents (200 people) with a disabled child who attends to the Giresun Special Education, Job and Application School. The houses of the families determined at this school were visited and the objective of the study was explained to them. The study was carried out with the families (128 parents) who voluntarily accepted to participated in the study. Families accepting to interview were informed about the research process in accordance with the Helsinki criteria. A survey form created by the researchers and based on the literature information was applied in the first house visit and then three more house visits were paid to the families by the researchers including the mentorship application towards the education and care of the disabled child. The research application was carried out between 14 September-11 December 2018. The data obtained in the research was evaluated by means of Statistical Package for the Social Sciences-22 (SPSS-22).

The dependent variables of the study include whether there is any change in the family bonds after the birth of the disabled child, the type of the change, whether the private lives of the parents changed, whether the person blames oneself or the spouse because of the disabled child, whether they were informed about the disability of the child before birth, whether they had any remorse, whether they plan to have another child, whether the close circle stood away from the family following the birth of disabled child, and whether there is any stress about the future caregiver of the disabled child. Independent variables are the socio-demographic qualities of the participants. Descriptive variables were given in number and percentage while chi-square analyses were done for the categorical data. Significant level was stated to be $p < 0.05$.

Results

The average age of the participants is 37.25 ± 6.25 (min:25, max:55) and the average age of their children is 10.56 ± 3.01 (min:6, max:17). The ratio of women is 89.8%. Those who spent most of their lives in the province centre are 44.5%, illiterate ones are 3.1% and more than half of the participants (51.6%) are primary school graduates.

Table 1. Functions changing after having a disabled child (N=128)

Changing Functions	Number	%
Change in family bonds		
Yes	60	46.9
No	58	45.3
No comment	10	7.8
Type of the change in family bonds (n=60)		
Positive	28	46.7
Negative	32	53.3
Presence of a family member who cannot accept the child		
Yes	31	24.2
No	95	74.2
No comment	2	1.6
Financial effect		
Positive	3	2.3
Negative	105	82.0
No comment	20	15.6
Private life change of parents		
Yes	68	53.1
No	60	46.9
Feeling guilty in the beginning		
Yes	40	31.3
No	86	67.2
No comment	2	1.6
Feeling guilty now		
Yes	5	3.9
No	118	92.2
No comment	5	3.9
Blaming the spouse for the disability of the child		
Yes	25	19.5
No	102	79.7
No comment	1	0.8
Planning to have another baby		
Yes	61	47.7
No	67	52.3
Thinking that the close circle stood away		
Yes	46	35.9
No	82	64.1

Table 2. Distribution of the state of remorse from the birth of the disabled child according to some socio-demographic qualities (N=128).

Some socio-demographic qualities	State of remorse from the birth of the disabled child *			Test Value
	Yes Number (%)	No Number (%)	No comment Number (%)	
Age				
Between 25-35	2 (3.6)	54 (96.4)	0 (0.0)	$\chi^2=3.797$ p=0.43
Between 35-45	0 (0.0)	57 (98.3)	1 (1.7)	
46 and above	0 (0.0)	14 (100.0)	0 (0.0)	
Sex				
Female	2 (1.7)	113 (98.3)	0 (0.0)	$\chi^2=9.115$ p=0.01
Male	0 (0.0)	12 (92.3)	1 (7.7)	
Place spending most of life				
Province	0 (0.0)	57 (100.0)	0 (0.0)	$\chi^2=8.479$ p=0.07
District	2 (3.9)	49 (96.1)	0 (0.0)	
Village	0 (0.0)	19 (95.0)	1 (5.0)	
Education status				
Illiterate	0 (0.0)	4 (100.0)	0 (0.0)	$\chi^2=8.172$ p=0.61
Only literate, no school	0 (0.0)	5 8100.0)	0 (0.0)	
Primary school	0 (0.0)	65 (98.5)	1 (1.5)	
Secondary school	2 (7.1)	26 (92.9)	0 (0.0)	
High school	0 (0.0)	22 (100.0)	0 (0.0)	
University	0 (0.0)	3 (100.0)	0 (0.0)	
Income level perception				
Income in excess	1 (1.6)	60 (98.4)	0 (0.0)	$\chi^2=4.320$ p=0.36
Expense in excess	1 (3.2)	29 (93.5)	1 (3.2)	
Equal income and expense	0 (0.0)	36 (100.0)	0 (0.0)	
Kinship with spouse				
Yes	1 (3.1)	31 (96.9)	0 (0.0)	$\chi^2=1.003$ p=0.60
No	1 (1.0)	94 (97.9)	1 (1.0)	
Living together with the spouse				
Yes	2 (1.7)	118 (97.5)	1 (0.8)	$\chi^2=0.178$ p=0.91
No	0 (0.0)	7 (100.0)	0 (0.0)	
Private life change after the birth of the disabled child				
Yes	2 (1.7)	66 (97.1)	0 (0.0)	$\chi^2=0.178$ p=0.91
No	0 (0.0)	59(98.3)	1 (1.7)	
Knowing the disability during pregnancy				
Yes	1 (3.6)	27 (96.4)	0 (0.0)	$\chi^2=1.211$ p=0.54
No	1 (1.0)	98 898.0)	1 (1.0)	
Disability type				
Mental	1 (1.1)	90 (97.8)	1 (1.1)	$\chi^2=2.156$ p=0.90
Physical	0 (0.0)	14 (100.0)	0 (0.0)	
Hearing	0 (0.0)	1 (100.0)	0 (0.0)	
Multiple	1 (4.8)	20 (95.2)	0 (0.0)	

*Row percentage was taken.

The ratio of university graduates is 2.3%. 47.7% of the participants stated that their income was satisfactory, 53.5% of them stated their income to be between 1001-2000 Turkish lira. The ratio of the participants with an income of more than 3001 TL was 2.3%. 56.3% of the participants had a first-degree kinship with the spouse. Disability types of the children were 71.9% mental, 10.9% physical and 0.8% hearing with 16.4% of the children having multiple disabilities. Majority of the parents taking care of the child at home are mothers (70.3%). 46.9% of the participants stated that their family bonds were affected after birth (53.3% negatively). 31.3% of the participants stated that they blamed themselves because of the disability of the child.

As shown in Table 1, 46.9% of the participants stated that their family bonds changed after the birth of the disabled child, 82% stated that their financial conditions were negatively affected, 53.1% said their marital relations were changed. The private life changes after the birth of the disabled child include: not sparing time for spouse (44.1%), numerous problems (29.4%), problems in sexual life (10.3%), reduced respect between spouses (5.9%), positive effect (5.9%), nearly divorce (4.4%).

As shown in Table 2, sex is an effective socio-demographic quality ($p=0.01$) and women have more percentage of remorse. Other variables didn't create any difference with regards to the remorse from the birth of the disabled child ($p>0.05$).

This study was obtained with the following results.

- People in the age group of between 25-35 years have a high ratio of self-blaming ($p=0.044$)
- Women have a higher self-blaming ratio ($p=0.009$)
- Housewives have a higher self-blaming ratio ($p=0.010$)
- Women have a higher ratio of blaming the spouse ($p=0.007$)
- Housewives have a higher ratio of blaming the spouse ($p=0.006$)
- Women have a higher ratio of stating that their private lives were changed ($p=0.001$)
- Those with primary school education have a higher ratio of stating that their private lives were changed ($p=0.017$)

- People with sufficient income have a higher statement that their private lives were affected ($p=0.001$)
- People spending most of their lives in the village have a higher statement that the family was financially affected after the birth of the disabled child ($p=0.037$)
- People with sufficient income have a higher statement that family finance was negatively affected after the birth of the disabled child ($p=0.001$)
- Those who state that their family bonds changed after the birth of the disabled child have a higher statement that they want to have another child ($p=0.045$)
- People who blame themselves for the disability of the child have a higher belief that the close circle stood away from them ($p=0.008$)
- Those who blame their spouse for the disability of their child have a higher belief that the close circle stood away from themselves ($p=0.007$)
- Those who state that their family bond was changed after the birth of the disabled child have a higher belief that the close circle stood away from themselves ($p=0.009$)
- Those who state that their private life was changed have a higher belief that the close circle stood away from themselves ($p=0.001$)
- Those whose family bonds were changed after the birth of the disabled child have a higher ratio of concern regarding the future care of the child ($p=0.027$)

Discussion

Being a disabled child or having a disabled child creates a burden for the child, family and society which turns into a stressed life experience including physical, emotional, social and economic problems. This study showed that several socio-demographic qualities in families with a disabled child were significant with the problems particularly experienced with parents.

This study revealed that the ratio of having remorse from the birth of the disabled child was higher in women. Having a disabled child causes parents to feel guilt in society (Yildirim & Conk, 2005). The studies in the literature demonstrated that the families with a disabled child couldn't have sufficient support from family, close circle or society; that they couldn't have sufficient and satisfying information regarding the condition of

the child; that the requirements of the disabled child increased due to both education and health problems, and that the family was insufficient about this matter (Kaytez et al., 2015).

The study found that the self-blaming ratio after the birth of the disabled child was higher among women and among the people who are between 25 to 35 years old. In addition, it was found that women and housewives had a higher ratio of blaming the spouse due to this condition. Studies in the literature include the statements that mothers felt guilty similar to this study (Ayyildiz et al., 2012; Lafcı et al., 2014). Different from the present study, Sevinç's study found that the sex of the parent and the disability type of child was not important in the family burden. However, most women take the role and responsibility of caring for the child, whether disabled or not, which causes them to question themselves more or to get exhausted more.

Within the socio-cultural structure of Turkey, generally, women assume the tasks like the care and relevant responsibilities for the disabled child, special education and rehabilitation. It is believed that the fact that mothers assume such tasks since the birth of the disabled child, spending more time with the child than the father and being usually alone in this process might have negative effects on their physical, moral, social and environmental living qualities. In reviewing the literature, we see that mothers give up the other roles and have less participation in social activities and social life as they assume the majority of the care responsibility of the disabled child (Duygun & Sezgin, 2003; Erguner Tekinalp & Akkok, 2004). Similarly, the present study found that the ratio of women who stated that their private life was changed was higher among those who have primary school education and sufficient income. Lafcı et al. stated that there was an increase in communication with the spouse together with the birth of the disabled child (Lafcı et al., 2014). The study by Cangur et al., reported a relationship between the education level and income and the change in future plans of the families as well as a decrease in communication with the spouse and friends while these variables were stated to be statistically significant (Cangur et al., 2013). The study by Mugno et al. reported a more deterioration in the life qualities and health in general as well as the physical activities and social relations of the families with a disabled child (Mugno et al., 2007). There are similar results in the literature

with regards to the functions of the families with a disabled child and their education level. This lead to the idea that families with higher education level may reach to more satisfactory information about the condition of their child from more sources and be more successful in finding social support.

In addition, the ratio of the families who stated that the family was financially affected after the birth of the disabled child was higher in those who spend the majority of their lives in villages and who have sufficient income. In another study, it was stated that raising a disabled child causes three times more additional costs compared to raising a non-disabled child (Luther et al., 2005). The study of Kaytez et al. reported that the financial burden of the family increased after the birth of the disabled child (Kaytez et al., 2015). Similarly, Kahriman & Bayat reported that 81.7% of families with a disabled child had financial difficulties (Kahriman & Bayat, 2008). It is a fact that families with a disabled child have more financial needs together with the birth of the child including hospital, care, nutrition, new arrangements and additional costs and that one parent (usual mother) assumes the care of the child and the other has to work harder. Therefore, such matters can bring a financial burden to the families even if they have a good economic level (Canarslan & Ahmetoglu, 2015).

On the other hand, those who blame themselves and spouses because of the disability of the child, and those who have a change in family bonds and private life have a higher ratio in believing that close circle stands away from them. Social support is crucial in reducing the stress in the family with a disabled child (Singer et al., 2007; Chang & McConkey, 2008; Wulffaert et al., 2009). No matter necessary measures are taken by the public institutions to ensure the participation of the disabled person in economic, social and cultural life, social relations and perceptions may cause social exclusion of the disabled people in some case.

The study by Ayyildiz found that families don't have support from the social circle as they have a disabled child and that the age of the participant and the number of the disabled children are not significant with regards to coping with stress (Ayyildiz, 2012). Kaytez et al. stated that education level is a factor increasing the stress of the family (Kaytez et al., 2015).

Parents with a disabled child experience an intense concern from the moment of the diagnose (Cigerli et al, 2014). The present study found a higher ratio of experiencing concern for the future care of the child among those who stated that the family bonds changed after the birth of the disabled child. Similar to this study, Avsaroglu didn't find the age variable to be significant for the concern of future (Avsaroglu & Gilik, 2017). Lafcı et al. found that families had a concern for the future of the disabled child (Lafcı et al., 2014).

Another study found that the education level and the disability type of the child were not significant for the depression of the families (Kacan Softa, 2013). Kaytez found that high school graduates and those with a disabled child of a younger age had more concerns about the future of their children (Kaytez et al., 2015). Durat found a higher despair level among those with lower education level (Durat et al., 2017). Another study found that age, education, income level, sex of the disabled child were significant with regards to the stress of the parents which is different from the present study (Akandere et al., 2009). Also different from the present study, another study found the education level of the families to be a variable causing a difference in experiencing a concern (Cin et al., 2017).

Conclusions

Having a disabled child is a condition that increases the burden of women particularly in the family and causes several negative results throughout the family. Feeling remorse regarding the birth of the disabled child, blaming oneself and spouse, change in private life, increased financial burden, close circle standing away and concerns about the future care of the child are the leading problems.

Being a woman, low-income level perception, low education level, spending the majority of time in a village, being a housewife or being unemployed are found to be important parameters for these problems. Age, kinship with the spouse, living together or separately with the spouse, knowledge about the disability of the child during pregnancy and type of disability are found to be non-determinant.

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