

Hopelessness Levels of Mothers with and Without Disabled Children

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Abstract: This study aims to determine whether a difference exists between the hopelessness levels of mothers with and without disabled children and whether the hopelessness levels of mothers with disabled children depend on children's sex, birth order, type of disability, age, reactions given at the time of diagnosis and actions taken thereafter. The sample comprised 150 mothers, 75 of whom had disabled children attending special education and rehabilitation centers in Kırşehir and the remaining 75 of whom had children with regular development attending standard primary schools. Demographic data was collected using a "General Information Form" and data about mothers' hopelessness levels was collected using "Beck Hopelessness Scale". The data was then analyzed using Mann Whitney U and Kruskal-Wallis H tests. The results suggested that the hopelessness levels of mothers with disabled children were higher than others. Additionally, it was found that mothers who were shocked at the diagnosis or were looking for solutions on their own experienced higher hopelessness levels than others and that hopelessness did not depend on children's sex, birth order, type of disability or age.

Key words: Disabled child, family, anxiety, stress, depression, hopelessness

INTRODUCTION

Having a different child when expecting and hoping for one with regular development may have a substantial impact on families' social environment, expectations, plans, work life and finances. It has been shown through numerous studies that families with disabled children experience a very high level of stress (Beckman, 1983; Wilton and Renaut, 1986; Bebko *et al.*, 1987; Aral *et al.*, 2006; Carthy *et al.*, 2006; Oelofsen and Richardson, 2006). Magana *et al.* (2004) concluded in a study that mothers with disabled children have more familial problems and display more depressive symptoms. The most important reasons for stress in parents of disabled children were shown to be difficulties in childcare, children's behavioral problems and the severity of the disability (Plant and Sanders, 2007).

Rudolph *et al.* (2003) concluded in a study on mothers of children with speech problems that they had serious worries about their children's future and their acceptance into social groups. Oelofsen and Richardson (2006) showed that parents of children with developmental disabilities experience consistently high levels of parenting stress when compared to others.

Additionally, it was suggested that mothers of these children experienced more stress when compared to their spouses and had worse health.

In hopelessness too, factors such as sadness, negative expectations from the future, negativity and pessimism-related emotional disorders may be influential. Individuals may too easily see themselves and their future as negative and perceive life as full of obstacles and challenging events. As a result of these experiences, they may feel hopeless (Durak, 1994). An earlier study suggested that mothers whose children did not go through integrated education had higher hopelessness levels when compared to mothers whose children did go through this education (Ceylan and Aral, 2006).

Mothers of disabled children are also thought to have the risk of misinterpreting their experiences, feel desperate and disturbed about their children's future and experience hopelessness as a result of the difficulties they have in solving their children's problems. An earlier study showed that mothers of disabled children have worries about their children's future and whether they will be accepted into their social environments (Rudolph *et al.*, 2003).

The present study aims to determine whether any difference exists between the hopelessness levels of mothers with and without disabled children and whether the hopelessness levels of mothers with disabled children vary according to children's sex, birth order, type of disability, age, reactions given at the time when the disability was diagnosed and actions taken thereafter.

MATERIALS AND METHODS

Participants: The study was carried out with mothers of 6-11 year-old disabled children attending special education and rehabilitation centers in Kırşehir and children with regular development. Mothers who were willing to participate in the study and living with their spouses and children, whose children did not have more than one disability and whose children were between 6 and 11 years old were included in the study. The sample thus comprised a total of 150 mothers. Seventy-five of these mothers had disabled children attending special education and rehabilitation centers in Kırşehir and the other 75 in the comparison group had children with regular development in standard primary schools.

Measures: The "General Information Form" developed by the researchers was used in the study to collect information about children's sex, birth order, type of disability, age, reactions given and actions taken when the disability was diagnosed. In order to identify mothers' hopelessness levels, Beck Hopelessness Scale used. This was designed by Beck *et al.* (1974) and adapted to Turkish by Kutlu (1998) (Beck *et al.*, 1974). As a result of reliability and validity studies of the Beck scale, it was found to have three factors named "emotions and expectations about the future" $\alpha = 0.78$, "loss of motivation" $\alpha = 0.72$ and "hope" $\alpha = 0.72$. The validity coefficient of the scale was 0.64 and the reliability coefficient 0.92 (Seber, 1991; Durak, 1994; Kutlu, 1998).

Data collection: Administrators at the participating children's schools were contacted and the aim of the study was explained in order to obtain permission for interviews with mothers. The researchers met participating mothers at their children's school, at an appropriate time and place, in order to complete the General Information Form. Then, statements on the Beck Hopelessness Scale was read to the mothers and they labeled each statement as "true" or "false" according to how they personally felt about it. The interviews lasted around 30 min.

Data analysis: When distributions according to the personal characteristics (variables) of mothers with and without disabled children were examined, it was seen that

the numbers were rather low and the hopelessness scale scores did not correspond to the normality assumption of parametric tests within small groups. Therefore, the non-parametric Mann Whitney U test was used to see whether there was any difference between the hopelessness levels of mothers with and without disabled children. In order to determine whether certain variables affected the hopelessness levels of mothers with disabled children, Mann Whitney U test was used in variables consisting of two sub-groups and Kruskal Wallis test was used in variables consisting of three or more sub-groups. Whenever the difference was significant, the group causing the difference was identified by using Mann Whitney U test (Büyüköztürk, 2003).

RESULTS AND DISCUSSION

Total 59.7% of participating mothers were 35 or younger, 43.6% were either literate or primary school graduates, 40.3% were high school graduates, 16.1% were university graduates and 77.2% were not working. Among the disabled children, 61.3% were boys, 41.3% were last-born children, 33.3% had listening or speech disabilities, 26.7% were mentally disabled and 29.3% were 6 or 7 years old. The mothers stated that 34.7% were shocked to discover that their children were disabled and 60% established contact with relevant centers and individuals.

Table 1 shows that there is a significant difference between mothers' hopelessness levels with respect to having or not having disabled children ($U = 1559$, $p < 0.01$). The rank averages suggest that the hopelessness levels of mothers with disabled children was higher than others'. Similarly, studies cited in the literature report that mothers with disabled children experience more anxiety and stress when compared to mothers without disabled children and that they have higher levels of depression (Rudolph *et al.*, 2003; Eisenhower *et al.*, 2005; Antshel and Joseph, 2006; Oelofsen and Richardson, 2006). In light of these, it can be concluded that the hopelessness levels of mothers with disabled children may also be higher. A disabled child may lead to negative emotions in parents and require more childcare than children with normal development. Such negative feelings, coupled with the responsibility of childcare and the anxiety that their children may be rejected by the society, may be increasing hopelessness levels in mothers.

A study done by Plant and Sanders (2007) listed difficulties of childcare, behavioral problems and the severity of the disability as the most prominent factors leading to parental stress. Others studies also concluded that mothers with disabled children had worries about the future and acceptance of their children (Rudolph *et al.*, 2003; Ceylan and Aral, 2006).

Table 1: Mann Whitney U test results about the hopelessness levels of mothers with and without disabled children

Group	n	Rank average	Rank total	U	p
Mothers with disabled children	75	92.21	6916	1559	0.000
Mothers without disabled children	75	58.79	4409		

Table 2: Mann Whitney U test results about the hopelessness levels of mothers of disabled children with respect to the children's sex

Sex of child	n	Rank average	Rank total	U	p
Girls	29	40.57	1176,50	592,50	0.416
Boys	46	36.38	1673,50		

Table 3: Kruskal-Wallis H analysis results of the hopelessness levels of mothers of disabled children with respect to the children's birth order

Birth order of child	n	Rank average	sd	X ²	p
First born	26	43.29	2	2,378	0.305
Middle born	18	34.69			
Last born	31	35.48			

Table 4: Kruskal-Wallis H analysis results of the hopelessness levels of mothers of disabled children with respect to the children's type of disability

Type of disability	n	Rank average	sd	X ²	p
Hearing and speech	25	38.60	3	1.910	0.591
Physical	12	30.42			
Mental	20	41.08			
Learning and adaptation	18	38.81			

Table 5: Kruskal-Wallis H analysis results of the hopelessness levels of mothers of disabled children with respect to the children's age

Age of child	n	Rank average	sd	X ²	p
4-5 years old	15	42.00	3	1.029	0.794
6-7 years old	22	34.42			
8-9 years old	19	37.55			
10-12 years old	19	38.97			

As shown in Table 2, the rank averages suggest that mothers of girls had higher levels of hopelessness than mothers of boys. However, the difference was not statistically significant ($U = 592,50$, $p > 0.05$). This shows that mothers' hopelessness levels are not dependent on children's sex. While some other studies have yielded similar results to ours' (Kutlu, 1998; Aydoğan, 1999), yet others have been inconclusive. To illustrate, Bristol and Schopler (1984) identified that disabled boys cause more anxiety in the family than do disabled girls. Fırat (2000) also concluded likewise while Beşikçi (2000) claimed that mothers of girls experience more intense anxiety. On the other hand, other studies concluded that the sex of the child does not affect mothers (Beckman, 1983; Glidden and Schoolcraft, 2003; Beck *et al.*, 2004). As a result, it may be contended that what really affects families is the fact that they have a disabled child, not the sex of the child. Numerous other studies (Beckman, 1983; Wilton and Renaut, 1986; Bebko *et al.*, 1987; Magana *et al.*, 2004; Ahmetoğlu and Aral, 2005; Carth *et al.*, 2006; Oelofsen and Richardson, 2006) have also concluded that families with disabled children experience more anxiety and stress simply because they have disabled children.

As seen in Table 3, the rank averages show that although mothers whose first-born children are disabled experience higher levels of hopelessness, no statistically significant difference was actually found between groups with respect to birth order ($X^2_{(2)} = 2,378$, $p > 0.05$). This suggests that hopelessness levels do not vary according to the birth order of children. In other words, mothers whose middle or last born children are disabled can be equally prone to hopelessness. This leads one to conclude that birth order alone is not as important as the disability itself in causing hopelessness. Supporting this finding, Bebko *et al.* (1987) found no relationship between birth order of disabled children and their parents' anxiety levels.

Table 4 and the rank averages shown in it reveal that, except for mothers of physically disabled children, all other mothers had similar levels of hopelessness. Additionally, it can also be seen that mothers' levels of hopelessness did not statistically differ from each other in each type of disability ($X^2_{(3)} = 1.910$, $p > 0.05$), suggesting that hopelessness levels do not depend on the type of disability. This leads to the inference that the type of disability does not affect levels of hopelessness; however, what really counts is children's behavioral problems and the severity of the disability. Similar to our findings, others have concluded that the type of disability is not a significant factor in affecting mothers' depression, anxiety and hopelessness levels (Aksaz, 1990; Akkök *et al.*, 1992; Şenveli *et al.*, 1994; Ceylan and Aral, 2006). However, studies that suggest otherwise can also be found in the literature (Eisenhower *et al.*, 2005; Antshel and Joseph, 2006).

Table 5 shows that mothers had similar levels of hopelessness when children's age was considered and that the hopelessness levels of mothers from different groups did not statistically differ ($X^2_{(3)} = 1.029$, $p > 0.05$). This means that mothers' hopelessness levels are not influenced by the age of their disabled children. There are previous studies in the literature that have reached similar conclusions (Glidden and Schoolcraft, 2003; Johnston *et al.*, 2003; McCarthy *et al.*, 2006). What is more important than the children's age is that mothers accept their children's disability, learn to live with their disabled child and focus on their education. However, it is worth noting that there are several studies which have concluded that disabled children's age is an important factor in mothers' hopelessness, anxiety and depression levels (Wilton and Renaut, 1986; Aydoğan, 1999; Macias *et al.*, 2003).

As shown in Table 6, mothers' hopelessness levels do not depend on their initial reactions to their children's disability ($X^2_{(4)} = 8.888$, $p > 0.05$). However, although Kruskal-Wallis H analysis did not yield a significant

Table 6: Kruskal-Wallis H analysis results of the hopelessness levels of mothers of disabled children with respect to the their feelings at the time of diagnosis

Mothers' feelings at the time of diagnosis	n	Rank average	sd	X ²	p
I was shocked	26	44.77	4	8,888	0.064
I was angry and I blamed myself	8	43.25			
I was in deep pain	19	39.29			
I was disappointed	13	28.46			
I was saddened	9	24.83			

Table 7: Kruskal-Wallis H analysis results of the hopelessness levels of mothers of disabled children with respect to the actions taken after diagnosis

What actions were taken after diagnosis	n	Rank average	sd	X ²	p
I rejected the diagnosis	5	51.30	3	7,051	0.070
I started looking for various solutions myself	14	46.82			
I took on too much responsibility	11	41.77			
I tried to establish contact with relevant institutions and individuals	45	32.86			

difference, it was deemed necessary to examine a possible significant difference between the sub-groups due to the rather high p value (0.064). Consequently, Mann Whitney U test was performed between the sub-groups and a difference was found in favor of "I was shocked-I was disappointed", rather than "I was shocked-I was saddened" or "I was in deep pain-I was saddened" (U = 98.50, p<0.05, U = 56, p<0.05 and U = 45.50, p<0.05). In other words, the hopelessness levels of those in the first group are higher than others. The initial reaction of most mothers to finding out about their children's disability is shock. This is normal as no mother is prepared for the birth of a disabled baby. This reaction is often accompanied by frequent crying, numbness and desperation. Naturally, as individuals have different personalities, their emotions may be of differing nature or intensity. The fact that those mothers who said they were shocked were seen to have higher levels of hopelessness may mean that they have intense feelings and fewer hopes for the future.

According to Table 7, mothers' hopelessness levels do not depend on the actions they took upon finding out about their children's disability ($X^2_{(3)} = 7.051$, p>0.05). However, although the Kruskal-Wallis H analysis did not yield a significant difference, the rather high p value (0.070) necessitated an examination of the sub-groups. Accordingly, Mann Whitney U test was conducted between the sub-groups "I started looking for various solutions myself - I tried to establish contact with relevant institutions and individuals" and a difference was found in favor of the former (U = 200.50, p<0.05). To be more precise, the hopelessness levels of mothers who sought various different solutions on their own were significantly higher than those who sought help from

relevant institutions and individuals. It is natural that mothers will have different reactions to and take different actions about their children's disability. Some mothers may display denial by rejecting the diagnosis and others may be more accepting. Blacher (1984) reports that mothers' anxiety levels are lower when they start to accept the situation. It is presumed that mothers who contacted relevant others were at this stage of acceptance and therefore had lower hopelessness levels. On the other hand, those who were seeking solutions on their own were still in a state of uncertainty, did not know what to do, could not accept the situation and therefore had higher hopelessness scores.

CONCLUSION

Similar to numerous earlier studies, our study has shown that the hopelessness levels of mothers of disabled children may be higher than others. The results have also indicated that mothers who were shocked or who started to look for solutions on their own had higher hopelessness levels and that mothers' hopelessness was not affected by the sex, birth order, type of disability or age of the child. In sum, it can be stated that families with disabled children need to be supported so that they do not become desperate. The society and families both need to be educated about disabled children and their parents, which may reduce the feelings of self-blame and loneliness experienced by mothers and give them hope for the future. As psychological counseling is believed to be helpful in reducing mothers' hopelessness and anxiety, such services may be offered to families with disabled children.

The present study was limited to identifying the hopelessness levels of mothers with and without 6-11 year-old disabled children and the impact of certain variables on their levels of hopelessness. Studies conducted on larger groups will help the generalization of the findings. Therefore, larger scale studies need to be conducted on this issue.

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