THE INVESTIGATION OF THE DEPRESSION LEVELS OF SIBLINGS OF CHILDREN WITH AUTISM

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ABSTRACT

Individuals with disabled siblings feel differentiated when compared to other families and their own families, and may suppress feelings and thoughts that they can not express. Focusing on their parents to their disabled siblings makes them feel lonely. This situation can cause depression in individuals who have complex feelings and thoughts due to sibling differences. A total of 50 individuals, 29 females and 21 males, voluntarily participated in this research, with at least one autistic sibling who has been living in Istanbul and with whom these siblings have been specially trained. A questionnaire form was used to determine the personal information and socio-demographic characteristics of the individuals with autistic siblings and "Beck Depression Inventory (BDI)" used to determine depression levels of individuals with autistic siblings was administered by face-to-face interview method. The frequency distribution, mean and standard deviation of the obtained data from demographic characteristics and Beck Depression Inventory were determined in SPSS 22 (Statistical Package for Social Sciences) program. The data were tested at a significance level of 0,05. According to Beck depression scale results; gender, age group, educational level, occupation, number of siblings, number of autistic siblings, age group of autistic sibling, gender of autistic sibling; there was no statistically significant difference according to the variables (p>0,05). Additionally, there was a statistically significant difference was found in the depression levels according to the monthly income variable of the participants (p<0,05). When our study findings are interpreted with literature, it is predicted that the sources obtained by determining the levels of stress and depression experienced by the autistic siblings have a limited number and more definite results can be obtained by providing more research on the subject.

Keywords: Familes, Children, Autism, Depression

INTRODUCTION

Autism is a complex neurodevelopmental disorder that characterized by repetitive behaviors, impaired social interaction, verbal and non-verbal

communication (Avci, 2007). Recently, a part of children with special needs is composed of children with autism. Autism is, in the broadest sense, a neuropsychiatric disorder that begins in the early stages of life and lasts for life and adversely affects the life of the child and the family. Some symptoms of autism are followed; delay and deviation in social relationships, communication, behavioral problems, developmental cognitive problems (Yanardag et al., 2009; Arslan & Ince 2015; Top, 2009, Gulec et al., 2009).

Many families with autistic children are concerned about what they will do to their children or how they will affect their own lives. Engaging in the needs and desires of a child who can not communicate, trying to stay in the family environment, coping with strange and unusual behaviors, constantly checking the child who does not know the danger is a tiring and stressful situation (Yuksel, 2008; Cengiz et al., 2016). There are some difficulties in ensuring that this child, who has very special needs, can adapt to his / her family life. On the basis of all these worries lies the fear that families feel against unknown (Top, 2009). In this process, the other children in the family also have feelings similar to that of their parents as a result of having disabled siblings (Sari, 2004). Relationships of the siblings are affected by some factors such as the structure of the family, the lifestyle of the family, the parenting style of the family, the number of children, the age difference between children, the sex of the children, the socio-economic status of the family, the inadequacy, disability type and the level of disability of the children. (Kaytez et al., 2015). Some research shows that having a disabled sibling has a negative effect on the other siblings in the family (Kahraman & Karadayi, 2015).

The sibling of autistic individual cannot take enough time for his / her needs because he/she assumes more responsibility for the care and development, material and spiritual difficulties, limitations of treatment and education services, the difficulty of dealing with the negative views of people and relatives in the periphery and future worries (Kucuker, 2001).

Because these siblings are concerned about future problems of their siblings, their care, planning of their care, developing strategies for their own lives (Er, 2011).

The autistic characteristics of each autistic child differ from each other. The family is confronted with a series of very difficult behaviors. Looking after the needs and desires of a child who can not communicate, try to keep the order of the family environment, cope with different forms of behavior in children and protect them from danger is causing serious stress in the family. Therefore, the anxiety and stress that family members experience are causing depression (Girli, 2006; Top, 2009). According to the Turkish language institution (TDK); depression can be defined as a state of sorrow, it can also be defined as a state of lack of happiness from the activities that individuals do happily and intentionally before due to the facts that various environmental, hormonal and genetic disorders (Filiz and Kolukisaoglu, 2015). Depression often occurs at the end of the suffering process (Kaytez et al., 2015; Ergin et al., 2007).

Individuals with disabled siblings feel differentiated when compared to other families and their own families, and may suppress feelings and thoughts that they

can not express. Focusing on their parents to their disabled siblings makes them feel lonely. This situation can cause depression in individuals who have complex feelings and thoughts due to sibling differences.

The aim of this study was the investigation of the depression levels of siblings of children with autism.

METHODOLOGY

Research Group

A total of 50 individuals, 29 females and 21 males, voluntarily participated in this research, with at least one autistic sibling who has been living in Istanbul and with whom these siblings have been specially trained.

Data Collection Tools

A questionnaire form was used to determine the personal information and socio-demographic characteristics of the individuals with autistic siblings.

The "Beck Depression Inventory (BDI)" used to determine depression levels of individuals with autistic siblings was administered by face-to-face interview method.

BDE was developed by Beck et al. (1978), while in our country, Hisli (1988) conducted validity and reliability studies. The BDI consists of a total of 21 questions and the score range is 0-63.

The Beck Depression Scale is as follows;

0 - 10 points: Normal

11 - 16 points: Mild mental distress

17-20 points: Clinical depression at the border

21 - 30 points: Moderate depression

31 - 40 points: Severe depression

40 points and over: Very serious depression

Collection of Data

Surveys were conducted face-to-face by distributing the alleged individuals.

Analysis of Data

The frequency distribution, mean and standard deviation of the obtained data from demographic characteristics and Beck Depression Inventory were determined in SPSS 22 (Statistical Package for Social Sciences) program. The data were tested at a significance level of 0.05.

FINDINGS

The siblings of autistic individuals (n = 50) who educated in the rehabilitation centers serving the autistic children, were participated in the research.

***Table 1.** Mann-Whitney U Results of Beck Depression Scale Scores According to Gender Variables of the Participants*

Gender	n	$\overline{x}$	± ss	Z	p
Male	21	23,95	11,23	-,610	,542
Female	29	22,31	11,84		

21 of the participating individuals were male (42%) and 29 were female (58%).

***Table 2.** Kruskal-Wallis Results of Beck Depression Scale Scores According to Age Group Variables of the Participants*

Age Group	N	$\overline{x}$	± ss	Chi-square	p
15 – 20	5	30,6	16,68		
21 – 25	21	21,62	12,15		
26 – 30	17	23,29	9,56	1,387	,846
31 – 35	4	22,5	7,55		
36 – 40	3	19	14,17		

21 of the participants were in the age group of 15 - 20 (%10), 21 of them were in the age group of 21 - 25 (42%), 17 of them were in the age group of 26 - 30 (34%), 4 of them were in the age group of 31 - 35 years (8%), 3 of them were in the age group of 36 - 40 years (6%).

***Table 3.** Kruskal-Wallis Results of Beck Depression Scale Results According to Educational Level Variables of the Participants*

Educational Level	n	$\overline{x}$	± ss	Chi-Square	p
Secondary	11	25,36	12,92		
High School	12	25,67	10,6		
University	20	23,1	11,53	4,895	,298
Master's Degree	5	15	4,24		
Doctorate Degree	2	14,2	9,57		

11 of the participants were graduated from secondary school (22%), 12 from high school (24%), 20 from university (40%), 5 from Master's degree (10%) and 2 from Doctorate degree (4%).

Table 4. *Kruskal-Wallis Results of Beck Depression Scale Results*
According to Occupational Variances of the Participants

Occupation	n	$\bar{x}$	± ss	Chi-Square	p
House wife	13	28,54	10,5		
Employee	17	24,24	11,85		
Civil servant	9	20,00	10,19	7,809	,099
Retired	4	22,25	12,81		
Other	7	14,00	9,23		

13 of the participants were housewives (26%), 17 were employees (34%), 9 were civil servants (18%), 4 were retired (8%) and 7 were from other professions (14%).

Table 3. 5. *Kruskal-Wallis Results of Beck Depression Scale Results*
According to Monthly Income Variables of the Participants

Monthly Income	n	$\bar{x}$	± ss	Chi-Square	p
1500 TL and below	5	32,8	9,09		
1501 TL – 2000 TL	12	28,92	9,74		
2001 TL – 2500 TL	18	24,56	9,35	19,96	,001*
2501 TL – 3000 TL	10	15,5	9,05		
3001 TL and above	5	8,4	8,79		

*p<,05

5 of the participants were in the 1500 TL and below monthly income group (10%), 12 were in the 1501 TL – 2000 TL (24%), 18 were in the 2001 TL – 2500 TL (36%), 10 were in the 2501 TL – 3000 TL (20%) and 5 were in the 3001 TL and above group (10%).

Table 3. 6. *Kruskal-Wallis Test Results of Beck Depression Scale Results*
According to Number of Siblings Variables of the Participants

Number of Siblings	n	$\bar{x}$	± ss	Chi-Square	p
1	9	14	8,04		
2	15	20,67	11,06		
3	12	22,13	10,48	7,13	,129
4	10	22,08	9,96		
5	4	31,1	13,44		

There were 1 sibling of 9 participants (18%), 2 siblings of 15 (30%), 3 siblings of 12 (24%), 4 siblings of 10 (20%) and 5 siblings of 4 (8%).

Table 3. 7. *Mann-Whitney U Results of Beck Depression Scale Scores According to Autistic Sibling Number Variable of the Participants*

Autistic Sibling Number	n	$\overline{x}$	± ss	Z	p
1	48	22,46	11,14	-1,288	,198
2	2	36	16,97		

48 of the individuals participating in the study had 1 autistic sibling (96%), 2 of them have 2 autistic siblings (4%).

Table 3. 8. *Kruskal-Wallis Test Results of Beck Depression Scale Scores According to Autistic Sibling's Age Variable of the Participants*

Autistic Sibling's Age	n	$\overline{x}$	± ss	Chi-Square	p
1 – 5 age group	9	20,22	13,15		
6 – 10 age group	10	22,5	9,6	3,796	,284
11 – 15 age group	11	21,6	12,25		
16 and above	20	28,27	9,98		

9 participant's autistic siblings were in the age group of 1 - 5 (18%), 10 participant's autistic siblings were in the age group of 6 - 10 (20%), 11 participant's autistic siblings were in the age group of 11 - 15 (22%), 10 participant's autistic siblings were in the age group of 16 and above (40%).

Table 3. 9. *Mann-Whitney U Results of Beck Depression Scale Scores According to Autistic Sibling's Gender Variable of the Participants*

Autistic Sibling's Gender	n	$\overline{x}$	± ss	Z	p
Male	30	22,55	12,24	-,248	,824
Female	20	23,3	11,18		

30 of the autistic siblings of the participating individuals were male (60%) and 20 of them were female (40%).

Table 3. 10. *Beck Depression Scale Results of the Participants*

Depression Levels	n	%	$\overline{x}$	± ss
Normal	7	14		
Mild mood disturbance	8	16		
Borderline clinical depression	5	10	23	11,56
Moderate depression	19	38		
Severe depression	6	12		
Extreme depresion	5	10		

The average of the scale results of the individuals participating in the study was found as 23±11,56. Of the individuals participating in the study, 7 were at normal level (14%), 8 were at mild mood disturbance (16%), 5 were at borderline clinical depression (10%), 19 were at moderate depression level (38%), 6 were at severe depression level (12%) and 5 of them were at extreme depression level (10%).

DISCUSSION

As a result of a qualitative research; it has been determined that individuals are forced to accept it when their siblings are diagnosed with autism, that their lifestyle changes to a great extent, that they abstract themselves from environments, are more emotional, are worried for the future and they decided to give up many things they wanted to do. Despite all, it was in the result that taking care of their brothers gave them happiness and that they changed greatly in the way of life.

58% of the individuals participating in the survey were female and 42% were male. According to the results of this study, although the depression level of males (23,95±11,23) was higher than the depression level of females (22,31±11,84) according to the gender variables. Although the mean levels of depression of individuals differ in terms of gender variables, this difference is not statistically significant. When we examine the literature, there are studies that suggest that there is no meaningful difference in terms of gender in support of our findings in our study (Duru, 2008; Duyan et al., 2008).

When the depression levels of the participants were examined according to the age group variable, there is no statistically significant relationship between depression levels and age group variable. However, it has been observed that as age increases, the mean scores of the depression levels decrease. The age group with the highest depression level is the age range of 15-20 years (30,6±16,68), the age group with the lowest depression level is the range of 36-40 years (19±14,17).

A vast majority (40%) of the individuals participating in this research were graduated from university. 12 participants (24%) were graduated from high school and 11 participants (22%) were graduated from secondary school. When participants' mean depression scale scores and educational level variables were examined, no statistically significant difference was found according to educational levels. However, as the level of education increases, the average scores of depression scale decrease. the average level of depression of secondary graduates is at the highest level (25,36±12,92) whereas the level of depression levels of doctoral graduates is at the lowest level (14,2±9,57). No resources were available when the subject was searched.

17 persons (34%) who work as an employee are the most seen in terms of the occupational variable. The next 13 people (26%) were determined as housewives. The mean of depression scores of housewives is highest (28,54±10,5).

In our study, 18 participants were the most engaged group (36%) and they were in the 2001 TL – 2500 TL monthly income level.

The group with the lowest income level was found to have the highest mean scores of depression levels (32,8±9,09), while the group with the highest level of income had the lowest average scores of depression levels (8,4±8,79). As the level of income increases, the average level of depression level decreases. As the level of income increases, the change in mean values of depression levels indicates a statistically significant difference. There are also studies that show that low income is one of the main stressors that support our research. In these studies, it was observed that as the level of income decreased, depression level increased. There is a low incidence and poverty among other situational causes and consequences of stress. (Duyan et al., 2008; Heinrichand & Gullone, 2006; Kavlak and Saruhan, 2002; Yasar, 2007).

In terms of the number of siblings it was identified that 9 participants (18%) have 1 sibling, 15 participants (30%) have 2 siblings, 12 (24%) have 3 siblings, 10 (20%) have 4 siblings and 4 (8%) have 5 siblings. In this respect, there are differences in the mean scores of depression levels. The mean scores of depression level of the participants who had 1 sibling were the lowest (14±8,04) while the scores of depression level of the 5 siblings had the highest level (31,1±13,44). When findings are interpreted; the results of our study are thought to increase the level of stress and depression as well as the increase in sibling numbers in terms of sibling numbers.

Participants with 1 autistic sibling were found to have less average scores of depression level (22,46±11,14) than those with 2 autistic siblings (36±16,97). It is stated that living with autistic siblings is quite difficult and that behavioral and emotional problems have commonly occured (Walton, 2016).

When the ages of the autistic siblings of the individuals are examined, it is seen that 20 (40%) are over 20 years old. The mean scores of depression levels were lowest in the age group of 1 - 5 years (20,22±13,15) while the highest mean scores were in the age group of 16 and above (28,27±9,98). It is seen that the stress and worries experienced by the individual are more prevalent due to the age variable of the siblings. In addition, although there are no consistent results with our findings in the literature, it has been reported that it is seen most adolescently compared to other age groups (Kocak, 2008).

In our study, 30 of the autistic siblings were male (60%) and 20 were female (40%). The incidence of autism is higher in males than in females. Individuals with male autistic siblings have lower levels of average depression scores (22,55±12,24) than the average scores of individuals with female autistic siblings (23,3±11,18). According to the gender of autistic siblings variable, the mean scores of the levels of depressions were different but this difference is not statistically significant. It was stated that there was no significant difference in the behavioral characteristics of the autistic children according to gender variable (May et al., 2017). In the study conducted in America, it was determined that autism was more likely to be boys than girls with a rate varying between 3.4 and 6.5. These findings indicate an average of 3-4 times more (www. tohumotizm.org.tr 2008).

When the depression levels of the individuals with autistic siblings were examined, it was seen that the depression score averages were moderate depression (23,0±11). In a similar study in which the depression level of disabled

families was investigated, it was stated that the families were in severe depression (39,91±10,78) (Yildirim et al., 2012). They are reported to have positive relations with their handicapped brothers (Aksoy and Yildirim, 2008).

RESULTS AND RECOMMENDATIONS

According to Beck depression scale results;

- Gender
- age group
- educational level
- occupation
- number of siblings
- number of autistic siblings
- age group of autistic sibling
- gender of autistic sibling

There was no statistically significant difference according to the variables. Additionally, there was a statistically significant difference was found in the depression levels according to the monthly income variable of the participants.

Individuals with autistic siblings should be provided with comprehensive and detailed information about autism.

Individuals with autistic siblings should be more helpful in every aspect.

Education and care facilities should be provided by the state to families with autistic children.

Autistic children should not be separated from other normally growing children.

Individuals with autistic siblings are more likely to socialize and spend time with their siblings.

Psychological counseling and support should be provided to individuals with autistic siblings.

When our study findings are interpreted with literature, it is predicted that the sources obtained by determining the levels of stress and depression experienced by the autistic siblings have a limited number and more definite results can be obtained by providing more research on the subject.

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