

## Siblings of Disabled Children: A General Overview in terms of Academic Studies

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**ABSTRACT:** Having a disabled child causes stress for parents and other members of the family. In this process, siblings of the disabled child should be considered as well as parents. It is a difficult situation for a child to have a disabled sibling. Knowing thoughts, emotions and relations of siblings of disabled child provide a perspective about supporting siblings. Consequently, academic studies about children with disabled sibling come into prominence. In the current study, it is aimed to review results of a few studies about children with disabled sibling in Turkey and to reveal a perspective. It is seen that studies generally have focused on self-esteem, academic success, relation with siblings, attitudes, behaviors, experienced problems, ect. There are too few studies about intervention or support program for siblings of disabled children. Studies have revealed the problems and level of self-esteem or anxiety or relationships, but studies also must suggest support programs for children with disabled sibling to cope with these problems.

**KEYWORDS:** sibling; disability; disabled sibling; having disabled sibling; Turkey.

### 1 INTRODUCTION

All parents and members of family expect to have healthy child when they are informed about pregnancy. Having a disabled child causes stress for parents and other members of the family and creates changes in family structure, functioning and role of the members [1], [2]. In this process, sibling of the disabled child should be considered as well as parents. Siblings have an important role in each other's development, because they observe and learn behaviors of other. Having a disabled sibling can cause to experience emotional and behavioral challenges. Existence of disability can affect relationships between siblings directly [2]. Child with typical development worries about being disabled and about future of disabled sibling and they need information about disabled sibling [cited by 3]. Also, child with typical development may be neglected by parents, because they spend time mostly by engaging with disabled child. Consequently, it is a difficult situation for a child to have a disabled sibling [4].

A few studies (e.g. Benderix and Sivberg, 2007; Dawson, 2008; Gurian, 2010; Kurnoff, 2008; Osman, 2008) revealed that most children with disabled sibling had emotional trouble and needed care and interest of parents and needed to spend time with parents [cited by 4]. So, considering in terms of siblings of disabled children, siblings with typical development need support as well as disabled siblings. Because of providing best intervention program for children with typical development, we must know about their feelings, thoughts, behaviors and relationships with siblings. Accordingly, data from academic studies which is conducted with siblings of disabled children is very important. In the current study, it was aimed to review results of a few studies about children with disabled sibling in Turkey and to reveal a perspective.

#### 1.1 STUDIES ABOUT CHILDREN WITH DISABLED SIBLING

Gozun Kahraman and Soylu Karadayi (2015) investigated views of children about experiences with disabled sibling. They interviewed with 13 typically developing 9-15 aged children with disabled sibling using semi structured interview technique. They asked 10 questions about experiences with disabled sibling and about how their life effected from disability of sibling.

According to results of the study, children explained that they did not have enough knowledge and they were not explained about disability of sibling. Also they stated that their feelings toward sibling changed positively in time; negative behaviors of disabled siblings affected their life negatively; they worried about negative views of other people toward their disabled sibling [5].

Aykara (2015) aimed to determine the perception of experiences and difficulties of individuals who had mentally handicapped siblings. Researcher worked with total 28 adults (older than 18 aged) using in depth semi structured interview technique. It was found that adults with disabled sibling had difficulties about missing life experiences, home desertion, health problems of mentally disabled siblings, physical environmental circumstances and socio-economic status. The burden of caring for a handicapped sibling differentiates with the role of the individual in the family, so female and male siblings had been observed to have different experiences [6].

Coskun (2015) aimed to examine theory of mind skills of 7-12 aged children with typical development who had disabled sibling and not. 83 children (43 girls, 40 boys) who had disabled sibling and 86 children (43 girls, 43 boys) who did not have disabled sibling attended to the study. In order to measure theory of mind skills *Reading the Mind in the Eyes Test (RMET) Child Form* was used. Levels of receptive language of participants was determined by *Peabody Picture Vocabulary Test*. Personal information form developed by researcher was used to gather socio-demographic information. According to results of the study, there was significant difference between theory of mind skills of typically developing children who had disabled sibling and not. For the sub problems, girls had higher scores than boys for each group (children who had disabled sibling and not). Also, it was seen that when education level of mother and father and level of income increased, skills of theory of mind also increased [7].

Angın (2015) investigated psychological adjustment, sibling relationships and perceived maternal acceptance-rejection of siblings of children with autism and specific learning disability. This study was a descriptive study and examine existing situation. The sample of the study was consisted of 9-17 aged children. All participants have either a sibling with disability (Autism or Learning Difficulties) or a healthy sibling. The data was collected by *Parental Acceptance Rejection Questionnaire/Control form*, *Personality Assessment Questionnaire for children*, and *Sibling Relationship Questionnaire*. According to results of the study, girls reported that they perceived their mother more rejective than boys and boys reported more hostility and negative self-competence than girls. Also, boys had more conflicted relationships with their siblings than girls. It was found that there was a significant difference between sibling diagnosis (autism or learning difficulties) and perceived warmth in maternal acceptance, neglect and control. It revealed that perceived warmth between siblings, competence and having conflicting situations significantly differ according to the diagnosis of siblings [8].

Yavuz and Coskun (2014) conducted a study to examine indoor and outdoor recreation of typically developing children and their mentally disabled siblings. Participants of the study composed of 22 typically developing individuals with disabled siblings. A criterion for participation in the study was to be a student of high school and university. Study data were collected with a data collection tool designed by the researchers. Results of the study revealed that participants spent time with disabled sibling at home mostly than outside. Researchers concluded that this situation originated from social problematic behaviors of disabled sibling and failure to control disabled sibling. Typically developing siblings are more willing to spend time with their disabled sibling indoor than outdoor [9].

Ustdag and Bumin (2014) aimed to examine the effects of group activities which are applied to 5-13 aged disabled children and their healthy siblings on social participation and sibling relationships. Study was conducted as an experimental method. Experimental group consisted of four disabled children and their typically developing siblings; control group consisted of four disabled children and their typically developing siblings. Children in experimental group received group activities during four weeks. Group activities have been implemented one day a week for 1.5 hours in accordance with the children's interests. *Demographic Data Collection Survey*, *Child and Adolescent Participation Scale (CASP)* and *Schaeffer Sibling Behavior Rating Scale* were used to collect data. Scales have been applied again after 4 weeks, the first and the last scores have been compared. As a result of the study, no statistically significant difference determined between the study group and the control group based on the results of the CASP and Schaeffer Sibling Behavior Rating Scale. Researchers concluded that in this pilot study, due to insufficient number of cases, even though there were significant improvements in social participation and sibling relationships according to the pre and post evaluation results, when compared with the results of the control group, this improvement could not be included in the results [10].

Koc (2014) aimed to determine self-respect and school success of healthy siblings of mentally handicapped children. For that purpose, 9-18 aged children (n: 91) who had mentally handicapped sibling were included to the study. *Demographic Information Form* and *Coopersmith Self Esteem Scale* were used to collect data. School success of healthy siblings was evaluated through e-school system. According to the results of the study, self-respect point average of the healthy siblings of the mentally disabled children was  $59.2 \pm 14.9$ ; and 69.2 % of them had medium level, 27.5 % of them high level of self-

respect. It was found that the self-respect of the healthy siblings was affected by the gender of the mentally disabled sibling and the employment status of the father. The school success level of 60.4 % of the healthy siblings at the end of the year was found to be 'good'. In this study, no relationship was established between the self-respect of the healthy siblings and their levels of success at school [11].

Mutlu (2013) conducted a study about investigating the attitudes of 18-30 aged adults with disabled siblings to marriage. Researcher worked with total 120 unmarried adults (65 female and 55 male) with disabled sibling to collect data. *Attitudes toward Marriage Scale* and *Personal Information Form* were used. According to results of the study, it was found that attitudes toward marriage of female adults with disabled siblings were more negative than attitudes of male adults with disabled siblings. It was seen that when level of disability increased, attitudes toward marriage were more negative. Also, it was found that attitudes of adults who took care of sibling with disability were more negative than attitudes of adults who did not take care of sibling with disability [12].

Konuk Er (2011) examined the effect of The Parent Education Program (PEP) and The Sibling Education Program (SEP) which was giving to sibling with typical development who needed support about disabled sibling and to their mothers. Researcher aimed to reveal of effect of SEP on 10-14 aged children's attitudes and behaviors toward disabled sibling. Researcher worked with 30 elementary school children and children divided into three groups as experimental group 1, experimental group 2 and control group. Also, 10 parents of children in experimental group 2 attended to the study. Experimental group 1 received SEP, experimental group 2 received PEP and control group received no program. *The Achievement Test*, *The Attitude towards Disabled Sibling Scale*, *The Basic Skills Scale*, *The Schaffer Sibling Behavior Rating Scale-Sibling Form* and *The Schaffer Sibling Behavior Rating Scale-Mother Form* were used as data collection tools. These scales were implemented before starting the programs; collected data was analyzed and it was seen that there was not a statistically significant difference between the pretest score averages of the groups. Researcher also prepared *The Achievement Test* and validity of other scales was also checked. The SEP consisted of 15 sessions and each session was held for nearly 90 minutes once a week; The PEP included 11 sessions and each one lasted 90 minutes and was applied once a week. The applications in both groups were conducted as the group education. The PEP and SEP were prepared by the researcher. After implementation of the programs, scales were implemented again. According to the results of the study; in consequence of the PEP and SEP conducted on the experimental groups, it was seen that there was a great increase in information level access (pretest-posttest) of typically developing children about disabled siblings; a considerable increase was observed in the control group. Also, there was not a meaningful achievement difference between the experimental groups. The results of the applied Sibling Education Program and Parent Education Program showed that while there was a meaningful increase in attitude access (pretest-posttest) of typically developing children towards mentally disabled siblings, the control group did not show the same increase. Also, the programs had achievement differences in making attitudes of normal children towards siblings more positive. This difference was identified between the control group and the experiment group, but not between experiment groups [4].

Saban (2010) examined to self esteem and anxiety level of children who had disabled sibling and not. Researcher also aimed to determine factors that affect self esteem and anxiety. Participants composed of 15-18 aged 227 healthy children (119 of them did not have mental retarded sibling and 108 of them had mental retarded sibling). *Personal Information Form*, *Rosenberg Self-Esteem Scale* and *Trait Anxiety Scale* were used to collect data. Results of the study were showed that there was no difference of trait anxiety and self esteem scores of children who had mentally retarded sibling and not. Trait anxiety level of 17-18 aged children who had mentally retarded sibling was found higher than those children who did not have mentally retarded sibling. Mean score of trait anxiety of girls who had mentally retarded sibling was higher than girls who did not have mentally retarded sibling. Self esteem of children who had mentally retarded sibling did not affect from sibling's disability. It was seen that when anxiety of children, who had mentally retarded sibling and not, increased, self-esteem decreased [13].

Ertürk (2009) aimed to determine problems of 9-18 aged children with typical development who had mentally handicapped sibling received integrated education and not. Researcher worked with 120 people as two groups: one of the groups included 30 mentally handicapped children received integrated education, their siblings and mothers (n: 60), other group included 30 mentally handicapped children not received integrated education, their siblings and mothers (n: 60). *Schaeffer Sibling Behavior Rating Scale* and *Siblings Problem Questionnaire* were used to collect data. According to mean score of Siblings Problem Questionnaire, children who had mentally handicapped sibling received integrated education got higher score than children who had mentally handicapped sibling not received integrated education. It was seen that siblings of mentally handicapped children received integrated education confronted less problem about disabled siblings [14].

Unal (2009) examined childcare attitudes of mothers of mentally handicapped children and behaviors of healthy children towards mentally handicapped siblings. The study included the mothers of the 5-15 aged mentally disordered children as well

as the 9-17 aged healthy siblings of the disordered children. Researcher used *General Information Form, Family Life and Childcare Attitude Scale (PARI)* and *Schaeffer Sibling Behavior Rating Scale* to collect data. According to results of the study; diagnosis time of disabled child, knowledge of parents about disability, disabled child's age of starting education, educational background of mother caused differences on mother's childcare attitudes. Also, knowledge of family about diagnosis, educational status of disabled sibling, age of mother and gender of the sibling created significant differences on behaviors of sibling. Relation between childcare attitudes of mothers and behaviors of healthy children towards mentally disabled sibling was found significant [15].

Korkmaz (2008) aimed to evaluate relationships between healthy children and their disabled siblings in terms of opinion of healthy siblings and mothers. Participants of the study were 7-18 aged healthy siblings of mentally handicapped children and their mothers. *An Information Form about the Handicapped Children and Their Families, The Sibling Problems Questionnaire* and *Schaeffer Sibling Behavior Rating Scale* were used to collect data. Results of the study revealed that when educational level, number of siblings and ages of healthy siblings were increased, experienced problems of healthy children with disabled siblings were decreased. Also, it was found that if siblings had apparent disability besides mental disability, relationships between siblings were affected negatively. Mothers perceived relationships between healthy and disabled siblings more negatively [16].

Onat Zoylan (2005) conducted a study to compare the sibling relationships of people who have handicapped and non-handicapped siblings. 107 participants (31 had autistic sibling, 36 had Down syndrome and 40 had non-handicapped sibling) attended to the study as experimental group (participants had handicapped sibling) and control group (participants had non-handicapped sibling). *Sibling Relationship Questionnaire* was used to collect information about sibling's relationship; also demographic information form was used. Results of the study showed that there were particular differences in the sibling relationships among 3 groups (participants who had autistic siblings, Down syndrome siblings and non-handicapped siblings). Participants with non-handicapped siblings (control group) had higher scores at the Sibling Relationship Questionnaire' subscales of "conflict" and "rivalry" than experimental groups. Also, there were no differences among groups on the scores of other subscales, namely "relative status/power" and "warmth/closeness". Furthermore, there was no effect of the variables "participant's own age", "sibling's gender and age", "age-spacing between siblings", "family type", and "number of children in the family" on any of the Sibling Relationship Questionnaire subscales [17].

Sizak (1999) studied with adolescents with disabled sibling and their parents to determine effects of a communication skills training program. Participants of the study were 16 adolescents, 16 mothers and 15 fathers. Participants divided into two groups: experimental group and control group. *Communication Skills Evaluation Scale* and *Evaluation Tool for Family Structure (ETFS)* were used for pretest and posttest evaluations. Experimental group received communication skills training program for 10 weeks. According to the results, there were significant differences between pretest ETFS scores and posttest ETFS scores of fathers in the experimental group. Other results showed no differences between two groups. However, according to observers of research and note of siblings, communication skills program had positive effects on communication skills of children and family communication patterns [18].

## 2 CONCLUSION

When reviewing the studies about children with disabled sibling in the current study, it can be seen that studies have focused on self-esteem, academic success, relation with siblings, attitudes, behaviors, experienced problems, ect. There are too few studies about intervention or support program for siblings of disabled children (ex. Ustdag and Bumin, 2014; Konuk Er, 2011; Sizak, 1999). Siblings of disabled children are as important as disabled children. Generally, it may be said that siblings of disabled children are neglected by parents and professions. It is thought that professions working with children must focus on supporting siblings of disabled children as well as disabled child. Studies have revealed the problems and level of self-esteem or anxiety or relationships, but studies also must suggest support programs for children with disabled sibling to cope with these problems. In Turkey, it may be said that there is no support program or choice for siblings of disabled children; disabled children get support from professions with government grant, but other sibling may not get support. Also, it is thought that siblings of disabled children should be determined and they should take support starting from early childhood period. Hereby, they may learn about disability, how to contact with disabled sibling, and how to overcome problems. Also, developmental problems that can be seen in time may be determined and supported earlier. Supporting intervention programs should be created for children with disabled sibling and these programs should become prevalent across the country.

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