European Journal of Special Education Research
ISSN: 2501 - 2428
ISSN-L: 2501 - 2428
Available on-line at: www.oapub.org/edu

DOI: 10.46827/ejse.v9i3.4925
Volume 9 │ Issue 3 │ 2023

AN INVESTIGATION OF EFFECT OF COMMUNICATION SKILLS OF CHILDREN WITH DOWN SYNDROME ON NEEDS, ANXIETY AND SOCIAL SUPPORT LEVELS OF THEIR MOTHERS

Pelin Piştav Akmeşe[1],
Necla Işıkdoğan Uğurlu[2][i],
Nilay Kayhan[3]
[1]Assoc. Prof. Dr.,
Department of Audiology,
Faculty of Health Sciences,
Ege University,
Izmir, Turkey
orcid.org/0000-0001-8269-3899
[2]Asst. Prof. Dr.,
Department of Special Education,
Faculty of Education,
Zonguldak Bulent Ecevit University,
Zonguldak, Turkey
orcid.org/0000-0002-1795-0470
[3]Assoc. Prof. Dr.,
Department of Special Education,
Faculty of Education,
Ege University,
Izmir, Turkey
orcid.org/0000-0002-0937-8013

Abstract:
This study aims to investigate the effect of communication skills of children with Down Syndrome on their mother's perceptions of needs, anxiety, and social support. The quantitative research method was used in the study, which was performed in the descriptive survey model. 71 mothers who have children between 4-16 years of age, diagnosed with Down Syndrome participated. The research data were collected using Communication Function Classification System (CFCS), Family Needs Survey (FNS), Questionnaire on Resources and Stress for Families with Chronically or Handicapped Members (QRS), and Social Support Scale (SSS). There was a positive significant relationship between CFCS and financial needs and QRS 2 and there was a negative significant relationship with social support. A negative significant relationship was found between QRS 3 and social support.

---

[i] Correspondence: email necla_idogan@hotmail.com

Keywords: anxiety, communication function classification system, Down Syndrome, needs of mothers, social support

1. Introduction

Down Syndrome (DS) is one of the chromosomal disorders which are frequently seen in children today (Selikowitz, 2010). According to data from World Health Organization (WHO, 2017) an average of 3000-5000 babies are affected by chromosomal disorders every year, it is stated that approximately 1 out of every 1000 babies has Down Syndrome (DS) It is seen that children with DS generally experience some limitations and delays in all developmental areas (Buckley, 2012). They experience mental disability, difficulties in language and communication skills as well as health problems because of an extra chromosome in the twenty-first chromosome (Selikowitz, 2010; Abbeduto, Warren & Conners, 2007).

Cognitive development levels of children with DS differ from mild level to moderate level. Parallel to this situation, differences are seen also in mental functions and performances. These differences in mental processing negatively affect transferring information from short-term memory to long-term memory, cause-effect relationships, perception/attention skills, and finding different solutions to problem skills of the children. Besides all these limitations, they also experience difficulties in generalization skills to transfer information to different environments, people, and areas. It is seen that these difficulties experienced in cognitive skills negatively affect children's development in language and communication skills (Kumin, 2012).

1.1 Development of Language and Communication Skills in Children with Down Syndrome

Language and communication skills, which are a part of our daily life, are in a complex structure and have critical importance for the development of all children. The primary condition for every child to reach their true potential is to learn how to express themselves appropriately. For children with DS, like their peers, communication is a basic need and they are expected to use language skills functionally. While communication difficulties are very common in some of those children, they are rarer in some children. Development of language and communication skills are frequently accompanied by recurrent ear infections, hearing loss, weak muscle tone around the face and mouth, having a smaller mouth than the size of the tongue, excessive or low tactile sensation around the mouth, difficulties in memory and intellectual dimensions in children with DS. Children with DS, who desire to communicate from an early age, communicate through crying, smiling, and facial expressions. The reactions given by the families to these communication efforts contribute to these expressions, facial expressions, and sounds becoming a way of communication. Thus, it is highly important to educate the family, especially the mother, and include them in the process for language and communication skills to become a part of daily life. With the studies starting in early periods, families can help their children by giving them a great number of opportunities to use the words they can use in new situations and by providing experiences that will reinforce the concepts (Kumin, 2012).

DS is diagnosed during the pregnancy of the mother or soon after the birth, in the early period. As children with DS experience limitations in receptive/expressive language in the early period, education services should be planned to start from the pre-linguistic period (Acarlar, 2006; Chapman, Hesketh & Kistler, 2002). The difficulties experienced in the receptive language skills of children with DS are related to the cognitive skills of the children. Thus, children who have difficulty in verbal communication usually try to express themselves with gestures and facial expressions in the early period (Fidler, 2005; John & Mervis, 2010). During the speaking period, they experience serious difficulties in talking about a topic, asking questions, understanding complex sentence structures, and continuing the conversation on the same topic (Acarlar, 2006; Ulkü-Kürkcüoğlu, 2009). It draws attention that the "babbling" period, which is seen in babies and called repetitive sequencing with murmuring continues in these children for a longer time and the transition to speech is prolonged (Vicari, Caselli & Tonucci, 2000). The language difficulties experienced by children with DS continue throughout their lives. Thus, the difficulty areas in the language skills of the children should be determined and they should benefit from appropriate intervention services as early as possible. It is important to plan early education services with the parents who know the children best. Children interact with whoever is the primary caregiver in the family from the moment they are born. This is generally the duty of the mother (Brassart & Schelstraete, 2000). Especially the mother's responsibilities increase when a child with disabilities is born into the family. With the birth of a child with disabilities, inter-family relationships break and some economic, social, and psychological problems occur. This situation causes emotions such as anxiety, hopelessness, stress, and burnout and cause some psychological problems in the family members (Natan, 2007). Mothers’ burden increases in terms of taking care and meeting the needs of the child with DS. All these factors are a serious resource of stress and the mother needs more social support. While mothers struggle with the care of the child and economic difficulties, on one hand, they also deal with problems such as their children's getting behind in development from their peers, or who will take care of their children after them on the other hand. The mothers need to be provided with both emotional and physical support in terms of supporting the development of their children and dealing with their problems (Allen, Ciambrone & Welch, 2000; Sen & Yurtsever, 2007).

The quality of life of mothers who are psychologically anxious, nervous, and stressed reduces, as a result, they experience limitations in reaching rehabilitation goals. It is important to determine the social and psychological needs of the mothers who have children with DS and to develop solution suggestions for these needs. This study aimed to investigate the effect of communication skills on the needs, anxiety, and social support levels of mothers. Answers to the following sub-problems were sought in the study:

Do the needs, anxiety, and social support levels of the mothers of children with DS differ

1) according to the ages of the children?
2) according to the gender of the children?
3) according to the communication levels of the children?
4) Is there a relationship between the communication level of the children with DS and the needs, anxiety, and social support level perceived by the mothers?

2. Material and Methods

2.1. Research Design

The quantitative research method was used in the study (Cohen, Manion & Morrison, 2000), which was performed in the descriptive survey model. All data were collected in one-on-one interviews with mothers.

2.2. Participants

Participants were the mothers of children with Down Syndrome who are between the ages of 4-16 years and speak Turkish. There were no other specific inclusion or exclusion criteria. The researchers contacted the administrators of the centers where the children who receive special education continue and explained the purpose of the study. Administrators of the institutions shared the official ethical permissions with the families and gave information. They shared the contact information of the mothers who volunteered to participate in the study with the researchers. The researchers conducted face-to-face interviews with the volunteer mothers. This questionnaire was used to collect all data for the study (including demographic data relating to the child, parent, and family as well as all outcome measures) Age and gender of children with Down Syndrome and the age and educational grade of parents were presented in detail in Table 1 and CFCS levels of children in Table 2.

Table 1: Characteristics of the children with Down Syndrome and their parents (n=71)

<table>
<tr><th>Characteristics</th><th colspan="2">Mean</th><th colspan="2">SD</th><th colspan="3">Min.-Max.</th></tr>
<tr><td>Age of Children</td><td colspan="2">8.25</td><td colspan="2">3.80</td><td colspan="3" rowspan="4">4-16</td></tr>
<tr><td>Gender</td><td colspan="2">n</td><td colspan="2">%</td></tr>
<tr><td>Female</td><td colspan="2">33</td><td colspan="2">46.5</td></tr>
<tr><td>Male</td><td colspan="2">38</td><td colspan="2">53.5</td></tr>
<tr><td rowspan="2"></td><td colspan="4">Mothers</td><td colspan="3">Fathers</td></tr>
<tr><td>M</td><td colspan="2">SD</td><td>Min.-Max.</td><td>M</td><td>SD</td><td>Min.-Max.</td></tr>
<tr><td>Age</td><td>39.06</td><td colspan="2">6.49</td><td>24-55</td><td>42.80</td><td>7.35</td><td>28-54</td></tr>
<tr><td colspan="8"></td></tr>
<tr><td>Education Grade</td><td colspan="3">n</td><td>%</td><td colspan="2">n</td><td>%</td></tr>
<tr><td>Elementary School</td><td colspan="3">40</td><td>56.3</td><td colspan="2">33</td><td>46.5</td></tr>
<tr><td>Secondary School</td><td colspan="3">8</td><td>11.3</td><td colspan="2">9</td><td>12.7</td></tr>
<tr><td>High School</td><td colspan="3">17</td><td>23.9</td><td colspan="2">18</td><td>25.4</td></tr>
<tr><td>University</td><td colspan="3">6</td><td>8.5</td><td colspan="2">11</td><td>15.5</td></tr>
</table>

Vocation				
Self-employed	-	-	30	42.3
Employee	2	2.8	26	36.6
Civil Servant	4	5.6	10	14.1
Retired	-	-	5	7.0
Housewife	65	91.5	-	-

The study included mean age of 8.25±3.80 years, 38 (53.5%) male and 33 (46.5%) female, 71 children with DS in total. When examining the demographic data regarding the families, it has been determined that the mothers are between the ages of 24-55 and the fathers are between the ages of 28-54; from the point of education level, both the mothers 40 (56.3%) and the fathers 33(46.5%) are primary school graduates. The age and gender of children with Down syndrome and the age and educational grade of parents were presented in detail in Table 1.

Table 2: CFCF Levels of Children with Down Syndrome

CFCS Levels	**n**	**%**
Level I	9	12.7
Level II	17	23.9
Level III	26	36.6
Level IV	13	18.3
Level V	6	8.5

Note: Level I, most able; Level V, least able; CFCS, Communication Function Classification System

Table 2 shows that CFCS levels included level I of 9 (12.7%), level II of 17 (23.9%), level III of 26 (36.6%), level IV of 13 (18.3%), and level V of 6 (8.5%) children with down syndrome. In the study, it has been determined most of the children (36.6%) belong to level III according to the CFCS level.

2.3. Outcome Measures

Participation was measured using Communication Function Classification System, Family Need Survey, Questionnaire on Resources and Stress for Families with Chronically or Handicapped Members, and Social Support Scale. The tests used and their features are given below in detail.

2.3.1. Communication Function Classification System

Communication Function Classification System (CFCS) provides 5 levels from Level I to Level V to describe everyday communication performance (Hidecker, Paneth, Rosenbaum et al., 2011). CFCS is now being used to describe the communication performance of individuals with any disability (Communication Function Classification System, http://cfcs.us/). The Turkish CFCS had been previously translated and back-translated from the original English version (http://cfcs.us/wp-content/uploads/2014/02/Turkish). The pediatric physiotherapist who classified the children had training on CFCS online training. The first researcher who is both an audiology and speech pathologist and physiotherapist classified the children in CFCS. The children with DS who participated in the study are divided into (3) groups in terms of CFCS. The groups are defined as follows: first group, I, II mild level, second group; III moderate level, and third group; IV, V severe level.

2.3.2. Family Need Survey

Family Need Survey (FNS) was developed by Bailey and Simeonsson in 1988 to determine the needs of families. Its validity and reliability studies were conducted and it was adapted into Turkish in 1995 by Sucuoğlu (Bailey & Simeonsson, 1988; Neely-Barnes & Dia, 2008). The validity and reliability studies of FNS were investigated on different disability groups and the tool was shown to be reliable (Akcamete & Kargın, 1996; Mert, 1997). The scale is applied with three response options: (1) “No,” (2) “Not Sure,” and (3) “Yes." Information, *explaining to others, and financial* sections of the scale was used in this study (Sucuoğlu, 1995).

2.3.3. Questionnaire on Resources and Stress for Families with Chronically or Handicapped Members

The anxiety levels of the mothers have been evaluated by the Questionnaire on Resources and Stress for Families with Chronically or Handicapped Members (QRS) which consists of three sub-scales, developed by Jean Holroyd (1988) and was adapted to Turkish by (Akkök, 1989). QRS consists of three dimensions and eleven sub-dimensions. Problems regarding the person with a disability or a permanent disease dimension consist of dependency and self-management, cognitive inefficiency, physical restrictions sub-dimensions (QRS1); personal problems of the family members dimension consist of life-long care, lack of personal rewards, consistent disease concern, preferring to be cared in an institution, difficulties for the family sub-dimensions (QRS2); inter-family problems dimension consists of restrictions on the family life, financial problems, inter-family inconsistency sub-dimensions (QRS3). The answers are given as true or false on this scale.

2.3.4. Social Support Scale

Social Support Scale (SSS) was used to evaluate the social support levels perceived by the mothers. It was developed by Cutrona and Russell (1987) to measure the social support types that were defined by Sacle, and Weiss (1974). It was adapted into Turkish by Duru and Balkıs (2007). The internal consistency coefficient of the scale is 90, and the test-retest correlation coefficient is 75. Each item on the scale is given points between 1-4 (4 "strongly agree", 1 "strongly disagree") (Işıklı, 1998).

2.4. Data Analysis

Statistical analyses were conducted using SPSS 25.0. Arithmetic mean, frequency, and percentage were calculated. Kruskal-Wallis, Mann-Whitney U test, and Spearman correlation analysis were performed (Leech, Barrett & Morgan, 2007). A probability level of $p<0.05$ was considered statistically significant.

3. Results and Discussion

This section has included the demographic data regarding the participants with the finding of the analysis conducted according to the research questions. Table 3 shows the analysis results of the scores of the mothers who have children at or under the age of 5, between 6-11 years of age, and above 12 years of age in the family needs (Financial, Explaining to others, Information, General support, and Community service), anxiety (QRS 1, QRS2, QRS 3) and social support scales in terms of age groups.

Table 3: Kruskal-Wallis analysis results of mothers' need, anxiety, and social support scores by age groups of children with Down Syndrome

Source	n	Mean Rank	df	χ^2	p
Information					
< 5	22	35.43	2	4.531	.104
6-11	29	41.43			
>12	20	28.75			
Explaining to others					
< 5	22	36.00	2	.065	.968
6-11	29	35.38			
>12	20	36.90			
Financial					
< 5	22	48.82	2	17.312	.000
6-11	29	35.50			
>12	20	22.63			
QRS 1					
< 5	22	27.27	2	6.490	.039
6-11	29	37.95			
>12	20	42.78			
QRS 2					
< 5	22	36.98	2	.147	.929
6-11	29	36.22			
>12	20	34.60			
QRS 3					
< 5	22	40.84	2	2.739	.254
6-11	29	36.17			
>12	20	30.43			
Social Support					
< 5	22	26.75	2	6.834	.033
6-11	29	41.74			
>12	20	37.85			

Note:
ORS: Questionnaire on Resources and Stress for Families with Chronically or Handicapped Members;
QRS1: Problems regarding the person with a disability or a permanent disease dimension;
QRS 2: Personal problems of the family members dimension;
QRS 3: Inter-family problems dimension.

When examining Table 3, family needs survey results indicated that three age groups with Down Syndrome differed significantly in mothers' financial needs χ^2 (2, n=71) = 17.312, p= .000 Post hoc Mann-Whitney U tests were used to compare three age groups with Down Syndrome in mothers' financial needs. The mean rank of mothers whose children were under 5 years of age (31.16, n=22) was significantly higher than mothers whose children were between the ages of 6-11 (22.29, n=29), z=-2.175, p=.030, r=.30, a small to medium effect size according to Cohen (1988). The mean rank of mothers whose children were under the age of 5 (29.16, n=22) was significantly higher than mothers who have children above the age of 12 (13.08, n=20), z=-4.282, p=.000, r=.65 a medium to large effect size according to Cohen (1988). The mean rank of mothers whose children were between the ages of 6-11 (28,41 n=29) was significantly higher than mothers whose children were 6-11 (20.05, n=20), z=-2.070, p=.038, r=.30 a small to medium effect size according to Cohen (1988). Mothers' anxiety results indicated that the mean rank of mothers whose children were under the age of 5 (21.34, n=22) was significantly lower than mothers whose children were between the ages of 6-11 in QRS1 (29.53, n=29), z=-1.976, p=.048, r=.28 a small to medium effect size according to Cohen (1988). There was no difference between the scores of the mothers with children under the age of 5 and mothers who have children above 12 years of age z=-.950, p=.342. Social support results indicated that three age groups with Down Syndrome differed significantly in mothers' social support χ^2 (2, n=71) =6.834, p=.033. Post hoc Mann-Whitney U tests were used to compare the three age groups with Down Syndrome in mothers' social support levels. The mean rank of mothers whose children were under the age of 5 (20.02, n=22) was significantly lower than mothers whose children were between the ages of 6-11 (30.53, n=29), z=-2.175, p=.012, r=.30 a small to medium effect size according to Cohen (1988). There was no difference between the scores of the mothers whose children were under the age of 5 and mothers whose children were above 12 years of age (z=-1.816, p=.069) and there was no difference between the scores of the mothers whose children were between the ages of 6-11 and mothers whose children were above 12 years of age (z=-.713, p=.476)

Table 4 shows the analysis results of the scores received from needs, anxiety, and social support scales in accordance with gender.

Because the dependent variables were ordinal and the variances were unequal, Mann-Whitney U tests were performed to compare the gender. 38 male children with Down Syndrome have a significantly higher mean rank (40.72) than the 33 females (30.56) on financial need, U=447.5, p=.036, r=.25 which, according to Cohen (1988), is small effect size. Likewise, there was a significant difference in the mean rank of males (40.87) and females (30.39) on explaining to others, U=442, p=.032, r=.25, which is considered a small effect size. There was a significant difference in the mean rank of males (42.54) and females (28.47) on QRS3, U=378.5, p=.004, r=.34, which is considered a small to medium effect size. There was a significant difference in the mean rank of males (29.49) and females (43.50) on social support, U=379.5, p=.004, r=.39, which is considered a small to medium effect size. However, male and female children with Down Syndrome did not differ in information needs, QRS1, QRS 2.

Table 4: Comparison of male and female children with Down Syndrome, needs, anxiety, and social support test scores of mother

Variable	**N**	**Mean Rank**	**Sum of Ranks**	**U**	**p**
Information					
Female	33	34.53	1139.50	578.500	.574
Male	38	37.28	1416.50		
Explaining to others					
Female	33	30.39	1003.00	442.000	.032
Male	38	40.87	1553.00		
Financial					
Female	33	30.56	1008.50	447.500	.036
Male	38	40.72	1547.50		
QRS 1					
Female	33	33.80	1115.50	554.500	.398
Male	38	37.91	1440.50		
QRS 2					
Female	33	35.56	1173.50	612.500	.866
Male	38	36.38	1382.50		
QRS 3					
Female	33	28.47	939.50	378.500	.004
Male	38	42.54	1616.50		
Social support					
Female	33	43.50	1435.50	379.500	.004
Male	38	29.49	1120.50		

Note:
QRS 1: Problems regarding the person with a disability or a permanent disease dimension;
QRS 2: Personal problems of the family members dimension;
QRS 3: Inter-family problems dimension.

Table 5 shows the analysis results of the scores the mothers obtained from the needs, anxiety, and social support scales according to CFCS levels of children.

A Kruskal-Wallis analysis of variance indicated that CFCS levels with Down Syndrome differed significantly in mothers' information needs χ^2 (2, n=71) = 7.189, p= .027. Post hoc Mann-Whitney U tests were used to compare three levels of Down Syndrome in mothers' information need levels. The mean rank of mothers whose children were level I-II was significantly lower than mothers whose children were level IV-V (z=- 1.989, p=.047, r=.30), a small to medium effect size according to Cohen (1988). CFCS levels with Down Syndrome differed significantly in mothers' financial needs χ^2 (2, n=71) = 10.116, p=.006. Post hoc Mann-Whitney U tests compared the three age groups with Down Syndrome on mothers' financial needs. The mean rank of mothers whose children were Level I-II was significantly lower than mothers whose children were Level III (z=-2.558, p=.011, r=.35 a small to medium effect size according to Cohen (1988). The mean rank of mothers whose children were Level I-II was significantly lower than mothers whose children were Level IV-V (z=-2.852, p=.004, r=.43), a small to medium effect size according to Cohen (1988). There was no difference between Level III and Level IV-V (z=-.658, p=.510).

Table 5: Kruskal Wallis analysis results of mothers' needs, anxiety, and social support levels according to CFCS levels of children with Down Syndrome

CFCS	**N**	**Mean Rank**	**df**	χ^2	**p**
Information					
Level I-II	26	33.83	2	7.189	.027
Level III	26	30.46			
Level IV-V	19	46.55			
Explaining to others					
Level I-II	26	30.71	2	2.815	.245
Level III	26	39.81			
Level IV-V	19	38.03			
Financial					
Level I-II	26	26.06	2	10.116	.006
Level III	26	40.17			
Level IV-V	19	43.89			
QRS 1					
Level I-II	26	39.27	2	1.842	.398
Level III	26	36.42			
Level IV-V	19	30.95			
QRS 2					
Level I-II	26	30.52	2	3.344	.188
Level III	26	37.52			
Level IV-V	19	41.42			
QRS 3					
Level I-II	26	28.52	2	6.174	.046
Level III	26	38.23			
Level IV-V	19	43.18			
Social support					
Level I-II	26	43.83	2	5.990	.050
Level III	26	32.23			
Level IV-V	19	30.45			

Note:
CFCS: Communication Function Classification System;
QRS1: Problems regarding the person with a disability or a permanent disease dimension;
QRS 2: Personal problems of the family members dimension;
QRS 3: Inter-family problems dimension.

For the anxiety scores, there was no difference between QRS 1 and QRS 2. QRS 3 indicated that three age groups with Down Syndrome differed significantly $\chi 2$ (2, n=71) =6.174, p=.046. Post hoc Mann- Whitney U tests were used to compare CFCS levels with Down Syndrome on mothers' QRS 3. The mean rank of mothers whose children were level I-II was significantly lower than mothers whose children were level IV-V (z=- 2.193, p=.028, r=.33) a small to medium effect size according to Cohen (1988). There was no difference between levels I-II and level III (z=-1.857, p=.063). There was no difference between level III and level IV-V (z=-.987, p=.325).

According to the CFCS levels of the children with Down Syndrome, the scores of the mothers' from the social support scale did not differ significantly χ2 (2, n=71) =5.990, p= .050.

Table 6 shows the correlation results between the CFCS levels of the children with Down Syndrome and the scores of the mothers they received from needs, anxiety, and social support scales.

Table 6: Correlation between CFCS levels of the children with Down Syndrome and needs, anxiety, social support perception of the mothers

Variables		Family Need Survey			QRS			Social Support
	1	2	3	4	5	6	7	8
1. CFCS	--	.174	.127	349**	-.155	.254*	.284*	-.257*
2. Information	--	--	.341**	.312**	-.110	.122	.221	-.179
3. Explaining to others	--	--	--	.562**	-.074	.067	.388**	-.323**
4. Financial	--	--	--	--	-.284*	-.045	.466**	-.381**
5. QRS 1	--	--	--	--	--	.007	-.016	.137
6. QRS 2	--	--	--	--	--	--	.302*	.050
7. QRS 3	--	--	--	--	--	--	--	-321**
8. Social support	--	--	--	--	--	--	--	--

*p <.05, **p<.01
CFCS: Communication Function Classification System
QRS1: Problems regarding the person with a disability or a permanent disease dimension
QRS 2: Personal problems of the family members dimension
QRS 3: Inter-family problems dimension
* Spearman correlation analysis.

There was a positive significant relationship between CFCS and financial needs and QRS 2 (personal problems of the family members dimension), and a negative significant relationship between CFCS and social support. There was a significant relationship between all sub-dimensions of the family needs survey tool. There was a negative relationship between the family needs survey in financial needs and QRS1 (problems regarding the person with a disability or a permanent disease dimension), a positive relationship with QRS3 (inter-family problems dimension), there was a positive relationship between explaining to others and QRS3, a negative relationship between financial and explaining to others and social support. a negative significant relationship was found between QRS3 (inter-family problems dimension) of the anxiety and stress level tool and social support.

This study aims to investigate the effect of communication skills of children with Down Syndrome on the needs, anxiety, and social support levels of their mothers. Besides, this study examines whether the anxiety levels of the mothers differ in accordance with the age, gender, and communication function levels of the children. In this section, findings obtained regarding the purpose of the study and the literature are discussed.

DS, an inherited disease that is the most common among mental disabilities, negatively affects language and communication skills. Language and communication difficulties can be limiting for children with DS to socialize/interact with their peers and fulfill the roles expected from themselves (Bradley, 2002). Social problems resulting from their language and mental development can cause behaviors such as deficiencies in expected behaviors, and externalizing/internalizing. Externalizing problems (like aggressive behavior) can be more dominant than internalizing problems (like anxiety, or withdrawal). Studies on the functional use of social skills indicate that variables of language, socioeconomic status, age, and gender are predictive. Although socioeconomic level (SEL) is an important determinant in terms of social functionality, the second determinant that follows it is age (Bradley, 2002; Patterson, DeBaryshe & Ramsey, 1989). While some studies state that SEL does not have negative effects on the functional use of social skills by children with DS (McCarthy, 2008), it is stated that age is more prominent in the functional use of social skills (Bradley, 2002; Rosner, Hodapp & Fidler, 2004; Eisenhower, Baker & Blacher, 2005). It is emphasized that while social skills and communication activities increase with age in children with typical development, children with DS at young ages experience more difficulties in the functional use of social skills. There also are study findings that state that externalizing problems increase in children with DS as age progresses and gender is not effective in social skills (Dykens & Kasari, 1997; Eisenhower, Baker & Blacher, 2005). The results of our study show that there is a relationship between the age of the children with DS and the needs, anxiety, and social support levels of the mothers. It is seen that as the age of the children increases, the anxiety levels of the mothers decrease. It is thought that the decrease in the mothers' anxiety can be related to the decrease in the uncertainties about their children and an increase in their knowledge level over time. In these circumstances, it draws attention that mothers stated that they overcome difficulties more easily and spend more time with their children over time thanks to the fact that the children with DS benefit from education services starting from a young age.

In our study, there is a significant difference between the variable of the gender of the children with DS and the needs, anxiety, and social support levels of the mothers. Our study shows that the mothers of female children have higher anxiety levels than the mothers of male children. The literature has similar results to the findings of our study (Besikçi, 2000). For example, it is stated that the mothers of female children with disabilities experience more anxiety than the mothers of male children. It is thought that this situation mainly results from the cultural structure. Based on the view that female children are culturally more vulnerable and in need of support than male children in the region where the study was conducted, it is thought that the findings support the results about approaching female children more protective and having anxiety about the future. In literature, in the studies that investigated the developmental skills of the children with DS compared to their peers or themselves regarding the gender factor, it is stated that the verbal, perceptual-performance, social skills, memory, and motor skills scores of the male children are lower than the female children (Allhusen et al., 2003; van Gameren-

Oosterom, Fekkes, Buitendijk et al, 2011). In some studies that do not support the findings regarding the gender factor in our study, it is stated that there is not a significant difference in the anxiety levels of the families according to the gender of the children with DS and the families experience general anxiety and stress resulting from the disability of the children independently of the gender (Cengelci, 2009; Coskun & Akkas, 2009). It is thought that the main reason for this situation may be due to the cultural differences of the region as well as the severity of the disability of the child. It is thought that the anxiety levels of the parents increase as the severity of the child's disability increases. The depression level of the family can differ according to the gender of the child. Especially the families of male children with disability who need caring stated that they accepted the care of the male child more easily (Ergin, Şen, Eryılmaz, Pekuslu & Kayacı, 2007). In terms of gender factors, our study shows that the information needs of the mothers do not differ, however, mothers of male children with DS have higher scores in financial support needs and explaining to others; their scores are significantly different from the scores of the mothers of the female children. The finding of our study is similar to the finding that states that the quality of life and social support levels of the family do not differ according to gender in the literature (Sarıkaya, 2011).

The social development of children with DS should be evaluated in many ways. The families stated that they care about the participation of children with DS in community life, however, the children prefer inactive, individual activities such as watching TV outside of school life (MacDonald, Leichtman, Esposito, et al., 2016; Wuang, Su, 2012). Participation in community life and social skills may differ in accordance with the factors related to the child (such as behaviors, and cognitive skills) and factors related to the family (such as difficulty in managing daily family responsibilities, and lack of time) (Lyons, Brennan, Carroll, 2016). Although parents have great responsibilities with the birth of children with DS, the biggest responsibility falls on the mothers. Thus, social support levels perceived by the mothers are an important variable in the decrease or increase of anxiety levels. While the support provided to the mothers will make their adaptation to the environment and their child easier, it is also an important factor for them to deal with the difficulties (Kırbas, 2013). The fact that there is a decrease in the social support needs as the children grow older shows that the maternal age of the mothers is important for their adaptation period to their children with DS (Akandere, Acar & Bastug, 2009). Because children with DS who have language problems experience more social problems, families tend to support the language skills of their children in the early childhood period. It is observed that progress is seen in the children with DS whose language skills are supported and their problem behaviors decrease (Brassart & Schelstraete, 2015; Delaney & Kaiser, 2001; Petersen, Bates, 2013). The studies that show the language skills of children largely develop due to the family-child interaction draw attention to the applied interventions in the early childhood period (Sen & Yurtsever, 2007).

With CFCS applied in the study, a positive significant relationship was found with the financial need dimension, personal problems of the family members dimension (QRS2), inter-family problems dimension (QRS3), and a negative significant relationship was found with the social support. It is determined that mothers have anxiety about the care services for their child, especially after themselves. This result shows that they need more social support. Besides care difficulties, economic difficulties, problems in reaching the rehabilitation centers; problems such as the fact that their children fall behind their peers and who will take care of the child after themselves can cause anxiety and stress for the mothers. The lack of correlation between problems regarding the person with a disability or a permanent disease dimension (QRS1) and CFCS can be explained by the low education level of most mothers, their being housewives, and their acceptance of their children's condition. In the studies, it is stated that mothers who have children with disabilities experience anxiety about topics such as health and feeding in the first times after birth (Neely-Barnes & Dia, 2008). When the mothers are seen as the primary responsible for the care of the children, they have more duties and responsibilities. Mothers experience more stress when the care services of children with disabilities are completely left to the mothers compared to healthy children in this process in which the fathers participate less (Karner, 2004). Whether the social support levels of the family are sufficient or not forms a great part of the problems experienced. Mothers stated that they feel lonely and have a limited social life. They stated that the heavy care services of the children at young ages and the attitudes of society put a physical burden on them and they need social support services more to overcome these difficulties (Olsson, 2004). Similarly, it is emphasized that mothers need more intense social support for the issues such as adaptation to children with disability and condition, and dealing with the problems (Jones & Passey, 2004). Besides the social support services provided in different ways, emotional support provided by the relatives and family has an important place for the mothers. As for the perceived social support, when the support provided is sufficient and efficient, the mothers perceive themselves as a part of society. Thus, it is seen that the anxiety levels of the mothers decrease and their quality of life increases (Pelchat, Lefebvre & Levert, 2007). Strategies and support applied in the early period positively affect the language skills of the children. During this period, the stress levels of the parents decrease thanks to the education services provided for the families (Delaney & Kaiser, 2001; DeVeney, Hagaman & Bjornsen, 2017; Fey et al., 2006).

4. Conclusion

The results of this study revealed that the needs of the mothers who spend more time with their children should be met and support should be provided to the mothers. It is thought that the stress and anxiety levels of the mothers will decrease thanks to this support. Meeting the information needs and providing social support will help the mothers to increase the adaptation levels of mothers to their children and to deal with the problems. It is thought that if the support is qualified, accessible, and sustainable, mothers will be able to follow the development of their children more closely and their family life will be affected positively. Determining the mothers' anxiety levels and stress perceptions regarding the communication skills of their children with DS will guide in planning the social support that will be provided for them and their children.

Acknowledgements

The authors would like to thank the families who shared their thoughts and time with us.

Funding Statement

The author(s) reported there is no funding associated with the work featured in this article.

Conflict of Interest Statement

The authors declare no conflicts of interest.

About the Author(s)

Assoc. Prof. Dr. Pelin Piştav Akmeşe graduated from Hacettepe University, Department of Physical Therapy and Rehabilitation in 1997. She did her first master's degree at Ankara University Department of Child Development in 2004, her second master at Hacettepe University Faculty of Medicine Department of Otorhinolaryngology Field of Audiology and Speech Disorders in 2008, and completed her doctorate in Ankara University Faculty of Education Department of Special Education. She worked as a faculty member in Ege University Faculty of Education Department of Special Education between 2014-2021. She received the title of associate professor in the field of Special Education Speech Disabled People and Their Education in 2018. The research subjects of the author who has still been working in Ege University Faculty of Health Sciences Department of Audiology include language and narration development, assessment and intervention in language and speech disorders, diagnosis, assessment, and intervention in children with hearing loss, sign language in the early period, primary education, and higher education.

Asst. Prof. Dr. Necla Işıkdoğan Uğurlu completed her master's and doctoral studies at Ankara University, Department of Special Education. In her master's thesis, she studied reading and reading comprehension with children with intellectual disabilities. In her doctoral thesis, she worked on the morpho-syntactic awareness skills of hearing-impaired students. Currently, he is a professor at Zonguldak Bülent Ecevit University, Department of Special Education. He continues to work as a faculty member. Within the research areas; special education, intellectual disability, hearing impairment, inclusive education.

Assoc. Prof. Dr. Nilay Kayhan graduated from the University of Çukurova in 2003 and had the second highest average grade in her department. Kayhan graduated in June 2003 and enrolled in the postgraduate program in the Basic Education Department of Social

Sciences Institute of the University of Çukurova as the top-scoring student in September Individual differences, techniques for acquainting with students, teaching methods and techniques, communication skills, measurement and evaluation in education, qualitative research, multiple intelligence practices, and scientific research methods and graduated in 2008 after submitting her dissertation analyzing the relationship between the levels of acceptance of new primary education programs among form teachers and their professional satisfaction. Kayhan enrolled in the doctoral program of Special Education Department of the Education Sciences Institute of the University of Ankara in 2008. Kayhan was employed by the Education Faculty of the University of Aksaray as a research assistant in 2009 and worked for the Pre-School Education department until 2014 and served as a unit coordinator for the inclusive education of higher education students with different needs. She worked as a lecturer in the Special Education Department of the Education Faculty of the University of Eastern Mediterranean from 2014 through 2016 and received a doctoral degree with her study entitled "Effect on effective teaching skills of form teachers in inclusive settings of the lecturing observer model among unified teaching approaches" which she completed in consultation with Prof. Gönül Akçamete, Ph.D. in 2016. Kayhan's dissertation aimed at improving teachers' effective teaching and planning skills, and teaching implementation and evaluation skills in order to support their social and academic involvement while enhancing the quality of education provided by individuals with special needs and with different linguistic skills and cultures and spreading integration practices in our country and she is currently working as a lecturer for the Special Education Department of the Education Faculty of Ege University.

References

Abbeduto L, Warren SF, Conners FA, 2007. Language development in down syndrome: from the prelinguistic period to the acquisition of literacy. Mental Retardation and Developmental Disabilities Research Reviews. 13(3):247–61. doi:10.1002/mrdd.20158.

Acarlar F, 2006. Language development in children and adults with Down syndrome. Ankara University Faculty of Educational Sciences Journal of Special Education.7(01): 11.

Allen SM, Ciambrone D, Welch LC, 2000. Stage of life course and social support as a mediator of mood state among persons with disability. Journal of Aging and Health. 13:318-342. Available from http://dx.doi.org/10.1177/089826430001200303

Allhusen V, Belsky J, Booth-LaForce C, Bradley R, 2003. Social functioning in first grade: associations with earlier home and childcare predictors and with current classroom experiences. Child Dev. 74(6):1639–1662. DOI:10.1046/j.1467-8624.2003.00629.x

Akandere, M, Acar, M, & Bastug G, 2009. Investigating The Hopelessness And Life Satisfaction Levels of The Parents With Mental Disabled Child. Journal of Selcuk University Institute of Social Sciences. 22(1): 23-32. Retrieved from https://dergipark.org.tr/en/pub/susbed/issue/61799/924411

Akcamete G, Kargın T, 1996. Determining the needs of families with a hearing-impaired child. Journal of Special Education. 2(1): 7-24.

Akkök F. (1989). Reliability and validity study of the anxiety and anxiety level measurement tool of parents with a disabled child. Journal of Psychology. 23(7): 26-38.

Bailey, D. B., & Simeonsson, R. J. (1988). Assessing Needs of Families with Handicapped Infants. *The Journal of Special Education*, *22*(1), 117–127. https://doi.org/10.1177/002246698802200113

Besikçi H. (2000). Anxiety levels and family structure of autistic and nonautistic normal children's parents. (Unpublished Master Thesis). Istanbul University/Institute of Social Sciences, Istanbul.

Bosc M, 2000. Assessment of social functioning in depression. Comprehensive Psychiatry. 41(1):63–69. doi: 10.1016/S0010-440X(00)90133-0

Bradley RH, Corwyn RF, 2002. Socioeconomic status and child development. Annu Rev Psychol. 53(1):371–399. https://doi.org/10.1146/annurev.psych.53.100901.135233

Brassart E, Schelstraete, MA, 2015. Enhancing the communication abilities of preschoolers at risk for behavior problems: Effectiveness of a parent-implemented language intervention. Infants and Young Children. 28(4): 337- 354. doi: 10.1097/IYC.0000000000000049

Buckley S, Sacks B, 2012. An overview of the development of infants with Down Syndrome (0-5 years). E-book Edition: Down Syndrome Education International.

Cengelci B. A, 2009. Comparison of Level Of Anxiety, Hopelessness and Burnout Syndrome of Mothers Who Have Children With Diagnosis of Audism or Down Syndrome. Ege Education Journal. 2009; 10(2): 1–22.

Chapman RS, Hesketh, LJ, Kistler DJ, 2002. Predicting longitudinal change in language production and comprehension in individuals with Down syndrome: Hierarchical linear modeling. J Speech Lang Hear Res; 45: 902–15.

Cohen L, Manion L, Morrison K, 2000. Research methods in education. 5th Ed. London New York: Routledge Falmer.

Coskun Y, Akkas G, 2009. The Relation between Anxiety Level Of the Mothers Who Have Disabled Children and Social Support. Journal of Ahi Evran University Kirsehir Education Faculty. 10(1): 213-227.

Delaney EM, Kaiser AP, 2001. The effects of teaching parents blended communication and behavior support strategies. Behavioral Disorders. 26(2): 93- 116. doi: 10.1177/019874290102600201

DeVeney SL, Hagaman JL, Bjornsen AL, 2017. Parent-implemented versus clinician-directed interventions for late-talking toddlers: A systematic review of the literature. Communication Disorders Quarterly. 39(1): 293-302. https://doi.org/10.1177/1525740117705116

Dykens EM, Kasari C, 1997. Maladaptive behavior in children with Prader-Willi syndrome, Down syndrome, and nonspecific mental retardation. Am J Ment Retard. 102(3):228–237.

Eisenhower AS, Baker BL, Blacher J, 2005. Preschool children with intellectual disability: syndrome specificity, behavioural problems, and maternal well-being. J Intellect Disabil Res. 49(8):657–671. Doi: 10.1111/j.1365-2788.2005.00699.x

Ergin D, Nesrin Sen, Eryılmaz N, Eryılmaz NE, Pekuslu S, Kayacı M, 2007. Level of Depression of Parents with Handicapped Children and Determination of the Affecting Factors. Journal of Atatürk University School of Nursing. 10(1): 41-48.

Fey ME, Warren SF, Brady N, Finestack LH, Bredin-Oja SL, Fairchild M, Sokol S, Yoder PJ, 2006. Early effects of responsivity education/prelinguistic milieu teaching for children with developmental delays and their parents. Journal of Speech, Language and Hearing Research. 49(3): 526-547. DOI: 10.1044/1092-4388(2006/039)

Fidler DJ, 2005. The emerging Down syndrome behavioral phenotype in early childhood: Implications for practice. Infants & Young Children. 18(2): 86-103. https://doi.org/10.1097/00001163-200504000-00003

Hidecker MJ, Paneth N, Rosenbaum PL, Kent RD, Lillie J, Eulenberg JB, Chester K Jr, Johnson B, Michalsen L, Evatt M, Taylor K, 2011. Developing and validating the Communication Function Classification System for individuals with cerebral palsy. Dev Med Child Neurol. (53):704-10. doi: 10.1111/j.1469-8749.2011.03996.x.

Işıklı S, 1998. A prospective study of life stress, social support and assertiveness among Turkish university students. (Unpublished Master Thesis). Middle East Technical University, Institute of Social Sciences, Department of Psychology, Ankara.

John, A. E., Mervis, C. B, 2010. Comprehension of the communicative intent behind pointing and gazing gestures by young children with Williams syndrome or Down syndrome. Journal of Speech, Language, and Hearing Research, 53(4): 950-960. doi: 10.1044/1092-4388(2009/08-0234).

Jones J, Passey J, 2004. Family adaptation, coping and resources: Parents of children with developmental disabilities and behaviour problems. Journal on Developmental Disabilities. 11(1): 31- 46. Available from https://psycnet.apa.org/record/2005-02672-004

Kaner S, 2004. Perceived Stres, Social Support and Life Satisfaction in Parents with Disabled Children. Ankara University Rectorate Research Project, Project Number: 2001-0901-007.

Kırbaş Z.Ö, 2013. Assessment of the family function perception and social support levels of mothers of the children with Down syndrome (Unpublished Master Thesis). Ataturk University, Erzurum.

Kumin L, 2012. Early communication skills for children with Down Syndrome; A guide for parents and Professionals. 3rd. Edition, USA by Woodbine House, Inc.

Leech N, Barrett K, Morgan GA, 2007. SPSS for Intermediate Statistics: Use and Interpretation, Third Edition (3rd ed.). Routledge. Available from https://doi.org/10.4324/9781410616739

Lyons R, Brennan S, Carroll C, 2016. Exploring parental perspectives of participation in children with Down syndrome. Child Language Teaching Therapy. 32(1):79–93. doi: 10.1177/0265659015569549

MacDonald M, Leichtman J, Esposito P, Cook N, Ulrich DA, 2016. The participation patterns of youth with Down syndrome. Front Public Health. 11(4):253. doi: 10.3389/fpubh.2016.00253

McCarthy J, 2008. Behaviour problems and adults with Down syndrome: childhood risk factors. J Intellect Disabil Res. 52(10):877–882. doi: 10.1111/j.1365-2788.2008.01104.x.

Mert E, 1997. A Comparision of the needs of parents with different handicapped children. (Unpublished Master Thesis). Abant İzzet Baysal University, Institute of Social Sciences, Bolu.

Natan K, 2007. Mentally reatrded children's mothers anxiety and depression levels. (Unpublished master's thesis), Maltepe University/Social Sciences Institute, Istanbul.

Neely-Barnes SL, Dia DA, 2008. Families of children with disabilities: A review of literature and recommendations for interventions. Journal of Early and Intensive Behavior Intervention. 5(3): 93–107. Available from https://doi.org/10.1037/h0100425

Olsson MB, 2004. Parents of children with ıntellectual disabilities, goteborgs universitet, Unpublished Doctorate Thesis, Sweden (AAT C816832). Available from http://proquest.umi.com/pqdweb?did=764651691&sid=6&Fmt=2&clientId=42977&RQT=309&VName=PQD

Patterson GR, DeBaryshe B, Ramsey E, 1989. A developmental perspective on antisocial behavior. Am Psychol. 44(2): 329–335.

Pelchat D, Lefebvre H, Levert, MJ, 2007. Gender differences and similarities in the experiences of parenting a child with a health problem: Current state of knowledge, Journal of Child Health Care. 11(2): 112–131. doi: 10.1177/1367493507076064.

Petersen IT, Bates JE, D'Onofrio BM, et al, 2013. Language ability predicts the development of behavior problems in children. J Abnorm Psychol. 122:542–557. doi: 10.1037/a0031963.

Rosner BA, Hodapp RM, Fidler DJ, Sagun J, 2004. Social competence in persons with Prader-Willi, Williams and Down's syndrome. Journal of Applied Research in Intellectual Disabilities, (17):209–217. DOI:10.1111/j.1468-3148.2004.00200.x

Sarıkaya S, 2011. The investigation of coping strategies and life satisfaction levels of parents with mentally retarded children. Doctoral Dissertation, DEU Institute of Education Sciences.

Selikowitz M, 2010. Down Syndrome (3rd ed.), New York: Oxford University Press.

Sen E & Yurtsever S, 2007. Difficulties experienced by families with disabled children. Journal for Specialists in Pediatric Nursing; (12):238-252. Available from http://dx.doi.org/10.1111/j.1744-6155.2007.00119.x PMid:1795637

Sucuoğlu B, 1995. Determining the needs of parents with disabled children. Journal of Child and Youth Mental Health. 2(1): 10-18.

Ulkü-Kürkcüoğlu B, 2009. Development of communication skills. E. S. Batu (ed). Children aged 0-6 with Down syndrome and their development. Kök Publishing, Ankara.

van Gameren-Oosterom HB, Fekkes M, Buitendijk SE, et al, 2011. Development, problem behavior, and quality of life in a population based sample of eight-year-old children with Down syndrome. PLoS One. 6(7): e2187, doi: 10.1371/journal.pone.0021879

Vicari, S., Caselli, C.M., Tonucci, F. A, 2000. Synchrony of lexical and morphosyntactic development in children with Down syndrome. Neuropsychologia; 38: 634–644. doi: 10.1016/s0028-3932(99)00110-4.

World Health Organization [WHO], 2017. International Consortium in Psychiatric Epidemiology. Depression and other common mental disorders global health estimates. World Health Organization. Available from http://apps.who.int/iris/bitstream/handle/10665/254610/WHO-MSD-MER-2017.2-eng.pdf

Wuang Y, Su C-Y, 2012. Patterns of participation and enjoyment in adolescents with Down syndrome. Res Dev Disabil. 33(3):841–848. doi: 10.1016/j.ridd.2011.12.008

Creative Commons licensing terms
Authors will retain the copyright of their published articles agreeing that a Creative Commons Attribution 4.0 International License (CC BY 4.0) terms will be applied to their work. Under the terms of this license, no permission is required from the author(s) or publisher for members of the community to copy, distribute, transmit or adapt the article content, providing a proper, prominent and unambiguous attribution to the authors in a manner that makes clear that the materials are being reused under permission of a Creative Commons License. Views, opinions and conclusions expressed in this research article are views, opinions and conclusions of the author(s). Open Access Publishing Group and European Journal of Special Education Research shall not be responsible or answerable for any loss, damage or liability caused in relation to/arising out of conflict of interests, copyright violations and inappropriate or inaccurate use of any kind content related or integrated on the research work. All the published works are meeting the Open Access Publishing requirements and can be freely accessed, shared, modified, distributed and used in educational, commercial and non-commercial purposes under a Creative Commons Attribution 4.0 International License (CC BY 4.0).