

In Swimming Branch, Identification of Family Burden of Families of Mentally Disabled Athletes

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Abstract

The families of individuals with down-syndrome, autism, and mental problem who need for special requirements experience physical problems, tiredness, and antisocial life, which bring additional cost to family budget, from time to time due to difficulties of their children. The aim of this study is to identify family burdens charged by kids with special education needs, and in terms of which variables it becomes different.

While the study was designed by the part literature, obtained from scientific resources, personal information form, in which the demographic information of the families of kids with special needs take place, and the results of family burden assessment score, developed by Sarı and Basbakkal (2008) toward the aim of the study and consisted of 43 questions and 6 sub dimensions, were taken into consideration. In identifying family burdens, with moving from the assumption that mothers have dominant effect, the study was administered to the mothers

Majority of the families participating in the study are housewife. Total mean score obtained from family burden scale were 127 in the range of 45 to 215 points. In the study carried out, it was revealed that economic burden resulted from not employed housewives; and among the factors affecting perceived inabilities of mothers with disabled child, the concerns mothers experience toward the future of their children were very difficult case for the mothers.

However, families experience a concern in the form of "After my death, who will look after my child?". In the study carried out, it revealed that this case led the burdens of perceived inability to increase; and that the families tried to cope with this case, which causes concern for their kids with special needs.

In the world, the sincere of the mothers facing with this kind of difficulties in the face of these cases is a great chance for kids with special needs.

Keywords: family of disabled athlete, disabled athlete, family burden, disabled swimmer

1. Introduction

Burden is subjective perceptions or individual reactions a person/mother giving care to a disabled child experiences, while giving care to it. The feelings caregiver perceives are a concept encompassing her physical health, economic status, and social life (Chou, 2000).

The concept of family burden was first voiced in 1960s and defined as negative costs those having a mental disorder create for their families. In Western Australia (WA), governmental organ providing resource for disabled people is Committee of Disability Services. This committee has two separate financial flows supporting mentally disabled individuals for their living out of parental house: United Application Process and Community Life Plan (Naomi Catal. 2014) In Turkey, this service is carried out by Ministry of Family and Social Policies. Family burden can be also defined as all difficulties family experiences as a result of illness of a person (Sarı and Başbakkal, 2008).

Living with a mentally unable child in family and giving care to it form a burden sense on family members. Fishman and Wolf (1991) identified that the parents having child with Autism and Down Syndrome experienced stress in higher rate compared to the parents of normal children and, psychological states of especially mothers were negatively affected. (Fishman S, Wolf L. (1991).

They suggested that mothers were negatively affected from the looks turning to them and that they felt anger against these people. Another factor affecting emotional burden of families having mentally unable was stated to be concern

they experience toward the future of their children. Families experience anxiety in the form of “Who will look after my child after my death?” and this leads emotional burden of the families to increase (Sari et al. 2006).

The families that participated in the study by Alelson (1999) expressed that disabled children needed help in the areas of meal preparation, personal care, administering medication, bathing, protection from danger, clothing, dental care, toilet, and feeding, cloth replacing. The same families also expressed that because they viewed their families in danger, wanted to reserve time for the healthy sibling, needed holiday and shopping, they wanted aid for relieving care (Abelson. 1999).

In this study, the concept of family burden was researched and defined through the families giving care the kids with special education needs. The kids with special education needs are the individuals lifelong supported by their family from different aspects. Therefore, they have some positive and negative effects on the life of family giving care. In general, inabilities that cannot be corrected, that shows continuity, and that cannot be changed limit the functions of the family giving care, and, thus, causes uneasiness in the family. These children, due to lifelong experienced daily care needs and often experienced behavioral problems, increase difficulties of their parents (Kaner, 2004).

2. Material and Method

The study aiming to examine the burdens of disabled individuals to their family consists of the first part, developed by providing literature support, and the second part, where family burdens are determined. The individuals participating in the study were necessarily informed about the aim and method of the study and, with the people who consented, data collecting process were continued. While the family burdens of mentally disabled individuals were identified, the assumption that mothers are effective in identifying this burden was moved from and the study was designed on mothers.

“Family Burden Assessment Scale” toward identifying the burdens of disabled individuals developed by Sari and Basbakkal, consists of 43 questions. The scale has 6 sub dimensions expressed by the titles such as “Economic Burden”, “Perceived Inability”, “Social Burden”, “Physical Burden”, “Emotional Burden”, and “Time Requirement”. Cronbach alpha internal consistency coefficient of the scale was earlier found 0.92 and the coefficient identified for this study is 0.86.

From 5-point Likert type scale, among the scores obtained by adding points between 1 and 5 (1 = never, 2 = rarely, 3 = sometimes, 4 = mostly/often, and 5 = always), total points of minimum 43 and maximum 215 can be taken. Intersection point of Family Burden Assessment Scale was identified by those developing the scale as 97 points. The sensitivity of scale for 97 points is 84.1% and its specificity is 90.9%. According to this result, a classification can be made in the form of that the families, whose score of family burden assessment scale is 97 points and over, have burden, while the families having the score less than 97 do not have family burden Sari and Basbakkal, 2008)

In this study percentage and frequency tables on the other hand, in the comparisons’ more than two, the Anova test results have been taken consideration. An assessment was conducted about between which groups the discussion takes place, taking into consideration the results of Tukey Test. Considering the data obtained, as a results of general evaluations and deductions, with scientific based “Conclusion and Suggestions”, it was aimed that the study provides information for more detailed research.

3. Findings

Table 1. Table of Occupational and Educational Status

Occupation	n	%
Housewife	53	69.7
Wage Labor	6	7.9
Public Servant	13	17.1
Other Occupation	4	5.3
Educational Status		
	n	%
Primary School	31	40.8
Secondary School	26	34.2
Higher Education	19	25.0
Total	76	100.0

When the study is carried out on the mothers, all participants are women. When regarded to the occupation group of

mother, it was seen that 69.7% were housewife, 7.9%, wage labor; 17.1%, public servant; and 5.3%, from the other occupational groups. When educational statuses of mother are examined, 40.8% of them completed primary school; 34.2%, secondary school; and 25.8%, higher education.

Table 2. Descriptive Characteristics of Disabled Athletes

Gender	n	%
Female	28	36,8
Male	48	63,2
Age	n	%
Ages 0-10	2	2,6
Ages 11-20	44	57,9
Age 21 age and over	30	39,5
Disability State	n	%
Mentally Disables	39	51,3
Autistic	17	22,4
With Down Syndrome	20	26,3
Sate of Formation of Disability	n	%
In mother's womb	51	67,1
During delivery	10	13,2
After Accident –Disease	15	19,7
Years of Making Sports (Sports Age)	n	%
1-3 years	13	17,1
3-5 years	19	25,0
5-8 year	44	57,9
Total	76	100

In Table 2, when the descriptive characteristics of mentally disabled children are examined, 42.4% of them are female and 57.6% are male. When regarded to their pasts of sports, it is seen that 17.1% of them do swimming sports for 1-3 years; 25.1%, 3-5 years; and 57.9%, 5-8 years and over. When the disability case of special athletes are regarded, 51.3% is mentally disabled; 22.4%, autistic; and 26.3%, with down syndrome. When regarded to the ages of athletes; 2.6% are in the range of ages 6-10; 57.9% i ages 11-20; 39.5%, ages 21 and over. To the guardians of athletes participating in the survey when disability state is asked, it is seen that 67.1% of them became disable in mother's womb; 13.2%, during delivery; and 19.7% on the reason for accident-disease.

Table 3. General Mean of Family Burden

General Mean	Scale Mean	Maximum	Minimum	Standard Deviation
127.36	2.96	211	54	39.44

When regarded to general means of the families, the families of athletes have general mean of 127.36.

Table 4. Mean of Family Burden Sub factors

	General Mean	Scale Mean	Maximum	Minimum	Standard Deviation
Economic Burden	18.80	3.13	30	6	7.66119
Perceived Inability	31.21	3.90	40	9	8.60436
Social Burden	14.72	2.61	30	6	7.57293
Physical Burden	12.38	2.47	25	5	6.80386
Emotional Barden	26.64	2.47	55	11	11.74927
Time Requirement	23.60	3.37	35	7	6.88008

When the mean of family burden sub factors are regarded to, the highest mean score is seen to be on "Perceived Inability" and the lowest mean score, on "Physical Burden".

Comparison of the descriptive characteristics of the disabled children and their families with the mean score of family burden assessment scale.

Table 5. Comparison of occupation of families with the mean score of family burden assessment scale

Sub factor of occupation	Occupation	n	Mean	SD	f	p
Economic Burden	Housewife	53	3.3522	.16976	2.710	.051
	Wage labor	6	3.0000	.54603		
	Public Servant *	13	2.2692	.28529		
	Other Occupation	4	3.2500	.85662		
	Total	76	3.1338	.14647		
Perceived Inability	Housewife *	53	4.1108	.14684	2.886	.041
	Wage labor	6	3.7917	.25345		
	Public Servant	13	3.1923	.30277		
	Other Occupation	4	3.5938	.38654		
	Total	76	3.9013	.12337		
Social Burden	Housewife	53	3.0692	.25856	4.611	.005
	Wage labor	6	1.3333	.19720		
	Public Servant	13	1.7564	.26191		
	Other Occupation	4	1.2500	.25000		
	Total	76	2.6118	.20291		
Physical Burden	Housewife	53	2.7962	.19113	3.934	.012
	Wage labor	6	1.5000	.27689		
	Public Servant	13	1.9692	.32013		
	Other Occupation	4	1.3500	.17078		
	Total	76	2.4763	.15609		
Emotional Burden	Housewife	53	2.6604	.15470	3.213	.028
	Wage labor	6	1.8485	.34069		
	Public Servant	13	1.9371	.18681		
	Other Occupation	4	1.7045	.22074		
	Total	76	2.4222	.12252		
Time Requirement	Housewife	53	3.5876	.12668	3.319	.025
	Wage labor	6	2.8333	.33486		
	Public Servant	13	3.0000	.31821		
	Other Occupation	4	2.5357	.14725		
	Total	76	3.3722	.11274		

When occupation of families are compared with the physical burden, social burden, emotional burden, social burden, and time requirement, which are sub factors of family burden assessment scale, any significant difference could not be found ($p>0.05$). In the comparison of the mean scores of economic burden and perceived inability, a statistically significant difference was found ($p<0.05$). Advanced analysis was made to find between which groups there is a difference.

Making inter-group advanced analysis of economic burden, it was found that there was an inter-group difference between housewives and public servants ($p<0.051$) and that there was an inter-group difference of perceived inability between public servants and housewives ($p<0.041$).

Table 6. Comparison of educational status of families with the mean score of family burden assessment scale

Sub Factors	Education	n	Mean	SD	f	p
Economic Burden	Primary School	31	3.4731	.19509	2.364	.101
	Secondary School	26	3.0513	.30011		
	Higher Education	19	2.6930	.24723		
	Total	76	3.1338	.14647		
Perceived Inability	Primary School*	31	4.4032	.16907	8.098	.001
	Secondary School *	26	3.7596	.19001		
	Higher Education*	19	3.2763	.24754		
	Total	76	3.9013	.12337		
Social Burden	Primary School*	31	3.3333	.38482	7.508	.001
	Secondary School	26	2.5705	.26184		
	Higher Education*	19	1.4912	.19010		
	Total	76	2.6118	.20291		
Physical Burden	Primary School*	31	3.0581	.26088	5.806	.005
	Secondary School*	26	2.2231	.24641		
	Higher Education*	19	1.8737	.22332		
	Total	76	2.4763	.15609		
Emotional Burden	Primary School*	31	2.8387	.18586	6.009	.004
	Secondary School	26	2.3566	.22692		
	Higher Education*	19	1.8325	.15172		
	Total	76	2.4222	.12252		
Time Requirement	Primary School	31	3.5622	.16941	1.610	.207
	Secondary School	26	3.3791	.20046		
	Higher Education	19	3.0526	.22018		
	Total	76	3.3722	.11274		

When educational status of families are compared with the mean scores of physical burden and time requirement, which are sub factors of family burden assessment scale, any significant difference could not be found ($p > 0.05$).

In comparison of the mean scores of perceived inability, social burden, physical burden, and emotional burden, a statistically significant difference was found ($p < 0.05$). Advanced analysis was made to identify between which groups there was a difference. As a result of advanced analysis made, between educational groups of perceived inability, a difference was found between primary school-graduated family groups and secondary school and higher education-graduated ones ($p < .001$). In inter- groups of sub group of social burden, a difference was found between primary school and higher education ($p < 0.001$)

Table 7. Comparison of Gender Axis Family Burden Mean Scores

Sub Factor of the Scale	Gender	n	Mean	SD	f	p
Economic Burden	Female	28	3.3631	.27055	4.326	.041
	Male	48	3.0000	.16923		
Perceived Inability	Female	28	4.1518	.20223	.865	.365
	Male	48	3.7552	.15336		
Social Burden	Female	28	2.8274	.46144	2.560	.114
	Male	48	2.4861	.17822		
Physical Burden	Female	28	2.4786	.24653	1.664	.201
	Male	48	2.4750	.20296		
Emotional Burden	Female	28	2.5974	.22402	3.850	.054
	Male	48	2.3201	.14320		
Time Requirement	Female	28	3.4184	.20215	.410	.524
	Male	48	3.3452	.13557		

When the gender of special athletes is compared with mean scores of sub factors of family burden assessment scale, a significant difference could not be found ($p > 0.05$).

Table 8. Comparison of family burden mean scores according to the number of sports doing years

Sub Factors	Sports Year	n	Mean	SD	f	p
Economic Burden	1-3	13	3.1795	.28399	2.256	.112
	3-5	19	2.6140	.26523		
	5-8	44	3.3447	.20372		
	Total	76	3.1338	.14647		
Perceived Inability	1-3	13	4.0192	.24752	.586	.559
	3-5	19	3.6711	.26130		
	5-8	44	3.9659	.16655		
	Total	76	3.9013	.12337		
Social Load	1-3	13	3.1795	.88523	.975	.382
	3-5	19	2.2982	.26138		
	5-8	44	2.5795	.20941		
	Total	76	2.6118	.20291		
Physical Load	1-3	13	2.2462	.34206	.446	.642
	3-5	19	2.3474	.27481		
	5-8	44	2.6000	.22185		
	Total	76	2.4763	.15609		
Emotional Load	1-3	13	2.4266	.27512	1.124	.331
	3-5	19	2.1148	.15851		
	5-8	44	2.5537	.18191		
	Total	76	2.4222	.12252		
Time Requirement	1-3	13	3.7473	.21285	1.66	.194
	3-5	19	3.1053	.20316		
	5-8	44	3.3766	.15942		
	Total	76	3.3722	.11274		

When the time the special athletes do swimming sports is compared with the mean score of family burden assessment scale, any significant difference could not be found. ($p > 0.05$).

Table 9. According to disability states of athletes, comparison of the mean scores of family burden

Sub Factors	Disability Group	n	Mean	SD	f	p
Economic Burden	Mental	39	3.2179	.21078	.365	.695
	Autistic	17	2.9020	.28621		
	Down Syndrome	20	3.1667	.29444		
	Total	76	3.1338	.14647		
Perceived Inability	Mental	39	4.0417	.19576	1.054	.354
	Autistic	17	3.5882	.20943		
	Down Syndrome	20	3.8938	.20263		
	Total	76	3.9013	.12337		
Social Burden	Mental	39	2.8846	.34598	1.287	.282
	Autistic	17	2.5784	.28300		
	Down Syndrome	20	2.1083	.26909		
	Total	76	2.6118	.20291		
Physical Burden	Mental	39	2.4667	.21159	.109	.897
	Autistic	17	2.6000	.37652		
	Down Syndrome	20	2.3900	.29717		
	Total	76	2.4763	.15609		
Emotional Burden	Mental	39	2.5641	.18365	.779	.463
	Autistic	17	2.1979	.20584		
	Down Syndrome	20	2.3364	.24206		
	Total	76	2.4222	.12252		
Time Requirement	Mental	39	3.4139	.15795	.783	.461
	Autistic	17	3.5378	.17900		
	Down Syndrome	20	3.1500	.25774		
	Total	76	3.3722	.11274		

When special cases of athletes are compared with mean scores of sub factors of family burden assessment scale, any significant difference could not be found ($p > 0.05$).

Table 10. Comparison of family burden mean scores according to the ages of athletes

Sub Factors	Age	n	Mean	SD	f	p
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Economic Burden	Ages 0-10	2	3.7500	.41667	1.397	.254
	Ages 11-20	44	2.9318	.18688		
	Age 21 and over	30	3.3889	.24295		
	Total	76	3.1338	.14647		
Perceived Inability	Ages 0-10	2	4.1875	.06250	.689	.505
	Ages 11-20	44	3.7784	.16200		
	Age 21 and over	30	4.0625	.20198		
	Total	76	3.9013	.12337		
Social Burden	Ages 0-10	2	3.0000	.33333	.848	.433
	Ages 11-20	44	2.3864	.18092		
	Age 21 and over	30	2.9167	.43840		
	Total	76	2.6118	.20291		
Physical Burden	Ages 0-10	2	2.7000	.30000	.276	.760
	Ages 11-20	44	2.3773	.20462		
	Age 21 and over	30	2.6067	.25917		
	Total	76	2.4763	.15609		
Emotional Burden	Ages 0-10	2	2.7727	.22727	1.192	.309
	Ages 11-20	44	2.2624	.14672		
	Age 21 and over	30	2.6333	.21978		
	Total	76	2.4222	.12252		
Time Requirement	Ages 0-10	2	3.5714	.28571	.322	.726
	Ages 11-20	44	3.2955	.13140		
	Age 21 and over	30	3.4714	.21169		
	Total	76	3.3722	.11274		

When ages of special athletes are compared with mean scores of sub factors of family burden assessment scale, any significant difference could not be found ($p>0.05$).

Table 11. Comparison of family burden mean scores according to the disability times of athletes

Sub Factors	Disability Times	n	Mean	SD	f	p
Economic Burden	In mother's womb	51	3.0033	.16729	1.179	.313
	During delivery	10	3.1333	.40885		
	Result of Accident –Disease	15	3.5778	.39065		
	Total	76	3.1338	.14647		
Perceived Inability	In mother's womb	51	3.8039	.14890	.658	.521
	During delivery	10	4.0375	.31072		
	Result of Accident –Disease	15	4.1417	.30857		
	Total	76	3.9013	.12337		
Social Burden	In mother's womb	51	2.6144	.27330	.172	.843
	During delivery	10	2.3500	.32150		
	Result of Accident –Disease	15	2.7778	.40128		
	Total	76	2.6118	.20291		
Physical Burden	In mother's womb	51	2.4196	.18963	.135	.874
	During delivery	10	2.6200	.39379		
	Result of Accident –Disease	15	2.5733	.39466		
	Total	76	2.4763	.15609		
Emotional Burden	In mother's womb	51	2.3547	2.3547	1.368	.261
	During delivery	10	2.1818	2.1818		
	Result of Accident –Disease	15	2.8121	2.8121		
	Total	76	2.4222	2.4222		
Time Requirement	In mother's womb	51	3.2437	.13976	1.372	.260
	During delivery	10	3.5714	.18443		
	Result of Accident –Disease	15	3.6762	.28417		
	Total	76	3.3722	.11274		

How and when the disability states of athletes occurs are compared with mean scores of sub factors of family burden assessment scale, any significant difference could not be found ($p>0.05$).

4. Discussion and Conclusion

In the study, it was studied whether or not there was burden on the families of special children (mental autism, Down syndrome) doing swimming sports. With the results emerging in the light of data, being able to meet family burden of families having special children doing sports and guiding specialists about approaching these families were aimed.

In comparison of the mean FBAS (Family Burden Assessment Scale) with occupation of families, when the physical burden, social burden, emotional burden, and time requirement, among sub factors of family burden assessment scale, are compared, any significant difference could not be found. Making inter-group advanced analysis of economic burden and perceived inability, it can be thought that inter-group difference is present in housewives and public servants and that although there are less number of public servants, public servants can easily overcome the cases depending on economic burden, due to the fact they receive a salary from the government every month and in terms of their being sufficient to their children. Economic burden of housewives may result from not being employed of them and, among the factors affecting perceived inability of mothers with disabled child, there is a concern that mothers experience about the future of their children. Mothers experience a concern that “Who will look after my children after my death?” and it can be said that this case lead the burdens of perceived inability to rise. In the study of Sivri (2012), [it is seen] that the mothers having mentally unable children perceive family stress. That family In the study of identifying social aid and family burden, it is seen that burden turns out considerably high and has the highest mean emotional burden. Öztürk (2011), in the study he carried out, could not find any significant difference in comparison of occupation of families with the mean scores of family burden assessment score. There is a parallelism between our study and that of Öztürk (2011) in terms of physical burden, social burden, emotional burden, and time requirement.

In comparison of educational status of families with the mean scores of perceived inability, social burden, physical burden, and emotional burden, among sub factors of family burden assessment scale, it was found that there was a statistically significant difference. In the sub groups of perceived inability, physical burden, and emotional burden, it was found that there was a difference between the families graduated from primary school and the families graduated from the secondary school and higher education, while among the subgroups of social burden, there was difference between those graduated from primary school and higher education. In this case, it can be said that the perceived inability of the families graduated from primary is higher compared to the families graduated from the secondary school and higher education in terms of physical burden and emotional burden. When we deal with in terms of social burden, it can be said that social burden of the families graduated from higher education are less compared to primary school-graduated families. In the study, carried out by Öztürk (2002), in comparison of educational status of the families and the mean scores of family burden assessment scale, it revealed that there was not any statistically significant difference. Although it was not in the same direction with our study, in the study carried out by Bildirici (2014), a statistically significant difference between the total score of family burden assessment and mean scores of perceived inability subtest, economic burden subtest, social burden subtest, time requirement subtest, and emotional burden subtest. The indicator's and our study are on the same direction.

In comparison of the mean scores of family burden assessment scale in terms of gender of athletes, it was found that there was not any significant difference but economic burden was more in females compared to males; that perceived inability was lower in females than that of males; and, when regarded in terms of time requirement, that the times dedicated to females was higher compared to the males. When the mean scores are evaluated in terms of social burden, physical burden, and emotional burden, it was found that they were close to each other.

Any significant difference was not found between the disability state, the number of years they do swimming sports, when disability state occurs, and age of athletes and sub factors of family burden assessment scale.

According to these results, the mothers taking points over 97 have burden. In the study we have carried out, when regarded to the general mean score of family load, the mean score was found 127 and it revealed that the families of swimmers had family burden.

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