Analysis of Future Designs and Sense Self of Families with a Child with Autism

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ABSTRACT: Autism, which is considered as the child's inability to give normal responses to daily warnings, may lead to some problems in the families of children with these characteristics. The concept of self is the result of human interaction with the environment from the time when it emerged as the reason of human mind; is the perception of human being and the perception that occurs in itself. In our study, the future designs and the sense of self of families with a child with autism were examined based on these variables. The aim of this study is to examine how the families of a child with autism are affected by the sense of self and future designs. The sample of the study consisted of 150 autistic children parents and 150 healthy student parents who attend private kindergartens and day care centers. Personal Information Form, Rosenberg Self-Esteem Scale and Social Comparison Scale were used in the study. The data obtained by using the scales were analyzed with statistical methods according to the sub-objectives. The mean self-esteem of the families without a child with autism was found to be higher than the group with autism. The mean of social comparison of families with a child with autism was found to be higher than that of a child with autism. According to the study, families with a child with autism have a positive sense of self and self-esteem increases while positive sense of self increases. In addition to self-esteem and social comparison, there is a weak and directly proportional relationship as well as self-esteem in those with physical disabilities.

KEYWORDS: Autism, Sense of Self, Future Planning of Families

1.   INTRODUCTION

With parents having a child, which is perceived as a way of life, and with addition of a child to a family, an important transition stage that obliges the family members to adapt to the newly joined individual is seen. Along with the life changes that may emerge in many areas such as addition of a new member into the family and hence, sparing time for social activities, it also obliges the re-arrangement of parental duties and arising of new habits. If, during adaption to these habits, the parents learn that they do not have a child with normal development, the joy they have felt for the birth of their child may be replaced with sadness to an abnormal level with the feeling of shock (Köksal and Kabasakal, 2012). Learning, at this stage, that the child is with autism, parents realising that their healthy child has problem with establishing communication (Lee et al., 2008) and seeing that the withdrawn child is insufficient in the social development stage (Boyd, 2002), and in addition, witnessing that the child with autism is displaying inappropriate behaviours (Brobst, 2009) could cause serious stress, sadness and depression for the parents of the child with autism. Elements such as the ambiguity caused by the autism, awareness of autism, frequency of it within the society, and severity and duration of autism are considered to make it difficult for the parents to adjust and adapt and accept the diagnosis (Weinstein et al., 2010).

Despite this condition of the child, it is observed that such families experiencing this condition go through adaption stages that include emotional and cognitive processes and overcome the shock, and adjust living with a child with autism (Brown et al., 2012). From the moment when families learn that they have a child with autism, they try to change and shape their life accordingly. Families with a child with autism develop an understanding of a new life (Amran et al., 2018).

One of the most important factors that facilitate the families to accept and adjust to the situation successfully is the social support element. Social support is the most important element that helps meeting the needs of the child diagnosed with autism and the parents to minimise their problems, facilitates overcoming these problems (Kazak&Marvin, 1984), and helps minimising the stress level of the parents (Neely-Barnes et al., 2014). Provision of the necessary social support where the families fall short physically and psychologically in the care of their child with autism is important for the parents to handle the stress (Pepperell et al., 2018). From the point of view of Cobb (1976), social support is the knowledge ensuring that the individual believes to be cared, important, loved and part of a mutual communication. Social support (Kazak&Marvin, 1984) has features as offering services that are required by the individual, offering strategies to the members to cope with the problems by guiding them and protecting the members from

the effect of stress by establishing communication among individuals when needed (Dunst, 1986). Through these features, parents of a child with autism could facilitate their adaptation to the conditions they are in with the social support the receive from their close circle along with the support services they receive from specialists or institutions (Ünlüer, 2009) (Nealy, 2012). Hence the social supports lead the individuals to be more optimistic (Baltaş, 2000), to make realistic assessment (Brewing et al., 2008) and tackle the challenges by minimising the anxiety level of the individuals. At the same time, it has been expressed that the social support mitigates the feeling of desperation of the parents with new solutions (Meral, 2011). With the social support provided to the families of a child with autism, the quality of the families' life is also affected positively. Provision of psychological support to families by their close circle is also of significance in mitigating the stress perception and increasing life quality of the families (Marsack&Samuel, 2017). Communication and interaction of families of a child with autism with each other is seen as an important social support perception. With the technological development in particular, communication and interaction to be established on line among families of a child with autism is seen to be significant for the families in lifting their psychological wellbeing and responding the challenges they face more easily (Porayska-Pomsta, 2018).

Within the information expressed on the definitions, functions and benefits of social support, it is understood that the concept of social support is a very comprehensive structure (Boyd, 2002), and in particular, the areas of support types such as information, evaluation, material, material factors, emotional and social association, belonging and daily care are used in the field literature and their benefits are listed (Kazak & Marvin, 1984).

1.1. Research Problems
Is there a meaningful correlation between future plans and sense of self of families of a child with autism?

1.2. Research Sub-Problems
1. Is there a meaningful correlation between self-esteem subscales and social comparison scores according to the status of families with and without a child with autism?
2. Is there a meaningful correlation between the self-esteem subscales and social comparison scores and the number of children according to the status of families with and without a child with autism?
3. Is there a meaningful correlation between the self-esteem subscales and social comparison scores and educational status of the families according to the status of families with and without a child with autism?
4. Is there a meaningful correlation between the self-esteem subscales and social comparison scale scores according to the status of families with a child in special education?

Is there a meaningful correlation between the self-esteem subscales and social comparison scale scores according to the social security status of families with a child with autism?

1.3. Assumptions
The sample group of the research is assumed to represent the universe.
It is assumed that the employees participating in the research answered the questions in the Personal Information Form, Rosenberg Self-Esteem Scale and Social Comparison Scale to reflect their real situation.

2. METHOD
2.1. Research Model
The research is designed in a descriptive research model. The researches designed in the survey model are used to reveal the current situation as it is. Descriptive research is done to depict, describe and clarify "what" a situation, condition, relationship, activity and communication processes are (Karaasar, 1994).

Quantitative research method was used in this research model. Quantitative research results were preferred due to their generalizable features (Erdoğan, 2007).

2.2. Research Sample
The research sample consists of 150 autistic child parents who were randomly selected from those who regularly attended special education and rehabilitation centres, and 150 healthy student parents from those who attended private nursery and day care centres.

2.3. Data Collection Tools Used in Research

2.4. Personal Information Form
In the form in which personal information was researched, 14 questions were asked to the individuals regarding their ages, educational status, marital status, monthly income etc.

2.5. Rosenberg Self-Esteem Scale
The scale developed by Rosenberg (1965) to measure people's self-esteem is in English. The scale adapted to Turkish by Çuhadaroğlu (1986) has 63 items and 12 subscales. Sub-scales are: Self-esteem, Continuity of sense of self, Trust in people,

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Sensitivity to criticism, Depressive affect, Daydreaming, Psychosomatic symptoms, Feeling threatened in interpersonal relations, Degree of participation in discussions, Parent relationship, Relationship with father, Psychic isolation.

There is no specific time limit in the application of the scale, it is a type of scale developed for adolescents, which can be applied as a group and based on the self-expression of adolescents for all the given items. According to the answer key, items belonging to other subtests other than the "self-esteem" subtest are evaluated and the correct answer gets the "1" score. The 10-item questions are scored in the self-esteem subtest according to the "very correct" grade and the "very wrong" grade.

2.6.   Social Comparison Scale

The Turkish version of SCS was prepared by Şahin, Durak and Şahin (1993). SCS measures how the individual perceives himself in various dimensions when he compares himself to others. SCS, which can be applied to adolescents and adults as a group, is a self-assessment scale without time limitation. The scale consists of 18 items and has a six-point Likert type. Each item of the scale is between 1-6 points, and scores between 18 and 108 are obtained from the scale. High scores obtained from the scale show positive self-perception and low scores indicate negative self-perception (Savaşır & Şahin, 1997).

The reliability studies of the scale were performed on 501 subjects and Cronbach's Alpha was determined as 0.89. When the criterion-related validity of the scale was analysed, its correlation with Beck Depression Inventory was found to be -.19, (p <.000). It was observed that the correlations with the subscales of the Brief Symptom Inventory ranged from 0.14 to -0.34. Considering the structure validity of the SCS, it was seen that the groups with scores below 9 and above 17 from the Beck Depression Inventory could be distinguished according to the SCS (p <.001).

2.7.   Data Analysis Techniques

The data obtained by using the data collection scales were transferred to the computer in a numerical way and the analysis of these data was carried out using the statistics program 18 for social sciences.

3.   FINDINGS

In this section, the findings obtained through the general information form prepared by the researcher via the scales of Self-Esteem and Social Comparison Levels of the Group Consisting of Families with and without an Autistic Child. The distribution of the group constituting the sample according to the demographic differences from the people with and without diagnosis of autism is given in Table 1.

Table 1. Distribution of Various Variables from Families with and without an Autistic Child Participating in the Study (n = 300)

	With Autistic Child		Without Autistic Child	
Age	**N**	**(Percentage)**	**N**	**(Percentage)**
21 and younger	3	1	5	1.7
Between 21–39	79	26.3	87	29
39 and older	67	22.7	58	19.3
Educational Status	**N**	**(Percentage)**	**N**	**(Percentage)**
Illeterate	3	1	2	.7
Primary Education	31	10.3	17	5.7
Secondary Education	53	17.7	37	12.3
Higher Education	63	21	94	31.3
Marital Status	**N**	**(Percentage)**	**N**	**(Percentage)**
Married and together	127	42.3	132	44
Married and separated	13	4.3	7	2.3
Divorced	10	3.3	11	3.7
Number of Children	**N**	**(Percentage)**	**N**	**(Percentage)**
1 Child	53	17.7	60	20
2 Children	62	20.7	61	20.3
3 Children	31	10.3	29	9.7
4 children and more	4	1.3	0	0
Income	**N**	**(Percentage)**	**N**	**(Percentage)**
0–1000 TL	21	7	4	1.3
1000–2000 TL	37	12.3	30	10
2000 TL and above	92	30.7	116	38.7

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In the study, of the group of 300 who answered the personal information form and survey questions, it was known that of the families with a child with autism, 3 (1%) were 21 and younger; 79 (26.3%) were between 21-39, 67 (20%) were 39 and older; of the families without a child with autism, 5 (1.7%) were 21 and younger, 87 (29%) were between 21-39, 58 (19.3%) were 39 and older. Of the families with a child with autism, 3 (1%) were illiterate, 31 (10.3%) were Primary Education graduates, 53 (17.7%) were Secondary Education graduates, 63 (21%) were Higher Education graduates; of the families without a child with autism, 2 (7%) were illiterate, 17 (5.7%) were Primary Education graduates, 37 (12.3%) were Secondary Education graduates, 94 (31.3%) were Higher Education graduates.

Of the families with a child with autism, 127 (42.3%) were married and together, 13 (4.3%) were married and separated, 10 (3.3%) were divorced; of the families without a child with autism, 132 (44%) were married and together, 7 (2.3%) were married and separated, 11 (3.7%) were divorced.

Of the families with a child with autism, 53 (17.7%) had 1 child, 62 (20.7%) had 2 children, 31 (10.3%) had 3 children, 4 (1.3%) had 4 or more children; of the families without a child with autism, 60 (20%) had 1 child, 61 (20.3%) had 2 children, 29 (9.7%) had 3 children.

Of the families with a child with autism, 21 (7%) had an income of 0 - 1000 TL, 37 (12.3%) had an income of 1000 - 2000 TL, 92 (30.7%) had an income of 2000 TL and above; of the families without a child with autism, 4 (% 1.3) had an income of 0–1000 TL, 30 (10%) had an income of 1000- 2000 TL, 116 (38.7%) had an income of 2000 TL and above.

Table 2. Descriptive Statistics of Self-Esteem and Social Comparison Scale Scores with and without Autistic Child

Scales	Avarage	Standard Deviation	Minimum	Maximum
Self Esteem	25.47	2.47	15	32
Social Comparison	71.02	25.32	18	108

It is observed that the Self-Esteem scale mean score is ($\bar{x} = 25.47$), Social Comparison Scale mean is ($\bar{x} = 71.02$), Self-Esteem Scale maximum score is (32), Social Comparison Scale maximum scale is (108), Self-Esteem Scale minimum scale is (15), Social Comparison scale minimum score is (18), Self-Esteem Scale standard deviation is (2.47), and Social Comparison Scale standard deviation is (25.32). Since the standard deviation of the Social Comparison Scale is greater than the self-esteem scale, the Social Comparison reliability is higher than the Self-Esteem.

Table 3. "Mann Whitney U" Test Results in terms of Self-Esteem Sub-scales and Social Comparison Score by Status of Families with and without a Child with Autism

Scale	Disabled Child	N	Mean Rank	Total Rank	U	Z	p
Self-Esteem	With	150	131,90	19785,5	8460,50	-3.894	.000*
	Without	150	169,10	25364,5			
Scale	**Disabled Child**	**N**	**Mean Rank**	**Total Rank**	**U**	**Z**	**p**
Permanency of the Sense of Self	With	150	155,06	23259,5	10565,5	- .998	.318
	Without	150	145,94	21890,5			
Scale	**Disabled Child**	**N**	**Mean Rank**	**Total Rank**	**U**	**Z**	**p**
Trust in People	With	150	190,37	28556,0	5269,0	-8.435	.000*
	Without	150	111,07	16594,0			
Scale	**Disabled Child**	**N**	**Mean Rank**	**Total Rank**	**U**	**Z**	**p**
Sensitivity to Criticism	With	150	111,07	16660,5	5335,5	-8,354	.000*
	Without	150	189,93	28489,5			
Scale	**Disabled Child**	**N**	**Mean Rank**	**Total Rank**	**U**	**Z**	**p**
Depressive Affect	With	150	121,31	18196,5	6871,5	-6.076	.000*
	Without	150	179,69	26953,5			
Scale	**Disabled Child**	**N**	**Mean Rank**	**Total Rank**	**U**	**Z**	**p**
Daydreaming	With	150	188,25	28237,5	5587,50	-7.694	.000*
	Without	150	112,75	16912,5			
Scale	**Disabled Child**	**N**	**Mean Rank**	**Total Rank**	**U**	**Z**	**p**
Social Comparison	With	150	94,80	14220,0	2895,00	-11,124	,000*
	Without	150	206,20	30930,0			

*p<.05

A significant difference was observed between the Mann Whitney-U test performed to see if there was a significant difference between the families with and without a child with autism and the Self-Esteem sub-scale (U = 8460.50, p <.05). It was observed that the self-esteem mean of the families without a child with autism is higher than the group with a child with autism.

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It was observed that there was no significant difference between the Mann Whitney-U test performed to see if there was a significant difference between the families with and without a child with autism and the Permanency of the Sense of Self sub-scale (U = 10565.5, p> .05).

There observed a significant difference between the Mann Whitney-U test performed to see if there was a significant difference between the families with and without a child with autism and Trust in People sub-scale (U = 5269.0, p <.05). The Trust in People mean of the families with a child with autism is higher than the group without a child with autism.

A significant difference was observed between the Mann Whitney-U test performed to see if there was a significant difference between the families with and without a child with autism and the Sensitivity to Criticism sub-scale (U = 5335.5, p <.05). It was observed that the families who do not have a child with autism have a higher mean of Sensitivity to Criticism compared to the group who have a child with autism.

A significant difference was observed between the Mann Whitney-U test performed to see if there was a significant difference between the families with and without a child with autism and the Depressive Affect sub-scale (U = 6871.5, p <.05). It was observed that the Depressive Affect mean of the families without a child with autism is higher than the group with a child with autism. Between the Mann Whitney-U test performed to see if there was a significant difference between the families with and without a child with autism and the Daydreaming sub-scale, a significant difference was observed (U = 5587.50, p <.05). It was observed that the Daydreaming mean of families with a child with autism is higher than the group without a child with autism.

A significant difference was observed between the Mann Whitney-U test performed to see if there was a significant difference between the families with and without a child with autism and the Social Comparison scale (U = 2895.00, p <.05). It was observed that the Social Comparison mean of the families without a child with autism is higher than the group with a child with autism. Families without a child with autism have a positive sense of self.

Table 4. "Kruskal Wallis H" Test Results in terms of Self-Esteem Sub-dimensions and Social Comparison Scale Scores according to Disabled Status of Families with a Child with Autism

Scale	Disabled	N	Mean Rank	sd	X²	p
Self-Esteem	Mental	136	71,98	2	10,528	.005*
	Physical	8	108,38			
	Mental-Physical	6	71,98			
Scale	Disabled	N	Mean Rank	sd	X²	p
Permanency of the Sense of Self	Mental	136	73,82	2	2,674	,263
	Physical	8	87,75			
	Mental-Physical	6	97,17			
Scale	Disabled	N	Mean Rank	sd	X²	p
Trust in People	Mental	136	77,95	2	7,745	,021*
	Physical	8	37,00			
	Mental-Physical	6	71,33			
Scale	Disabled	N	Mean Rank	sd	X²	p
Sensitivity to Criticism	Mental	136	73,81	2	2,584	,275
	Physical	8	94,56			
	Mental-Physical	6	88,33			
Scale	Disabled	N	Mean Rank	sd	X²	p
Depressive Affect	Mental	136	72,26	2	9,711	,008*
	Physical	8	111,94			
	Mental-Physical	6	100,42			
Scale	Disabled	N	Mean Rank	sd	X²	p
Daydreaming	Mental	136	78,14	2	7,471	,024*
	Physical	8	36,88			
	Mental-Physical	6	67,17			
Scale	Disabled	N	Mean Rank	sd	X²	p
Social Comparison	Mental	136	76,49	2	3,785	,151
	Physical	8	83,44			
	Mental-Physical	6	42,58			

*p<.05

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As Type of the families with a Child with Autism, a significant difference was found according to the Self-Esteem subscale ($X^2 = 10.528$, p <.05). Self-esteem is high in people with physical disabilities.

As a result of the Kruskal Wallis H test performed to examine the presence of a significant difference in terms of the Disability Type of Families with a Child with Autism, there was no significant difference found according to the Permanency of the Sense of Self sub-scale ($X^2 = 2.674$, p> .05).

As a result of the Kruskal Wallis H test conducted to examine the presence of a significant difference in the Disability Type of Families with a Child with Autism, a significant difference was found according to the Trust in People sub-scale ($X^2 = 7.745$, p <.05). The trust in people of the ones with mental disability is high.

As a result of the Kruskal Wallis H test conducted to examine the presence of a significant difference in terms of the Disability Type of Families with a Child with Autism, no significant difference was found according to the Sensitivity to Criticism sub-scale ($X^2 = 2.584$, p> .05).

As a result of the Kruskal Wallis H test conducted to examine the status of finding a significant difference according to the Social Security Status of Families with a Child with Autism, a significant difference was found according to the Depressive Affect sub-scale ($X^2 = 9.711$, p <.05). Depressive Affect is more in those with physical disabilities.

As a result of the Kruskal Wallis H test conducted to examine the presence of a significant difference in the Disability Type of Families with a Child with Autism, a significant difference was found according to the Daydreaming sub-scale ($X^2 = 7.471$, p <.05). Daydreaming is high in people with mental disability.

As a result of the Kruskal Wallis H test conducted to examine the status of a significant difference in the Disability Type of Families with a Child with Autism, no significant difference was found according to the Social Comparison scale ($X^2 = 3.785$, p> .05).

4. DISCUSSION AND CONCLUSION

Every new member joining the family brings a new process for the individuals of the family. Especially in the period after the birth of the child, the families' learning that their child is with autism and have communication problems, bring important difficulties for them (Dunn et al., 2001; Van der Oord et al, 2012). Following the diagnosis of autism, the uncertainty of future in the family members may make it difficult for parents to adapt and accept the diagnosis (Özkubat et al., 2014; Meral & Cavkaytar, 2014). Having a child with autism causes families to experience fatigue both psychologically and financially and has a direct impact on their future plans. In addition to the high financial expenses for the education of children, concerns about their children in the future may increase the perception of stress in families (Lu et al., 2018). For this reason, it is important to determine the future expectations of families with a child autism and continue studies in this direction.

Families with a child with autism have high needs and social expectations. Having an uncertainty about the needs of the child after the diagnosis of autism increases the needs and expectations of the families (Wing, 2013). In this study, a significant difference was found between families with and without a child with autism according to the trust in people sub-scale. According to this, families with a child with autism have higher trust in people than the group without a child with autism. Families with a child with autism may have received more help from their environment and witnessed that people are trying to empathize with them more and act more tolerantly. When they really need help while taking care of their child with autism, they may have received unexpected help and care from their surroundings. This may have enabled them to have more trust in people. The events that families without a child with autism encounter in their lives may have pushed them to be more cautious towards people. Today, every day and every moment, people are warned against smugglers, fraudsters, thieves via social media accounts and written and verbal media, official messages are sent from the authorities to their mobile phones and people are asked to be cautious and be more careful towards people they do not know. In this case, families who do not need to receive support from the people around them in their lives other than the small-scale needs required by their daily lives, and who do not have a patient relative who need care in their homes may tend to be more sceptical about people who want to help them. However, families with a child with autism need constant help and support, and because this is met, they may have a more trusting attitude towards people. Halstead et al. (2018) have found in their researches that mothers with a child with autism need potential protective factors and in this concept, they have high social expectations.

A significant difference was found between families with and without a child with autism according to the sensitivity to criticism sub-scale. In other words, the sensitivity to criticism mean of families without a child with autism is higher than the group with a child with autism. This finding was interpreted as the society has imposed the individuals the task of giving birth to children, especially healthy ones, and that parents feel guilty due to the sense duty. The most important factor in the effectiveness of social support is the family's motivation to treatment.

A significant difference was found between the families with and without a child with autism according to the depressive affect sub-scale. According to this, the families with a child with autism have lower depressive affect mean than the group without a child with autism. The reason for this situation could be that families who have a child with autism are more resistant to a negative situation because they experience more stress, distress and problems than families without a child with autism. This may have increased their psychological resilience, as families are constantly dealing with many spiritual and material problems due to their children.

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Depressive feelings in families with a child with autism come to the forefront, according to Allen et al. (2017), especially with the onset of school life of children with autism under the effect of school failure and similar feelings. Again, Maurice et al. (1996) stated in their studies that uncertainties about future expectations in families with a child with autism trigger depressive emotions. In literature, different studies have found that families with a child with autism have higher stress and depression perceptions (Ingersoll & Hambrick, 2011; Al-Farsi, 2016; Benson, 2018; Shepherd et al., 2018). Ward et al. (2018) stated in their studies that the interaction between families with a child with autism through social media, especially with technological developments, positively improves the future expectations of families.

A significant difference was found between families with and without a child with autism according to the daydreaming sub-scale. Accordingly, the daydreaming mean of families with a child with autism is higher than the group without a child with autism. The belief and even dreams that their children will someday get better due to the rapidly advancing medicine make it easier for them to accept the fact that their children are autistic. Families with normal children experience their children's graduation, starting their working life and spontaneous situations in the flow of similar life. However, families with a child with autism may be more likely to imagine such situations, since they don't experience such events as often as the families with normal children may and perhaps never at all. This can be perceived as a mechanism that increases their resistance. Agazzi et al. (2017) stated their researches that mothers who have a child with autism make a lot of effort to make the child have a better future and this situation positively affects the future expectations of the families.

A significant difference was found between families with and without a child with autism according to the social comparison scale. Accordingly, the social comparison mean of families without a child with autism is higher than the group with a child with autism, and also families without a child with autism have a positive sense of self. The reason for this situation may be the case that the greatest focus of the families with a child with autism is the child with autism. It can be assumed that the biggest thoughts of the families are their children and their health, so they do not think about social life or perceiving themselves positively. The study by Miller (2016) supports this finding. In a study conducted by Gray (2016), it was stated that in families with a child with autism, the child with autism is taken into focus while making family plans. Cachia et al. (2016) stated in their researches that families with a child with autism consider their child's developmental characteristics in future planning and educational programming.

4.1. Limitations

This research.
- is limited to the data obtained from 150 autistic children's parents randomly selected from among those who live in Ankara Province and regularly attend Ankara Autism Foundation, S. Special Education and Rehabilitation Centre, Y.H. Special Education and Rehabilitation Centre, F. Special Education and Rehabilitation Centre, and 150 healthy students attending Private S. Nursery and Day Care Centre.
- The data obtained are limited to the Rosenberg Self-Esteem Scale and the Social Comparison Scale.
- a result of the Kruskal Wallis H test performed to analyse the presence of a significant difference according to the Disability

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