

The Quality of Life of Mothers that have Children with Autism, Down Syndrome and Typical Development in Albania

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Abstract

Autism spectrum disorder and Down syndrome are both disorders that last a lifetime and families who have children with these disorders have a unique life situation. These disorders require a mobilization by the parents, not only financial, but also physical, psychological and social. The aim of this study is to compare the quality of life of mothers who have children with autism spectrum disorder with mothers who have children with Down syndrome and mothers who have children with typical development. In this study are part mothers of children with autism (n = 30), mothers of children with Down syndrome (n = 30) and mothers who have children with typical development (n = 30). At the end of the study it was observed that in Albania there is an inherent difference in quality of life between mothers who have children with autism and those who have children with Down syndrome but there are considerable differences between them and the mothers who have children with typically development.

Keywords: mother, Down syndrome, autism, quality of life.

1. Introduction

Quality of life is a broad concept that encompasses all aspects of a man's existence. It can be defined as the position of the individual's perceptions of life, cultural context and system of values in which they live, and in relation to their goals, expectations, standards and concerns (Torrance, 1987). Families that have children with autism have a particular life situation. This disorder requires a mobilization by the parents, not only financial, but also physical, psychological and social quality of life (Vieira & Fernandes, 2012). The impact that caring a child with autism has on health and quality of life of primary care giver is not studied much, but the fact is that these people are associated with negative gains as anxiety, stress, and depression. These problems appear to be due, mostly, from cognitive problems that the child has, and other elements related to autism issue (Randall and Parker 1998).

Parents of children with autism report higher levels of stress associated with their child's problems than parents who have children with typical development. Parents of children diagnosed with autism report high stress level compared not only with parents who have children with typical development, but also parents who have children with Down syndrome. The level of stress depends on several parent characteristics, such as socio-economic level or marital status. There are studies that show that single mothers who have children with developmental difficulties have higher levels of depression, other studies see depression as related more to the level of education and income than marital status (Olsson & Heang, 2008). In a study conducted by (Dumas, Wolf, Fisherman, Culligan, 2009), which was intended to measure the differences in stress associated with parenting, addictive behavior and unhealthy eating to 150 families who have children with autism (n = 30), behavior disorder (n = 30), Down syndrome (n = 30), and typical development (n = 60), the conclusion of the study was that parents of children with autism and children with behavior disorder report higher levels of parenting stress than the other two groups. Mothers of children with autism report more problems with food than other groups. Even like (Higging, 2016), having a child with autism, causes considerable stress in the family. In his study were included 53 families who had children diagnosed with autism, and it was observed that parents of children with autism have a healthy self-esteem, lower marriage satisfaction and the lowest complies families.

But, if we make a comparison between mothers and fathers would say that in terms of daily care for children with mental disabilities, mothers are more involved than fathers. The only activity they are involved is the same game or other activities related to it. Even when they retire, and are not employed, fathers are not included alike as mothers in the daily care of their children (Ndrio, 2012). Another difference between mothers and fathers who have children with autism is related to the fact that mothers feel they have to make many sacrifices and have to give up their careers and material pleasures. Fathers feel they make more sacrifices outside the house to ensure the best materials to meet the needs of the child (Randall and Parker, 1998).

2. Methodology

2.1 Sample

Participated in the study are (n = 90) mothers. Mothers of children with autism (n = 30), mothers of children with Down syndrome (n = 30) and mothers who have children with typical development (n = 30). These are the biological mothers of the children.

2.2 Procedures

Institutions visited in which the study was conducted for mothers of children with disabilities are 'Down Syndrome Albania' and the 'National Center of Upbringing, Development and Rehabilitation of Children' in Tirana. In 'Down Syndrome Albania' were taken into study mothers of children with the syndrome Down while the 'National Center of Upbringing, Development and Rehabilitation of Children, was taken into studying mothers of children with autism. To achieve the study for mothers who have children with typical development are choose a pre-kindergarten, a kindergarten and a school in the city of Durres. The first meetings were held with the directors of these institutions. Once the study was explained in detail and signed permission from the questionnaires that were going to be applied, the work proceeded. They were promised a copy of the study if they would be interested. To mothers the questionnaires were explained in detail, the purpose of the study, and the fact that they will not be identified.

2.3 Instrument

The instrument used in this study to measure the quality of life is WOQOL-BREF (De Vries, Van Heck, 1997) The questionnaire is designed to measure quality of life in the last two weeks and is divided into five areas: 1. Quality of life and health in general, contains 2 questions. 2. Physical health contains 7 questions. 3. Psychological health contains 6 questions. 4. The scope of social relationship contains 3 questions. 5. The area that has the function to measure environmental quality in general, which contains 8 questions. Total measure has 26 questions. Rating scale is 1-5. 1- Means not so much, 2-means little, 3 average, 4-much, 5- in extreme amounts.

3. Results of the study

The table below provides some descriptive statistics tool, including average, standard deviation and 95% confidence interval for the dependent variable (quality of life for women) for any particular group (children autistic, syndrome Down and typically development) and all groups combined (Total). These results from the table are important to interpret the results of data being analyzed.

In the descriptive table in the end of the article, it is described that on average the quality of life for mothers is 3.6, where the number 5 means a maximum quality of life and the value of 1 means a minimum quality of life. Mothers who claim to have a lower quality of life, 3.5 are those with children suffering from Down's syndrome. Mothers who have autistic children express a quality of life at 3:55, slightly higher than those with the syndrome down. Mothers with Down syndrome have a standard deviation or volatility of their sense and in extreme cases a little better quality of life at 2.7 (3.5-0.76). By the interval of confidence with a level of security 95% of mothers who have autistic children report a quality of life between 3:27 and 3.82 (the difference 12:55), while those who have children with the syndrome Down fluctuate between 3.21 and 3.78 (the difference 12:57) showing a worse living quality and disparities in their feelings more pronounced.

Mothers of children with autism report that their physical health is converted with 3.3. That means that it is good enough but they have problems also. Mothers that have children with Down syndrome have a physical health 3.17 and mothers of children with typical health have a physical health mean 3.9. We can say that the difference between the groups it's not so large but mothers of children with Down syndrome have the lowest quality of physical health and the mother of children with typical development have the highest quality of physical health.

Mothers of children with autism are in the middle but nearest to mothers of children with Down syndrome. Psychological health of mothers of children with autism mean is 2.96, means that they have problems, mothers of children with Down syndrome psychological health mean is 2.99. Mothers of children with typical development have psychological health mean 3.87. In this case the mothers of children with autism have the lowest quality of psychological health and mothers of children with typical development have the highest quality of psychological health. But, the difference between mothers of children with autism and mothers of children with Down syndrome is really insignificant.

The quality of social relation is lower in mothers of children with Down syndrome, 2.8 and higher in mothers of children with typical development 3.7. Mothers of children with autism quality of social relation mean are 3.15. The quality of environment for mother of children with Down syndrome the mean is 2.7, for mothers of children with autism is 2.9 and for mothers of children with typical development is 3.3.

4. Conclusion

In conclusion, this study found that there is no clear great difference between the level of quality of life of mothers who have children with autism and those who have children with the Down syndrome. This means that the level of quality of life in the five fields of mothers of children with Down syndrome is almost similar with mothers of children with autism. That is a narrow margin between the quality of life of mothers who have children with the Down syndrome in relation to mothers who have children with typical development.

In the quality of life field the differences between mothers of children with autism and mothers of children with Down syndrome is insignificant, but between them and mothers of children with typical development is a large difference. In the physical health field mothers of children with Down syndrome have the lowest quality and mothers of children with typical health have the highest quality. In psychological health field the quality between mothers of children with Down syndrome and mothers of children with autism the difference is insignificant, but between them and parents of children with typical development there is a large difference. In the social relationship field Down syndrome children mothers have the lowest quality and the mothers of children with typical development have the highest quality. Also in environment field mothers of children with Down syndrome have the lowest quality of life and mothers of children with typical development have the highest quality.

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Table 1: The quality of life of mothers of children with autism, Down syndrome and typical development

		N	Mean	Std. Deviation	Std. Error	95% Confidence Interval		Min	Max	Between component variance
						Min Bound	Max Bound			
Physical health	Autism	30	3.3333	.60415	.11030	3.1077	3.5589	2.29	4.43	
	Down syndrome	30	3.1714	.66521	.12145	2.9230	3.4198	2.00	5.00	
	Typical development	30	3.9095	.41008	.07487	3.7564	4.0627	3.00	4.57	
	Total	90	3.4714	.64759	.06826	3.3358	3.6071	2.00	5.00	
	Model	Fixed Effects			.57028	.06011	3.3519	3.5909		
	Random Effects				.22398	2.5077	4.4351			.13966
Quality of life	Autism	30	3.550	.74683	.13635	3.2711	3.8289	2.00	5.00	
	Down syndrome	30	3.500	.76564	.13979	3.2141	3.7859	2.00	5.00	
	Typical development	30	3.933	.61214	.11176	3.7048	4.1619	2.50	5.00	
	Total	90	3.661	.72989	.07694	3.5082	3.8140	2.00	5.00	
	Model	Fixed Effects			.71150	.07500	3.5120	3.8102		
	Random Effects				.13687	3.0722	4.2500			.03933
Psychological health	Autism	30	2.9667	.61960	.11312	2.7353	3.1980	1.83	4.17	
	Down syndrome	30	2.9944	.82870	.15130	2.6850	3.3039	1.67	5.00	
	Typical development	30	3.5333	.48423	.08841	3.3525	3.7141	2.50	4.50	
	Total	90	3.1648	.70290	.07409	3.0176	3.3120	1.67	5.00	
	Model	Fixed Effects			.65958	.06953	3.0266	3.3030		
	Random Effects				.18443	2.3713	3.9584			.08755
Social relationship	Autism	30	3.1556	.83383	.15224	2.8442	3.4669	1.67	5.00	
	Down syndrome	30	2.8556	.86518	.15796	2.5325	3.1786	1.33	4.33	
	Typical development	30	3.7222	.63778	.11644	3.4841	3.9604	1.67	4.67	
	Total	90	3.2444	.85649	.09028	3.0651	3.4238	1.33	5.00	
	Model	Fixed effects			.78540	.08279	3.0799	3.4090		
	Random Effects				.25410	2.1511	4.3378			.17314

Environment	Autism	30	2.9224	.44748	.08310	2.7522	3.0926	2.13	3.75	
	Down Syndrome	30	2.7098	.41395	.07823	2.5493	2.8703	2.13	3.75	
	Typical Development	30	3.3565	.38056	.07192	3.2089	3.5041	2.38	4.00	
	Total	90	2.9954	.49078	.05323	2.8895	3.1012	2.13	4.00	
	Model/ Fixed Effects			.41531	.04505	2.9058	3.0850			
	Random Effects				.18929	2.1809	3.8098			.10138