International Journal of Religion
2024
Volume: 5| Number 4 | pp. 75 – 81
ISSN: 2633-352X (Print) | ISSN: 2633-3538 (Online)
ijor.co.uk
DOI: https://doi.org/10.61707/pvspj167

Qualıty of Lıfe in Parents of Chıldren Wıth Autısm

Tebessüm AYYILDIZ DURHAN[1], Ecem TÜRKMEN[2], Merve KARAMAN[3] and Ceren SUVEREN[4]

Abstract

Within the scope of the study aiming to investigate the current status of parents with children with autism in terms of quality of life, 52 parents residing in Ankara were included in the study. The data obtained on the basis of volunteerism and criterion sampling method, as well as the personal data form, were developed by Eapen, Crncec, Walter and Tay (2014) and adapted to Turkish by Gürbüz Özgür, Aksu and Eser (2017). The data were tested with normality distribution as well as as descriptive statistics, and non-parametric tests were applied since it was determined not to show normal distribution. Mann-Whitney U tests were used for binary comparisons, and Kruskall Wallis tests were used to compare groups of three and above. The internal reliability coefficient was determined as .91 for the parental quality of life scale in autism. Research findings show that parents with children with autism have below-average quality of life, this value is the age, gender, educational status, employment status, mother or father status of the child with ASD, having a girl or boy diagnosed with ASD, and ASD. reveals that the child does not differentiate with variables such as as age. As a result of the research, it can be said that the quality of life of parents with children with autism is low and certain variables do not change this level in the life-long process such as autism. It is recommended to increase the quality of life with the systemic applications to be performed on parents with children with autism and children with autism.

Keywords: *Autism, Quality of Life, Parent*

INTRODUCTION

Autism spectrum disorder is a neurodevelopmental disorder characterised by abnormalities in communication, repetitive and limited interests, and impaired social functioning (DePape & Lindsay, 2015), affecting 1 in 150 children and characterised by deficits in social interaction and communication and limited behaviour patterns in the World (Amaral, Schumann & Nordahl, 2008). According to Wang et al. (2009), childhood neurodevelopmental and neuropsychiatric disorders characterised by verbal communication deficits, repetitive interest and behaviour patterns are defined as autism spectrum disorders. It is estimated that there are around 550 thousand individuals with autism in Turkey and the number of children with autism in the 0-14 age group in our country is 140 thousand" (tohumotizm.org.tr). The disorder, which has such a high prevalence, is considered as a continuous disorder that affects both the individual and his/her family in general.

The expression of symptoms in children affected by autism affects the child's relationships with the environment and environmental factors can play a decisive role in the child's development and quality of life (Kanne, Abbacchi, & Constantino, 2009). Families also have a range of difficulties and different experiences in relation to the special needs of their children. Having a child with autism can be emotionally challenging for families. While trying to understand and support their children's needs, they may put themselves in the second plan or make extra efforts to keep them in balance.

According to Hayes & Watson (2013), families of these special children experience more parenting stress compared to families of children with normal development or other disabilities. In addition to parenting stress, it is also observed that family members experience lower levels of relationship satisfaction (Brobst, Clopton & Hendrick, 2009), social relationship deficits and regulation problems (Davis & Carter, 2008). In addition, according to Meadan, Halle & Ebata (2010), as a result of parental stress, the quality of life of the family is also negatively affected by the process.

---

[1] Gazi University Faculty of Sports Science. E-mail: tebessum@gazi.edu.tr
[2] Gazi University Faculty of Sports Science
[3] Gazi University Faculty of Sports Science
[4] Gazi University Faculty of Sports Science

It is not possible to measure quality of life with a single universal standard or indicators. There are various approaches to assess quality of life in different disciplines. According to Aydıner Boylu and Paçacıoğlu (2016), quality of life and its indicators are analysed as objective and subjective. While externally observable and measurable factors refer to objective measurements, those based on individuals' own perceptions and experiences are subjective measurements. When evaluated in this context, quality of life includes all conditions and elements that affect an individual's life (Akyol, 1993; Uzun et al., 2021; Çeviker et al., 2023). Therefore, quality of life assumes an important role that directly conveys the quality of the life the individual leads.

Although childcare is a natural part of the parenting experience, when it comes to the intensive care required by a child with autism who has long-term functional limitations, it can aggravate over time and negatively affect the quality of life of parents (Benjak, 2011). Especially in terms of stress and mental health, it is seen that the quality of life of families of children with autism is quite low and 40% of them have clinical depression symptoms (Kuhlthau et al., 2014). The development of their children and the medical and environmental supports they receive are critical for families to improve their mental health and quality of life. While these supports enable a healthier lifestyle by reducing the stress level of the family, they can also contribute to the better development of the child's potential and the strengthening of intra-family relationships (Hsiao, 2016). It is possible to say that the quality of life of the family, which is strengthened through the support received, is a determining factor for the quality of life of the child. Therefore, determining the quality of life of families with individuals with autism spectrum disorder gains importance in this respect. Within the scope of the research conducted in this context, it is aimed to investigate the current situation of parents with children with autism in terms of quality of life.

METHOD

The research was prepared with quantitative method and survey model was used. Within the scope of the research, which aims to investigate the current situation regarding the quality of life of parents with children with autism, 52 parents residing in Ankara were included in the study. Demographic data obtained on the basis of volunteerism and criterion sampling method are given in Table 1.

Table 1. Frequency and Percentage Distributions of Demographic Variables of the Participants

	N=(52)		
	Variable	f	%
Parent's age	40<	18	34,6
	40-50	16	30,8
	51>	18	34,6
Gender of Parent	Male	25	48,1
	Girl	27	51,9
Proximity status	Mum	27	51,9
	Father	25	48,1
Education status	Graduated below high school	17	32,7
	Graduated from high school and above	35	67,3
Employment status of parents	Yes	33	63,5
	No.	19	36,5
Age of the child with ASD	10<	24	46,2
	10-19	16	30,8
	20>	12	23,1
The sex of the ASD child	Male	42	80,8
	Woman	10	19,2

Data Collection Tools

In addition to the personal data form, data were obtained with the Quality of Life in Autism Scale Parent. The version of the Quality of Life in Autism Questionnaire-Parent Version (QoLA) was developed by Eapen et al. (2014) to determine the quality of life of parents of children with autism and is specific to autism spectrum disorder. The adaptation of this scale into Turkish was carried out by Gürbüz Özgür, Aksu & Eser (2017). QoLA consists of two parts, A and B. The A section of the QoLA consists of 28 items and is in the form of a five-point Likert scale including "not at all", "a little", "moderate", "a little more" and "very much". Of the 28 items in the scale, 4 items (2, 4, 17, 22) are reversed when scoring. Part A consists of 6 sub-dimensions:

independence, psychological-emotional well-being, social relations, environment, economic and financial status dimensions. The internal consistency coefficient for Part A was found to be 0.93 in the study in which the scale was adapted to Turkish and in our study. In our study, the internal consistency coefficient of Section A was found to be 0.91. The lowest score that can be obtained from section A is 28 and the highest score is 140. A low score in Section A indicates a low quality of life, while a high score indicates a high quality of life.

Analysis

The data obtained within the scope of the research were tested with normality distribution as well as descriptive statistics, and since it was determined that the data did not show normal distribution, nonparametric tests were applied. Mann-Whitney U test was used for pairwise comparisons and Kruskall Wallis test was used for comparisons of three or more groups. The internal reliability coefficient for the parental quality of life scale in autism was determined as .91. The findings revealed by analysing the data from the research are given below.

FINDINGS

Table 1. Arithmetic Mean and Standard Deviation Values of QoLA

QoLA	N=(52)					
	Min.	Max.	$\bar{x}$	sd	Skewness	Kurtosis
	56,00	152,00	96,36	14,81	0,651	4,119

Parental quality of life in autism was below the average. Since kurtosis and skewness values did not indicate normal distribution, the data were evaluated with non parametric tests.

Table 2. Kruskall Wallis test results between QoLA and parental age group

QoLA	N=(52)				
	Age	n	Rank mean	df	x^2
	40<	18	25.67	2	0,894
	40-50	16	27.97		
	51>	18	26.03		

When the analyses between the participants' responses to the measurement tool for parental quality of life and their ages were examined, it was determined that age did not significantly change parental quality of life, but it was observed that the group between the ages of 40-50 had a higher quality of life.

Table 3. Mann-Whitney U test results between QoLA and gender of the parent

Parental Quality of Life in Autism	N=(52)					
	Gender	n	Rank mean	Order total	z	p
	Male	25	26,60	665,00	-0,046	0,963
	Female	27	26,41	713,00		

When Table 3 is analysed, there is no statistically significant difference between the quality of life of the parents and their gender. Although there was no statistically significant difference, the quality of life levels of male parents were determined to be higher.

Table 4. Mann-Whitney U test results between QoLA and familial closeness status

QoLA	N=(52)					
	Familial closeness	n	Rank mean	Row total	z	p
	Mother	27	26,41	713,00	-0,046	0,963
	Father	25	26,60	665,00		

Being a mother or a father is not a factor that significantly changes the quality of life of the parents of the current sample group with children with autism. However, it was found that fathers had a higher quality of life in line with the prediction that the burden of care is more on the mother.

Table 5. Mann-Whitney U test results between QoLA and parental education level

	N=(52)					
	Education level	n	Rank mean	Row total	z	p
QoLA	High school and below	17	25,71	437,00	-0,264	0,792
	High school and above	35	26,89	941,00		

Educational status does not change parental quality of life. Therefore, there is no statistically significant difference between the measurement tool and the education variable. However, the quality of life averages of high school and above graduates are higher than the group of graduates below high school.

Table 6. Mann-Whitney U test results between QoLA and parental employment status

	N=(52)					
	Employment status	n	Rank mean	Row total	z	p
QoLA	Yes	33	28,92	954,50	-1,523	0,128
	No	19	22,29	423,00		

There is no statistically significant difference between the employment status of the parents and their quality of life. However, it is possible to say that the quality of life level of the working group is higher.

Table 7. Kruskall Wallis test results between QoLA and age group of the child with ASD

	N=(52)				
	Age	n	Rank mean	df	x^2
QoLA	10<	24	24,71	2	0,543
	10-19	16	26,13		
	20>	12	30,58		

No significant difference was found in the analyses between the age of the children and the quality of life of the parents, but it was determined that the quality of life of the group over 20 years of age was higher.

Table 8. Mann-Whitney U test results between QoLA and gender of the child with ASD

	N=(52)					
	Gender	n	Rank mean	Order total	z	p
QoLA	Male	42	25,79	1083,00	-0,698	0,485
	Female	10	29,50	295,00		

The findings obtained as a result of the analyses between the gender of their children and their quality of life are that there is no statistically significant difference. However, it is seen that the quality of life level of parents with daughters is higher.

DISCUSSION AND CONCLUSION

Autism indicates a process that requires lifelong care burden, may have compelling symptoms and should be walked together in all aspects of life. Therefore, the disability status of the children, which is seen as a determining factor for the parents' own quality of life in the relevant processes where the burden of care is on the parents, was analysed within the scope of the research. The findings revealed that the quality of life of parents with children with autism was below average, and this value did not differ with variables such as age, gender, educational status, employment status, being the mother or father of a child with autism, having a boy or girl diagnosed with autism, and the age of the child with autism.

When the findings of the current research are analysed, it is possible to say that the quality of life of parents with children with autism is generally at low levels. The reason for this can be interpreted as the result of the continuous care burden processes of parents in long-term disability situations, similar to individuals with chronic conditions. Similar findings are frequently found in the literature (Barış & Bayram, 2020; Kaya et al, 2020; Kotzampopoulou, 2015; Malhotra, Khan & Bhatia, 2012; Mugno et al., 2007; Sevgi, 2021; Puka et al., 2018; Vasilopoulou & Nisbet, 2016). The burden of having a child with a disability is perceived as likely to result in parents differentiating their own living standards (Leung & Li-Tsang, 2003). It is inevitable for parents to show depressive symptoms through decreased quality of life, as various findings reinforce this idea (Eapen, 2014; Kuhlthau et al., 2014). Since parents have to spend most of their time caring for their children with disabilities, their social life is shortened and their quality of life is negatively affected, especially if the child has a severe disability and cannot engage in other activities (Leung & Li-Tsang, 2003).

Parents with disabled children provide uninterrupted care to their children. It is thought that this challenging and self-sacrificing situation will cause a decrease in the quality of life of individuals and this situation may vary due to many factors such as education, age, economic status (Kurban, Tetikçok & Ünlü, 2022). The findings of the current study indicate that various variables of the parents do not change their quality of life, and that having a child with a disability directly has a negative effect on their quality of life. Therefore, while it is important to develop coping strategies with the situation that is the source of the problem, it is predicted that certain variables may have a partial effect on these problems.

The fact that the quality of life of parents with children with autism is low is also confirmed by the literature. At this point, what can be done to improve the quality of life of parents with children with autism, which is also underlined in the current research. In this direction, individuals who have children with autism or children with different disability groups, these individuals can be mothers or fathers, should be provided to benefit from various social support programmes. While rehabilitation programmes can be organised at the workplace for working parents, for non-working parents, social support practices organised by local governments should be offered and parents should be ensured to benefit from them. It is very important to protect the dynamics of the family, which is the backbone of society, and to adopt a social state approach instead of giving all care to the family. It is clear that all these support mechanisms are needed to make life livable. Otherwise, depressive symptoms, which are also encountered in the literature, fundamentally affect public health as severe psychological and physiological disorders. Considering that the number of diagnoses is increasing day by day, it is recommended that parents with children with autism should be included more in the social support programmes mentioned in cooperation with local administrations within the framework of preventive health services. In order to reduce the stress and hopelessness on families (Güzeloğlu, 2019), it is considered that relevant support programmes should be increased in order to bring families to life. The combination of various support programmes will contribute positively to the quality of life by increasing the commitment to life (Demiray, 2019). In this direction, it is necessary to conduct more studies to improve the quality of family life.

In the researches conducted, it is thought that the quality of family life of families will contribute to the trainings and psychological support to be given to families and children with disabled children (Alıcıoğlu, 2021; Gülsün & Cavkaytar, 2021; Soresi, Nota & Ferrari, 2007). At the same time, in a study conducted, it is stated that the way to increase the quality of life of parents is to increase the quality of life of their children (Sakız & Baş, 2019). Based on this finding, especially children with autism should be encouraged to participate in activities that will increase their quality of life through activities such as movement training, and the positive effect on the quality of life of children should have a direct effect on the quality of life of parents. It has been determined that especially sportive practices provide different contributions to the psychological and social characteristics of the individual, as well as the development of physical characteristics in an individual with special needs (Güngör, Yılmaz & İlhan, 2019). It is recommended that sportive practices should be prioritised in this context.

As a result of the research, it can be said that the quality of life of parents with children with autism in a lifelong process such as autism is low and certain variables do not change this level. It is recommended to increase the quality of life of parents with children with autism and children with autism through systematic applications. In future studies, more disability groups should be included in the studies and analyses should be carried out with expanded sample groups. At the same time, detailed programmes should be designed by evaluating the perspectives of parents through qualitative studies. In terms of raising awareness of the society towards individuals with disabilities, more applications are among the recommendations.

REFERENCES

Akyol, A. D. (1993). The guality Of Life And Indicators. Journal of Ege University Nursing Faculty, 9(2), 75-80.

Alıcıoğlu, S. (2021). Evaluation of the Quality of Life of Families of Children Using Hearing Aids. Master's thesis, Cappadocia University Graduate Education, Training and Research Institute.

Amaral, D.G., Schumann, C. M. & Nordahl, C. W. (2008). Neuroanatomy of autism. Trends in neurosciences, 31(3), 137-145.

Aydıner Boylu, A. & Pacacıoğlu, B. (2016). Quality of life and indicators. Journal of Academic Researches and Studies, 8(15), 137-150.

Baris, B. & Bayram, G. A. (2020). The Relationship of Gross Motor Function Level and Independence Level with Parents' Quality of Life in Preschool Children with Down Syndrome. Hacettepe University Faculty of Health Sciences Journal, 7(3), 381-393.

Benjak, T. (2011). Subjective quality of life for parents of children with autism spectrum disorders in Croatia. Applied Research in Quality of Life, 6, 91-102.

Brobst, J., Clopton, J. & Hendrick, S. (2009). Parenting Children With Autism Spectrum Disorders. Focus on Autism and Other Developmental Disabilities, 24(1), 38- 49.

Ceviker, A., Unlu, C., Kusan, M. & Eroglu, S. (2023). Examination of attitudes towards sport and life satisfaction of university students studying sport education. International Journal of Research in Education and Science (IJRES), 9(3), 677-687. https://doi.org/10.46328/ijres.3255

Davis, N.O. & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. Journal of autism and developmental disorders, 38, 1278-1291.

Demiray, G. (2019). Investigation of the relationships between quality of life, hopelessness and resilience in families with children with special needs. Doctoral dissertation, Marmara University.

DePape, A. M. & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. Qualitative health research, 25(4), 569-583.

Eapen, V., Črnčec, R., Walter, A. & Tay, K. P. (2014). Conceptualisation and development of a quality of life measure for parents of children with autism spectrum disorder. Autism research and treatment, 1-11.

Gülsün, İ. & Cavkaytar, A. (2021). Systematic review on family quality of life of families of children with intellectual disabilities. Journal of Uludag University Faculty of Education, 34(Special Issue), 38-83.

Güngör, N. B., Yılmaz, A. & İlhan, E. L. (2019). Gains of a special athlete in the context of quality of life: A case study in line with parents' views. Ankara University Faculty of Educational Sciences Journal of Special Education, 20(3), 421-443.

Güzeloğlu, B. (2019). Investigation Of The Relationship Between Spousal Support And Family Quality Of Life With Parents Whose Children With Specıal Needs' Stress And Hopelessness Levels.Master's thesis, Institute of Educational Sciences.

Hayes, S. A. & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. Journal of autism and developmental disorders, 43, 629-642.

Hsiao, Y. J. (2016). Pathways to mental health-related quality of life for parents of children with autism spectrum disorder: roles of parental stress, children's performance, medical support, and neighbour support. Research in Autism Spectrum Disorders, 23, 122-130.

Jamil, R. A., Qayyum, U., ul Hassan, S. R., & Khan, T. I. (2023). Impact of social media influencers on consumers' well-being and purchase intention: a TikTok perspective. European Journal of Management and Business Economics, (ahead-of-print).

Kanne, S. M., Abbacchi, A. M., & Constantino, J. N. (2009). Multi-informant ratings of psychiatric symptom severity in children with autism spectrum disorders: The importance of environmental context. Journal of autism and developmental disorders, 39, 856-864.

Kaya, L. Gültekin, G. I., Şahin, M., & Kırandı, Ö. (2020). Life Quality Levels Of The Parents Of The Children With Autism Spectrum Disorder Who Take Sport Classes. Journal of Sport Education, 4(2), 190-202.

Kotzampopoulou, I. (2015). Quality of life in families having children with disabilities: The parents perspective (Master's thesis).

Kuhlthau, K., Payakachat, N., Delahaye, J., Hurson, J., Pyne, J. M., Kovacs, E., & Tilford, J. M. (2014). Quality of life for parents of children with autism spectrum disorders. Research in Autism Spectrum Disorders, 8(10), 1339-1350.

Kurban, V., Tetikçok, R., & Ünlü, U. (2022). Quality of Life of Parents with Disabled Children and Affecting Factors Dicle Tıp Dergisi, 49(2), 324-323.

Leung, C. Y. S., & Li-Tsang, C. W. P. (2003). Quality of life of parents who have children with disabilities. Hong Kong journal of occupational therapy, 13(1), 19-24.

Malhotra, S., Khan, W., & Bhatia, M. S. (2012). Quality of life of parents having children with developmental disabilities. Delhi psychiatry journal, 15(1), 171-176.

Meadan, H., Halle, J. W. & Ebata, A. T. (2010). Families with children who have autism spectrum disorders: Stress and support. Exceptional children, 77(1), 7-36..

Mugno, D., Ruta, L., D'Arrigo, V. G., & Mazzone, L. (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. Health and quality of life outcomes, 5(1), 1-9.

Puka, K., Tavares, T. P., Anderson, K. K., Ferro, M. A., & Speechley, K. N. (2018). A systematic review of quality of life in parents of children with epilepsy. Epilepsy & Behaviour, 82, 38-45.

Sakız, H., & Baş, G. (2019). Determining the quality of life perceptions of children with learning disabilities and their parents. Ankara University Faculty of Educational Sciences Journal of Special Education, 20(1), 53-72.

Sevgi, T. (2021). Investigation of the Effect of the Effect of the Care Burden of Parents With Hemophilia Children on Perceived Social Support and Life Quality (Master's thesis, İnönü University Institute of Health Sciences).

Soresi, S., Nota, L., & Ferrari, L. (2007). Considerations on supports that can increase the quality of life of parents of children with disabilities. Journal of Policy and Practice in Intellectual Disabilities, 4(4), 248-251.

Uzun, R. N., İmamoğlu, O., Barut, Y., & Ceylan, T. (2021). Eski çağlarda çocuk ve oyun. ROL Spor Bilimleri Dergisi, 2(2), 103-111

Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. Research in Autism Spectrum Disorders, 23, 36-49.

Wang, K., Zhang, H., Ma, D., Bucan, M., Glessner, J. T., Abrahams, B. S., ... & Hakonarson, H. (2009). Common genetic variants on 5p14. 1 associate with autism spectrum disorders. Nature, 459(7246), 528-533.