# Psychological Stress and Life Satisfaction among Parents of Children with Autistic Spectrum Disorder

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# Abstract

**Background:** Parents of children with different disabilities have been found as a vulnerable group for significant levels of psychological stress; however, the stress is higher among parents caring for children with autism. Parents' stress negatively impacts children in many ways; it influences the cognitive function of children, in addition to their behavior and the communication skills.

*Aims:* This study aimed to measure the level of psychological stress among parents of children with autistic spectrum disorder, as well as measuring the relationship between parenting stress and their life satisfaction.

**Method:** A descriptive correlational study was conducted on a convenience sample (N = 75) of parents of autistic children. The Arabic Version of Cohen's Perceived Stress Scale and the Satisfaction with Life Scale were used to assess the level of stress and the level of life satisfaction among parents of children with autistic spectrum disorder (ASD)

**Results:** About 83% of parents have levels of psychological stress ranged between moderate to severe level and 36% of parents were dissatisfied with their lives. There was an inverse correlation between parents' psychological stress and their satisfaction with life.

**Conclusion and recommendations:** Having a child with autism is extremely stressful as a result of the total dependency on families in all children's daily life activities. Parents' satisfaction level with life is linked to their level of psychological stress; consequently, parents' stress can be an alarming sign against parents' future health and lives, which increases the need for significant attention in terms of stress management programs designed for parents and new strategies of making autistic children as self-dependent as possible.

Keywords: Psychological Stress, Life Satisfaction, Children with Autistic Spectrum Disorder

# Introduction

Autism spectrum disorder (ASD) is a developmental syndrome that is characterized by impairment in children's cognition, communication skills, and behaviors (Kareem, Hammoodi, & Sallih, 2017; Hasan, 2017; Neff & Faso, 2015; Bluth et al., 2013). A higher level of stress has been found among parents who have children with disabilities. Studies have shown a difference in the level of vulnerability to parenting stress; mothers of disabled children are highly vulnerable to emotional distress (70%) comparing to fathers about (40%). The reported distress negatively impacts children in many ways; it influences the cognitive function of children, in addition to their behavior and the communication skills (Gupta & Singhal, 2005). This research study aims to the level of psychological stress among parents of children with ASD, as well as the relationship between parenting stress and life satisfaction . Children with autism spectrum disorder depend on their family members in most of their needs; parents are considered as child's first trainers, teachers, and helpers from the first moment of his/her life. However, it is not an easy task to care for disable children, especially if there is not enough support for families. With autistic child, challenges and parenting stress;

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therefore, support can help caregivers to overcome challenges (Sung & Park, 2012). Researchers who compared the level of stress among parents of children with different types of disabilities stated that "parents of children with autism spectrum disorders are at an increased risk for acute and chronic stress compared to parents of children with other developmental disabilities and parents of children without disabilities" (Bluth et al., 2013, p. 194). Mothers usually concern not only about disabled child, but also about the healthy ones who may fell neglected, as a result of parents being always busy with their disabled siblings. Therefore, the concern about child's health condition and dependency severely impacting mother's emotional well-being (Yorke et al., 2018; Obaid & Al-Kadoumi, 2012). The experiences of parents caring for children with learning and communication problems, such as those with autistic spectrum disorder is totally different from those caring for children from different groups. The ongoing challenges and stress experienced by parents are not end with certain children's age, they last as much as the children live. Stress negatively impacts parents mental well-being, as well as their ability to balance between the needs of their family and the affected children (Bonis, 2016). Level of stress among parents of children with ASD has been significantly linked to the level of their psychological health (Nikmat et al., 2008).

## Methodology

## Objectives

The main objective of this study is to measure the level of psychological stress among parents of children with autistic spectrum disorder. It also aims to measure the link between psychological stress of parenting a child with autism and life satisfaction.

## **Study Sample and Design**

A descriptive correlational study was conducted on a convenience sample (N = 75) of parents of children with autism. Both parents (mother 24% and father 76%) were included in this study, and their age ranged between (26 - 55) years old. Sample was selected from four main autism services centers in Babylon Province of Iraq (Babylon Specialist Center for Autistic Care, Mazaya Center for Autism Care, Wissam Al Rahma Center, and Imam Hussein Center for Autism). Parents were asked for voluntary participation during their visits with their children to these centers. Parents were excluded if they had a history of psychiatric illnesses.

## **Study Instruments**

The Arabic Version of Cohen's Perceived Stress Scale was used to assess the level of stress among parents of children with autistic spectrum disorder (ASD). The original scale (14 items) was first developed in 1983 by Sheldon Cohen (Chaaya et al., 2010), then it was revised to 10 items to be used widely as a psychological tool to measure individuals' perceptions of stress (Cohen, Kamarck, & Mermelstein, 1994). This psychological tool is valid and reliable cross cultures; it has been translated to different languages, including Arabic for its high validity to measure the intended phenomenon (Almadi et al., 2012; Chaaya et al., 2010). The Arabic version of the scale also showed adequate reliability and validity to measure stress in Arabic communities. According to Almadi et al. (2012), the Cronbach alpha coefficient for the overall Arabic version scale was 0.80, and 0.74 according to Chaaya et al. (2010). The scale items are asking about an individual's thoughts and feelings during the last month. It was rated on 5-point Likert scale (0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, 4 = Very Often). Parents with higher score were considered to have higher level of stress .

The second tool is the Satisfaction with Life Scale that consist 5 items, which measures individuals' satisfaction with their lives. Participants respond to the scale items based on their levels of agreement or disagreement. It was developed to assess the satisfaction level with the life as whole not to assess specific life domain such as health or economic. According to Pavot and Diener (2009), "the SWLS is recommended as a complement to scales that focus on psychopathology or emotional well-being because it assesses an individuals' conscious evaluative judgment of his or her life by using the person's own criteria" (p. 11). The items are rated on 7-point Likert scale ranged from strongly disagree to strongly agree. Parents with lower scores are considered less satisfied with their lives .

## **Ethical Considerations**

Subjects were voluntarily participated in this study. Participants were informed that they had the right to withdraw their participation, even after they signed the informed consent. To maintain participants' confidentiality, the questionnaires were anonymous.

## **Results and Discussion**

The findings of the recent study show that more than 80% of those who parenting a child with autism have levels of psychological stress ranged between moderate to severe level. Parenting a child suffering from autism associated with high levels of anxiety, depression, and stress compared to other groups of parents. Parents usually encounter stress

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because of their children behavioral disturbance, learning problems, poor communication skills, and being totally dependent on parents. In addition, managing children's behavior remains a major concern by parents and very stressful task (Bonis, 2016; Bitsika & Sharpley, 2004)). Since behavioral problems of the affected children becomes the biggest concern of all parents, more than 90% of parents are unable to effectively cope with the behaviors of their children and feel angry, frustrated, inadequate, isolated, and depressed.

Psychological stress among parents or caregivers of disabled child is one of major consequences associated with the financial costs of healthcare services. The level of psychological stress among parents caring for disabled children is very high comparing to parents of normally developing children (Goudie et al., 2014). Studies that targeted the challenges and the financial care-cost for disabled children indicated that children with communication and behavioral problems cost higher comparing with the care for other disabled children who can communicate effectively with their care givers. Moreover, children who require residential facilities cost higher than foster care that is needed for children under 10 years old (Knapp, Romeo, & Beecham, 2009; Shimabukuro et al., 2008; Mandell et al., 2008).

The differences in the healthcare policies, support system, and financial system among countries make it different to compare the care cost. However, the health related cost was estimated that "among the subgroup of children with other psychiatric conditions, total mean annual costs were 45% higher for children with autism spectrum disorders; excess costs were largely explained by the increased use of psychotherapeutic medications." (Croen et al., 2006, p. 1203).

The results of the present study show that more than 35% of the parents of autistic children reported dissatisfaction about their lives. A statistically significant correlation was also found between parents' stress and their life satisfaction. Quality of life of families who parenting children with developmental disabilities can explain their high level of life dissatisfaction. Despite the limited number of research studies that targeted the quality of life (QOL) for parents of autistic child, it has been made clear that parents experience major challenges that increase their level of stress and negatively affecting their physical and psychological well-beings. The QOL is reduced significantly among parents of disabled children comparing to parents of sick children without disability. Level of stress is significantly higher among families with poor income (Bromley et al., 2004). Lower income families reported higher incidence of anxiety and depression as a response to the great challenges associate with the care for a child with autism. Income increases the accessibility to various healthcare services and help parents to provide more support for their children. Income also allowing temporary relief from caretaking responsibilities (Pakenham, Samios, & Sofronoff, 2005).

Wang, Huang, and Kong (2017) found an inverse relationship between parents' stress and their life satisfaction. Despite the fact that parenting a child with autism is challenging and stressful, family and friends support can help reducing stress and improving the level of satisfaction with life. According to Habib, Asmat, and Naseem (2016), parents' satisfaction with their lives can be predicted by the level of support they get. Researchers stated that "satisfaction which is person's personal evaluation of self is related to the support that they perceive from others. Support gives us relief and work as an asset when someone is in a stipulation of dissatisfaction" (p. 398). Therefore, awareness should be raised about the importance of social and family support for caregivers of disabled children, especially those who parenting children with autistic spectrum disorder.

# **Tables of the Study Results**

## Table 1. Level of stress among parents of disabled children

Level of Stress	F	%
Mild Level of Stress	13	17.3
Moderate Level of Stress	53	70.7
Severe Level of Stress	9	12.0
Total	75	100.0

This table indicates that about 83% of parents have levels of psychological stress ranged between moderate to severe.

## Table 2. Parents level of satisfaction with life

Satisfaction about Life	Frequency	Percent	
Extremely dissatisfied	3	4.0	
Dissatisfied	24	32.0	
Neutral	4	5.3	
Satisfied	42	56.0	
Extremely satisfied	2	2.7	

Total 75	100.0
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This table indicates that 36% of parents were dissatisfied with their lives.

Table 3. Correlation between variables (stress and life satisfaction).	Table 3.	Correlation	between	variables	(stress a	and life	satisfaction).
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Variables		Stress	Life Satisfaction
Psychological Stress	Pearson Correlation	1	716**
	Sig. (2-tailed)		.000
	N	75	75
Life Satisfaction	Pearson Correlation	716**	1
	Sig. (2-tailed)	.000	
	N	75	75
**. Correlation is signification	ant at the 0.01 level (2-tailed).		

Table 3 shows a significant inverse correlation between parents' stress and their satisfaction with life.

Variables		Levene's Test for Equality of Variances		t.Test		
		F	Sig.	t	df	Sig.
Psychological Stress	Equal variances assumed	.657	.420	205	73	.838
	Equal variances not assumed			201	53.772	.841
Life Satisfaction	Equal variances assumed	3.835	.054	.219	73	.827
	Equal variances not assumed			.204	44.985	.84

This table shows no significant difference between fathers and mothers in response to psychological stress and their level of satisfaction with life, p > 0.05.

# Conclusion

This study aimed to measure the level of psychological stress among parents of children with autistic spectrum disorder, as well as measuring the relationship between parenting stress and their life satisfaction. Parenting a disabled child is stressful for the whole family who live with that child; however, having a child with autism is extremely stressful and need more attention, since that child experiences impairment in cognition, communication skills, and behaviors, which make the child totally dependent on families in all of his/her daily life activities. The results highlighted that most of parents have psychological stress, which makes them unsatisfied about their lives, and that can be an alarming sign against their future health and lives.

## Recommendations

Stress management programs for parents play a significant role in managing emotional well-being and help maximizing parent's adjustment capabilities, which indeed helps improving the level of satisfaction with life. In addition, more disabled services centers are critically needed to effectively reach the needs of those children and give enough time for parents to care for themselves. (This can be governmental and/ or NGO responsibility). Importantly, train teachers appropriate learning and caring strategies to use with disabled children in order to makes disabled children as independent as possible.

### **Research Implications**

The findings of this study can have a significant implication for healthcare professionals working in the field of mental health. Parents of children with disabilities report higher psychological stress and poor life satisfaction. Focusing more on these psychological factors raise professionals' awareness about the problem and help them develop appropriate intervention to minimize the risk of stress among parents and maintain their behaviors to better care for their children.

### **References:**

- Almadi, T., Cathers, I., Mansour, A. M. H., & Chow, C. M. (2012). An Arabic version of the Perceived Stress Scale: Translation and validation study. International Journal of Nursing Studies, 49(1), 84-89.
- Bluth, K., Roberson, P. N., Billen, R. M., & Sams, J. M. (2013). A stress model for couples parenting children with autism spectrum disorders and the introduction of a mindfulness intervention. Journal of family theory & review, 5(3), 194-213
- Bitsika, V., & Sharpley, C. F. (2004). Stress, anxiety and depression among parents of children with autism spectrum disorder. *Journal of Psychologists and Counsellors in Schools*, 14(2), 151-161.
- Bonis, S. (2016). Stress and parents of children with autism: a review of literature. Issues in mental health nursing, 37(3), 153-163.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, 8(4), 409-423.
- Chaaya, M., Osman, H., Naassan, G., & Mahfoud, Z. (2010). Validation of the Arabic version of the Cohen Perceived Stress Scale (PSS-10) among pregnant and postpartum women. BMC psychiatry, 10(1), 111.
- Cohen, S., Kamarck, T., & Mermelstein, R. (1994). Perceived stress scale. Measuring stress: A guide for health and social scientists, 235-283
- Croen, L. A., Najjar, D. V., Ray, G. T., Lotspeich, L., & Bernal, P. (2006). A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics*, 118(4), e1203-e1211.
- Goudie, A., Narcisse, M. R., Hall, D. E., & Kuo, D. Z. (2014). Financial and psychological stressors associated with caring for children with disability. *Families, Systems, & Health, 32*(3), 280.
- Gupta, A., & Singhal, N. (2005). Psychosocial support for families of children with autism. Asia Pacific Disability Rehabilitation Journal, 16(2), 62-83.
- Habib, H., Asmat, A., and Naseem, S. (2016). Parental satisfaction with life and perceived social support of parents of children with intellectual disability. *International Journal of Innovation and Scientific Research*, 20(2), pp. 398-402
- Hasan, A. A. (2017). A Descriptive Study among Children suffering from Autism in Baghdad, Iraq. Research Journal of Pharmacy and Technology, 10(6), 1919-1923. doi: 10.5958/0974-360X.2017.00336.5
- Knapp, M., Romeo, R., & Beecham, J. (2009). Economic cost of autism in the UK. Autism, 13(3), 317-336.
- Mandell, D. S. (2008). Psychiatric hospitalization among children with autism spectrum disorders. *Journal of autism and developmental disorders*, 38(6), 1059-1065.
- Mohamed, S. H., & Kazim, A. A. (2016). Assessment of Psychological Status of Orphans in Orphanagesin Baghdad City. *kufa Journal for Nursing sciences*, 6(1), 121-129.
- Neff, K. D., & Faso, D. J. (2015). Self-compassion and well-being in parents of children with autism. Mindfulness, 6(4), 938-947.
- Nikmat, A. W., Ahmad, M., OON, N., & Razali, S. (2008). Stress and psychological wellbeing among parents of children with autism spectrum disorder. ASEAN journal of psychiatry, 9(2), 65-72.
- Obaid, M. A. S., & Al-Kadoumi, K. (2012). Family member needs of autistic children. American journal of health sciences, 3(4), 291.

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- Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment. Autism, 9, 191–212.
- Pavot, W., & Diener, E. (2009). Review of the satisfaction with life scale. In Assessing well-being (pp. 101-117). Springer, Dordrecht.
- Shimabukuro, T. T., Grosse, S. D., & Rice, C. (2008). Medical expenditures for children with an autism spectrum disorder in a privately insured population. Journal of autism and developmental disorders, 38(3), 546-552.
- Sung, M., & Park, J. (2012). The Effects of a Family Support Program Including Respite Care on Parenting Stress and Family Quality of Life Perceived by Primary Caregivers of Children with Disabilities in Korea. International Journal of Special Education, 27(3), 188-198.
- Wang, Y., Huang, Z., & Kong, F. (2017). Parenting stress and life satisfaction in mothers of children with cerebral palsy: The mediating effect of social support. *Journal of health psychology*, 1359105317739100.
- Yorke, I., White, P., Weston, A., Rafla, M., Charman, T., & Simonoff, E. (2018). The Association Between Emotional and Behavioral Problems in Children with Autism Spectrum Disorder and Psychological Distress in Their Parents: A Systematic Review and Meta-analysis. Journal of Autism and Developmental Disorders, 48(10): 3393–3415: doi: 10.1007/s10803-018-3605-y