

Family Resilience in Pakistani Families having Children with Autism

Naila Aslam, Iffat Rohail

ABSTRACT

Objective: To determine the resilience in families having Autistic children in Pakistan.

Methodology: A quantitative cross-sectional descriptive study was done involving 150 Pakistani families who had children with Autism spectrum disorder (ASD). Data was collected through a purposive convenient sampling technique. Family Resilience Assessment Scale was used to calculate the results.

Results: Descriptive statistic was used to analyze the data. The results indicated that only 4% of families of children with Autism exhibit high family resilience. A moderate level of family resilience was involved in 72.7% and 23.3% of families showed a low level family resilience. According to the results, family resilience indicated a significant relationship with education (p-value=0.000), gender (p-value=0.003), and family system (p-value=0.048).

Conclusion: Families of children with Autism have a moderate level family resilience. Also, parental education, family system, and gender are interdependent on each other for determination of the level of family resilience towards Autism.

Keywords: Family support. Autism. Resilience.

INTRODUCTION

Autism spectrum disorder is defined as a neurodevelopmental disorder categorized by a lack of communication, portraying repetitive behaviors, and restricted interests.¹ The incidence of ASD diagnosis increased from 0.07% in 2009 to 0.23% in 2017, with a higher increase in girls, and in children aged 2-5 years at the time of diagnosis. Literature shows that the prevalence of ASD in South Asia is up to one in 93 children. Parents of children with autism spectrum disorder experience unique challenges in terms of understanding the disorder, the child's needs, management of their behaviors as well as increased parental stress.² Stress and well-being of the parents having children with autism spectrum disorder have always been a major concern in the family. The severe increase in the stress level causes more anxiety and depression in parents and family of child with ASD. Mothers are more likely to be affected by depression as compared to the fathers of children with ASD. There have been certain reasons for parents' suffering from stress at different levels. The most significant is the difficulty in availing diagnostic services and lack of proper counseling sessions with health care providers. In addition, ASD austerity and verbal intelligence quotient in the child can be extremely challenging for the parents to adhere with.³ Resilience is frequently

described as a dynamic process that includes helpful environment adaptation. A person's ability to succeed in the face of adversity can be attributed to their resilience, which can involve the cumulative influence of their individual attitudes, beliefs, and skills.⁴ It is essential for the whole family and community to contribute their efforts to increase resilience. Family resilience boosts healthy family functioning with the inclusion of independent constructs and shielding against hardships.⁵

Currently, there are several factors which incorporate resilience amongst the families/parents of children diagnosed with ASD. Major factors that impact family resilience are social influence and support, financial challenges, awareness and contemplating ASD by parents, and concerns about the child's outlook. However, both family and personal resilience are correlated so much so that several factors incorporated with resilience in parents are also deemed to be reflected in family resilience and cohesiveness.⁶ According to Walsh Family Resilience Framework, nine key processes have been determined. These are further categorized into three dimensions dealing with the functioning of the family: family's assimilated belief systems, family configuration, and process of communication and problem-resolving techniques. The first dimension, family assimilated belief systems includes making sure that the family must have common sense-making efforts. A positive approach is one of the essential attributes in availing family resilience. Transcendence and spirituality ultimately assist in developing common efforts to eradicate detrimental challenges.⁷

Family resilience can only be beneficial if collaborative work is conducted towards building shared beliefs and strategies. The second dimension i.e. family

Sharif Medical & Dental College, Sharif Medical City,
Sharif Medical City Road, Off Raiwind Road, Jati Umra,
Lahore 54000, Pakistan.

Correspondence: Ms. Naila Aslam
PhD Scholar Department of Psychology
Foundation University, Islamabad
E-mail: nailabhatti89@hotmail.com

Received: March 21, 2023; Accepted: May 30, 2023

configuration, includes transactional processes which assist in strengthening, flexibility in the family while resolving problems, a firm belief in cohesion, availability of economic resources along with social support. There could be essential factors in contributing to the effective responses in order to overcome the aversive challenges. Lastly, the third dimension mainly focuses on communication strategies and resolving problem processes which involves clarity in their stance, ability to express emotionally, and resolving problems, collectively.⁸ Considering the negative impacts, it is pertinent to understand that adaptation of positive thinking and resilience are mandatory for the parents of children with ASD while bringing up their child. It shall be beneficial for both parents and children with ASD in the long term to overcome the forthcoming challenges. So, this study was planned to observe family resilience in Pakistani families of children with ASD.

METHODOLOGY

The present study was conducted at the Department of Psychology, Foundation University, Islamabad. The study was approved by the Board of Advanced Studies and Research. A descriptive research design was used to gather information about the family resilience levels in families who had children with Autism. The study was done in Islamabad and Rawalpindi region and data was collected through a purposive convenient sampling technique, where selection was focused on participants with pertinent characteristics that were associated with the research subject. A total of 150 parents participated in the study. Families having children with Autism but without physical disabilities were included. Families with Autistic children with physical disabilities and multiple disorders were excluded from this study.

Participants fulfilling the inclusion criteria were contacted through educational institutions situated in Islamabad and Rawalpindi. Willing participants were briefed about the nature of the study, and written consents were taken. Families were free to leave the study at any stage if they didn't feel comfortable. Demographic information was taken from the participants. Family resilience was measured by the family resilience assessment scale developed by Sixbey. It's a 5 point Likert scales with ranges between strongly agree to strongly disagree. Participants who scored 66-125 were considered to have low family resilience, 126-205 scores meant moderate family resilience, and scores 216-316 indicated a high level of family resilience.⁹ It was a validated scale with Cronbach alpha value of 0.94.

STATISTICAL ANALYSIS

Statistical Package for the Social Sciences (SPSS) version 25.0 was used to analyze the data. Descriptive statistics were applied on data to analyze and evaluate the family resilience level. Chi-square test was used to analyze the association between the degree of family resilience and demographic data. A p-value of ≤ 0.05 was taken as statistically significant.

RESULTS

The results indicated that 72.7% of participants had moderate family resilience towards their Autistic child. Data analysis indicated that family resilience had a significant progressive relationship with three demographic variables, i.e. education (p-value=0.000), gender (p-value=0.003), and family system (p-value=0.048). However, there was no relationship with the levels of family resilience and child's perceived Autism (p=0.375) (Table 1).

Table 1: Association of Demographic Variables with Family Resilience of the Study Participants

Demographic Variables		Low Family Resilience	Average Family Resilience	High Family Resilience	p-value
Respondent's Education	Below Master's	20(13.3%)	62(41.4%)	3(2%)	0.000*
	Master's	15(10%)	47(31.3%)	0(0%)	
	Above Master's	0(0%)	0(0%)	3(2%)	
Family System	Joint Family	16(10.7%)	58(38.6%)	6(4%)	0.048*
	Nuclear Family	19(12.7%)	51(34%)	0(0%)	
Gender	Male	15(10%)	19(12.7%)	0(0%)	0.003*
	Female	20(13.3%)	90(60%)	6(4%)	
Child's Perceived Autism Levels	Mild Autism	19(12.7%)	55(36.7%)	6(4%)	0.375
	Moderate Autism	11(7.3%)	38(25.3%)	0(0%)	
	High Autism	2(1.3%)	10(6.7%)	0(0%)	

*Significant p-value

DISCUSSION

Raising a child with a disability is a big challenge and families have to show resilience in this stressful situation.⁹ In this study, we observed family resilience among families of child with Autism. Our results showed that 72.7% of participants had moderate family resilience towards their Autistic child.

Another study reported that 79.5% of the families exhibited high resilience whereas 19.3% of the families have shown moderate resilience.¹⁰ According to another study, individuals tend to consider their family to have the capacity to overcome their difficulties in adverse conditions, however, they also believe the fact that their family does not possess the ability to create maximum protective factors to eradicate the difficult situations or risk factors. There are several protective factors and risk factors for resilience. Risk factors have the potential of enhancing the difficulties and maintenance of resilience in the family.¹¹

Our results also show that a correlation exists between the degree of family resilience and demographic variables like gender (p-value=0.003), family system (p-value=0.048) & education (p-value=0.000).

It was found by Hendrayu et al. that the gender of the child does not determine the level of family resilience and it has no co-dependency on the respective factor. It was also shown that the education, age of parents, and marital status can result in establishing differences in perceiving family resilience.¹² In another study conducted by Al-Jadiri et al., data of 151 children with ASD was analyzed. They reported low family resilience in 32% of families and it was associated with low-level family support.¹³ Another study conducted by Zhao et al., observed relationship between family support and resilience. They reported that neighborhood support was significantly associated with family resilience.¹⁴

A study conducted by Ghanouni et al. & Afifi et al., reported that the stress levels of parents were negatively associated with family resilience, whereas monthly income was positively associated with parental resilience. They also concluded that no significant correlation was found between child and parental age and resilience.^{4,15}

In our study, no correlation of severity of child's Autism and resilience was found (p-value=0.375). On contrary, other studies suggested a negative correlation between severity of ASD and family resilience.⁴ According to Sixbey, life experiences play a vital role in constituting family resilience as the family grows older. Moreover, these experiences can also aid in increasing the resilience in the family with the passage of time.⁹ Depending on the factors such as age, self-esteem, social orientation and interactions, achievement motivation, social comprehension, and cognitive and emotional development, children also

significantly contribute in developing family resilience.¹⁶

Our results show that education has an impact on developing efficient family resilience in family with ASD (p-value=0.000). For instance, an individual with a master's level education has the capacity to endure more family resilience as compared to a person with a lower level of education. According to Ungar and Theron, education can play a significant role in achieving higher levels of family resilience, for instance, if higher education is pursued then attaining a good level of family resilience becomes imminent.^{2,17}

CONCLUSION

Families of children with Autism have a moderate level of family resilience. Also, parental education, family system, and gender are interdependent on each other for determination of the level of family resilience towards Autism.

LIMITATIONS & RECOMMENDATIONS

The study sample was not too large to generalize the results and sample consisted of one particular disability. Future studies are recommended to compare the family resilience in families with different disabilities. It is recommended to strengthen family resilience in Autistic families through public awareness and counseling sessions.

REFERENCES

- Hodges H, Fealko C, Soares N. Autism spectrum disorder: definition, epidemiology, causes, and clinical evaluation. *Transl Pediatr.* 2020; 9(Suppl 1):S55-65. doi:10.21037/tp.2019.09.09.
- Masten AS. Resilience theory and research on children and families: past, present, and promise. *J Fam Theory Rev.* 2018; 10(1):12-31. doi:10.1111/jftr.12255.
- Thomas PA, Liu H, Umberson D. Family relationships and well-being. *Innov Aging.* 2017; 1(3):igx025. doi:10.1093/geron/igx025.
- Ghanouni P, Eves L. Resilience among parents and children with Autism spectrum disorder. *Mental Illness.* 2023. doi:10.1155/2023/2925530.
- Poehlmann-Tynan J, Eddy JM. A research and intervention agenda for children with incarcerated parents and their families. In J M Eddy & J Poehlmann-Tynan (Eds.). *Handbook on children with incarcerated parents: research, policy, and practice.* Springer Nature Switzerland AG. 2019; 353-71. doi:10.1007/978-3-030-16707-3_24
- Johnson EI, Arditti JA, McGregor CM. Risk, protection, and adjustment among youth with incarcerated and non-resident parents: a mixed-methods study. *J Child Fam Stud.* 2018; 27(6):1914-28. doi:10.1007/s10826-018-1045-0.
- Walsh F. Family resilience: a developmental systems framework. *Eur J Dev Psychol.* 2016; 13(3):313-24. doi:10.1080/17405629.2016.1154035.

8. Arditti JA, Johnson EI. A family resilience agenda for understanding and responding to parental incarceration. *Am Psychol.* 2022; 77(1):56-70. doi:10.1037/amp0000687.
9. Gardiner E, Masse LC, Iarocci G. A psychometric study of the family resilience assessment scale among families of children with autism spectrum disorder. *Health Qual Life Outcomes.* 2019; 17(1):45. doi:10.1186/s12955-019-1117-x.
10. Perez-Crespo L, Prats-Urbe A, Tobias A, Duran-Tauleria E, Coronado R, Hervas A, et al. Temporal and geographical variability of prevalence and incidence of autism spectrum disorder diagnoses in children in Catalonia, Spain. *Autism Res.* 2019; 12(11):1693-1705. doi:10.1002/aur.2172.
11. Widyawati Y, Scholte R, Kleemans T, Otten R. Parental resilience and quality of life in children with developmental disabilities in Indonesia: the role of protective factors. *J Dev Phys Disabil.* 2022. doi:10.1007/s10882-022-09878-1.
12. Hendrayu VG, Kinanthi MR, Brebahama A. Resiliensi keluarga pada keluarga yang memiliki kedua orangtua bekerja. *SCHEMA (Journal of Psychology Research).* 2017; 3(2):104-15. Available from: <https://ejournal.unisba.ac.id/index.php/schema/article/viewFile/3387/2351>.
13. Al-Jadiri A, Tybor DJ, Mule C, Sakai C. Factors associated with resilience in families of children with Autism spectrum disorder. *J Dev Behav Pediatr.* 2021; 42(1):16-22. doi:10.1097/DBP.0000000000000867.
14. Zhao M, Fu W. The resilience of parents who have children with autism spectrum disorder in China: a social culture perspective. *Int J Dev Disabil.* 2020; 68(2):207-18. doi:10.1080/20473869.2020.1747761.
15. Afifi TD, Merrill AF, Davis S. The theory of resilience and relational load. *Pers Relatsh.* 2016; 23(4):663-83. doi:10.1111/pere.12159.
16. Anderson LA. Rethinking resilience theory in African American families: fostering positive adaptations and transformative social justice. *J Fam Theory Rev.* 2019; 11(3):385-97. doi:10.1111/jftr.12343.
17. Ungar M, Theron L. Resilience and mental health: how multisystemic processes contribute to positive outcomes. *Lancet Psychiatry.* 2020; 7(5):441-8. doi:10.1016/S22150366(19)30434-1.

