

PARENT'S SATISFACTION LEVEL OF CHILDREN WITH AUTISM SPECTRUM DISORDER

By

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Title- "Parent's Satisfaction Level of Children with Autism Spectrum Disorder"

Aim of the study: To find out parent's satisfaction level of children with autism spectrum disorder (ASD).

Methodology: This paper describes parent's satisfaction level of children with Autism Spectrum Disorder (ASD) by using descriptive quantitative method design and cross sectional survey. The participants are parents of children with ASD (n=103), within total participant female were 92 and male were 11, and were asked to answer the Beach Center Family Quality of Life (FQOL) questionnaire translated version (Bengali). FQOL was used to assess the parent's satisfaction level of children with autism spectrum disorder about their family quality of life. In FQOL scale has five domains that rated from highest to lowest family interaction, physical/ material well-being, parenting, disability-related support and emotional well-being in this study.

Result: The result showed about satisfaction rate of parents of children with autism spectrum disorder that most frequent parents of children with ASD were satisfied about their family quality of life in which involves physical/material well-being, emotional well-being, parenting, family interaction and disability related support.

Conclusion: Worldwide increasing the number of autism spectrum disorder bay by day and this situation also same in Bangladesh. Nowadays in Bangladesh ASD is high concerning issue that are progress awareness about ASD, and proposing with new intervention pathway that may increase their quality of life of families. Children with ASD are facing difficulty to participate in home, school, and community's activity for different factors of them. Parents of children with ASD also feel isolation from other for their children. The study conducted with the purpose of finding of parent's satisfaction level of children with autism spectrum disorder. The result of the study showed that most of the participants are satisfied in selected area. In this study the results are showed the level of satisfaction of parents on overall family quality of life (FQOL) where have five dimensions such as disability related support, family interaction, and parenting etc. of children with autism spectrum disorder. So in the study has concluded that the most of the parents of children with ASD were satisfied in their overall family quality of life.

Limitation:

During the conduction study, there has some boundary related to research that are given below-

- i. According to perspective of Bangladesh some selected area of questionnaires was not generalizable for participants.
- ii. Investigator selected few participants that did not represent the whole phenomena.
- iii. Study related article was not available in the context of Bangladesh that was difficult to analysis study.
- iv. Most of the parent could not cooperate with investigator to give their some personal information like monthly family income that was difficult to fill-up the questionnaires' form.
- v. Some parents did not return the questionnaire that was given their home through special school of children with autism. That's why investigator faces challenging to collect data.
- vi. Total participants of this investigation were who lived in urban area.

Recommendation:

Considering the limitation of the study here did focus on the possible recommendation and further studies related to children with autism spectrum disorder is-

- i. A large part of children are suffering from ASD and their family also faces challenging in daily life. That's why government needs to increase awareness program to prevent and control ASD in different area of Bangladesh.
- ii. It would be better to conduct this study broadly with more participants in different area in the context of Bangladesh.
- iii. Further study would be comparative study between parents of typical children and parents of children with ASD.
- iv. In further study it would be study on other condition like Children with cerebral palsy, down syndrome, ADHD etc. and comparison.
- v. Further study would be comparison between participants who live in rural and urban area.

References:

- Akhter, S., Hussain, A. E., Shefa, J., Kundu, G.K., Rahman, F., &Biswas, A. (2018). Prevalence of autism spectrum disorder (ASD) among the children aged 18-36 months in rural community of Bangladesh: A cross sectional study [version 1; referees: 1 approved, 2 approved with reservations]. *F1000Research*, 7, 424. Retrieved from https://doi.org/10.12688/f1000research.13563.1
- Algood, C., & Davis A. M. (2019). Inequities in family quality of life for African-American families raising children with disabilities. *Social Work in Public Health*, *34*(1), 102-112. doi: 10.1080/19371918.2018.1562399
- Bailey, M. D. (1997). *Research for the Health Professional* (2nded.).USA: F. A. Davis Company.
- Bangladesh Bureau of Statistics (BBS). (2019). Report on the household income and expenditure survey 2016. Bangladesh.
- Baxter, A. J., Brugha, T. S., Erskine, H.E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, 45, 601-613. doi: 10.1017/S003329171400172X
- Berg, K. E., & Latin, R. W. (2014). Essentials of research methods in health, physical education, exercise science, and recreation (2nded.). USA: Lippincott Williams &Willkins.

- Blake, J. M., Rubenstein, E., Tsai, P. C., Rahman, H., Rieth, S. R., Ali, H., & Lee, L.C. (2017). Lessons learned while developing, adapting and implementing a pilot parent-mediated behavioural intervention for children with autism spectrum disorder in rural Bangladesh. *Autism*, 21(5), 611-621. doi: 10.1177/1362361316683890
- Brisini, K. S., & Solomon, D. H. (2018). Relationship transitions for parents of children with autism spectrum disorder: types, turbulence, and transition processing communication. *Journal of Applied Communication Research*, 46(4), 447-468. doi: 10.1080/00909882.2018.1498980
- Callander, E. J., & Lindsay, D. B. (2017). The impact of childhood autism spectrum disorder on parent's labour force participation: Can parents be expected to be able to re-join the labour force? *Autism*, 1-7. https://doi.org/10.1177/1362361316688331
- Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities.

 *Journal of Intellectual & Development Disability, 34(2), 153-162. doi: 10.1080/13668250902874608
- DePoy, E., &Gitlin, L. N. (1998). Introduction to research (2nded.). USA: John Schrefer.
- Drummond, A. (1996). Research methods for therapists. London: Chapman & Hall.
- Eskow, K., Pineles, L., &Summers, J. N. (2011). Exploring the effect of autism waiver services on the family outcomes. *Journal of Policy and Practice in Intellectual Disabilities*, 8(1), 28-35.
- Gardiner, E., &Iarocci, G. (2015). Family quality of life and ASD: the role of child adaptive functioning and behavior problems. *International Society for Autism Research*, 8, 199-213. doi: 10.1002/aur.1442
- Gine, C., Vilaseca, R., Gracia, M., Mora, J., Orcasitas, J. R., Simon, C.,...Simo-Pinatella, D. (2013). Spanish family quality of life scales: under and over 18 years old. *Journal of Intellectual and Developmental Disability*, 38(2), 141-148. Retrieved from http://dx.doi.org/10.3109/13668250.2013.774324
- Guajardo, N. R., Snyder, G., & Petersen, R. (2009). Relationships among parenting practices, parental stress, child bahaviour, and children's social- cognitive development. *Infant and Child Development*, 18, 37-60. doi: 10.1002/icd.578

- Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *J Autism Dev Disord*. doi: 10.1007/s10803-013-1812-0
- Hartley, S. L., Mihaila, I., Otalora-Fadner, H. S., &Bussanich, P. M. (2014). Division of labor in families of children and adolescents with autism spectrum disorder. *Family Relations*, 63, 627-638. doi: 10.1111/fare.12093
- Hartley, S. L., Papp, L. M., & Bolt, D. (2018). Spillover of marital interactions and parenting stress in families of children with autism spectrum disorder. *Journal of Clinical Child & Adolescent Psychology*, 47(1), 88-99. doi: 10.1080/15374416.2016.1152552
- Hickey, E. J., Hartley, S. L., & Papp, L. (2019). Psychological well-being and parent-child relationship quality in relation to child autism: an actor-partner modeling approach. *Family Process*, 1-15. doi: 10.1111/famp.12432
- Hicks, C. M. (2000). *Research Methods for Clinical Therapist* (3rded.). UK: Harcourt Brace and Company Limited.
- Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: psychometric evaluation of the beach center family quality of life scale. *Journal of Marriage and Family*, 68(4), 1069-1083.
- Hsiao, Y. J. (2018). Autism spectrum disorders: family demographics, parental stress, and family quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, 15(1), 70-79. doi: 10.1111/jppi.12232
- Hu, X., Wang, M., &Fei, X. (2012). Family quality of life of Chinese families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, *56*, 30-44. doi: 10.1111/j.1365-2788.2011.01391.x
- Jellett, R., Wood, C. E., Giallo, R., & Seymour, M. (2015). Family functioning and behavior problems in children with autism spectrum disorders: the mediating role of parent mental health. *Clinical Psychologist*, 19, 39-48. doi: 10.1111/cp.12047
- Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, S. M., &Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics*, 12(0).doi: 10.1542/peds.2008-1057

- Lecavalier, L., Leone, S., &Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50(3), 172-183. doi: 10.1111/j.1365-2788.2005.00732.x
- Mahdi, S., Albertowski, K., Almodayfer, O., Arsenopoulou, V., Carucci, S., Dias, J. C.,...Bolte, S. (2018). An international clinical study of ability and disability in autism spectrum disorder using the WHO-ICF framework. *Journal of Autism and Development Disorder*, 2188-2163. Retrieved from https://doi.org/1-.1007/s10803-018-3482-4
- McStay, R. L., Trembath, D., &Dissanayake, C. (2014). Stress and family quality of life in parents of children with autism spectrum disorder: parent gender and the double ABCX model. *J Autism DevDisord*, 44, 3101-3118. doi: 10.1007/s10803-014-2178-7
- Meisschaut, M., Warreyn, P., &Roeyers, H. (2011). What is the impact of autism on mother-child interactions within families with a child with autism spectrum disorder?

 International Society for Autism Research, 4, 358-367. doi: 10.1002/aur.217
- Miller, E., Buys, L., & Woodbridge, S. (2012). Impact of disability on families: grandparents'. *Journal of Intellectual Disability Research*, *56*(1), 102-110. doi: 10.1111/j.1365-2788.2011.01403.x
- Molla, M. A. (2018, July 13). Autism prevalence high in urban areas. *The Daily Star*. Retrieved from https://www.thedailystar.net/frontpage/autism-prevalence-high-urban-areas-1604551
- Nealy, C. E., O'Hare, L., Powers, J. D., &Swick, D. C. (2012). The impact of autism spectrum disorders on the family: a qualitative study of mothers' perspectives.

 *Journal of Family Social Work, 15(3), 187-201. doi: 10.1080/10522158.2012.675624
- National Institute of Mental Health. (2018, March). *Autism Spectrum Disorder*. U.S. Department of Health and Human Services, National Institute of Health. Retrieved July 17, 2019, from https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml
- Ntre, V., Papanikolaou, K., Triantafyllou, K., Giannakopoulos, G., Kokkosi, M., &Kolaitis, G. (2018). Psychosocial and financial needs, burdens and support, and major concerns among Greek families with children with autism spectrum disorder (ASD).

 International Journal of Caring Sciences, 11(2), 985-995.

- Paynter, J., Riley, E., Beamish, W., Davies, M., & Milford, T. (2013). The double ABCX model of the family adaptation in families of a child with an autism spectrum disorder attending an Australian early intervention service. *Australian Early Intervention Service*, 7, 1183-1195. Retrieved from http://dx.doi.org/10.1016/j.rasd.2013.07.006
- Perry, A., & Isaacs, B. (2015). Journal of Applied Research in Intellectual Disabilities. *Validity of the Family Quality of Life Survey- 2006*, 28, 584-588. doi: 10.1111/jar.12141
- Pisula, E., &Doersmann, A. P. (2017). Family functioning, parenting stress and quality of life in mothers and fathers of polish children with high functioning autism or Asperger syndrome. *PLoS ONE*, *12*(10). Retrieved from https://doi.org/10.1371/journal.pone.0186536
- Polger, S., & Thomas, S. A. (1991). *Introduction to Research in the Health Sciences* (2nded.). UK: Logman Group UK Limited.
- Pozo, P., Sarria, E., & Brioso, A. (2014). Family quality of life and psychological well-being in parents of children with autism spectrum disorders: a double ABCX model. *Journal of Intellectual Disability Research*, 58(5), 442-458. doi: 10.1111/jir.12042
- Renzaho, A., Mellor, D., McCabe, M., & Powell, M. (2013). Family functioning, parental psychological distress and child behaviours: evidence from the victorian child health and wellbeing. *Australian Psychologist*, 48, 217-225. doi: 10.1111/j.1742-9544.2011.00059.x
- Rodger, S., Keen, D., Braithwaite, M., & Cook, S. (2008). Mothers' satisfaction with a home based early intervention programme for children with ASD. *Journal of Applied Research in Intellectual Disabilities*, 174-182.
- Samadi, S.A., &McConkey, R. (2014). The impact on Iranian mothers and fathers who have children with an autism spectrum disorder. *Journal of Intellectual Disability Research*, 58(3), 243-254. doi: 10.1111/jir.12005
- Saunders, B. S., Tilford, J. M., Fussell, J. J., Schulz, E. G., Casey, P. H., &Kuo, D. Z. (2015). Financial and employment impact of intellectual disability on families of children with autism. *Families, Systems, & Health, 33*(1), 36-45. Retrieved from http://dx.doi.org/10.1037/fsh0000102
- Sim, A., Cordier, R., Vaz, S., &Falkmer, T. (2016). Relationship satisfaction in couples raising a child with autism spectrum disorder: a systematic review of the literature.

- Research in Autism Spectrum Disorders, 31, 31-52. Retrieved from http://dx.doi.org/10.1016/j.rasd.2016.07.004
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with daily autism spectrum disorder. *Journal of Autism Developmental Disorders*, 40, 167-178. doi: 10.1007=s10803-009-0844-y
- Vilaseca, R., Gracia, M., Beltran, F. S., Dalmau, M., Alomar, E., Adam-Alcocer, A. L., &Simo-Pinatella, D. (2015). Needs and supports of people with intellectual disability and their families in Catalonia. *Journal of Applied Research in Intellectual Disabilities*, 30, 36-46. doi: 10.1111/jar.12215
- Xiong, N., Yang, L., Yu, Y., Hou, J., Li, J., Li, Y., ... Jiao, Z. (2011). Investigation of raising burden of children with autism, physical disability and mental disability in China. *Research in Developmental Disabilities*, *32*, 306-311. doi: 10.1016/j.ridd.2010.10.003
- Zuna, N., Gracia, M., Haring, H., & Aguilar, J. M. (2016). Parental perceptions and satisfaction with family services in families of children with autism spectrum disorder and other developmental disabilities. *Journal of Intellectual & Developmental Disability*, 41(3), 233-242. doi: 10.3109/13668250.2016.1179272

[N.B. For better understanding of the study, please see hard copy & for any further information please contact: akhislt12@gmail.com]