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EFFECT ON QUALITY OF LIFE OF PARENTS OF CHILDREN WITH AUTISM: A META ANALYSIS

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Abstract: Autism is a Neurodevelopmental disorder that affects communication and behavior of children. Autism is known as “spectrum disorder” because there is wide variation in the type and severity of disorder (DSM-5). Nature of the research is Qualitative & consists of 25 studies. This study examined gender effect that Mothers are highly affected by Autism Children compared to Father. Purpose of the research was to examine the Quality of Life of Parents with Autism children. Studies revealed that Parent feel difficulty in daily living activities, restricted and repetitive behavior of autistic children, poor social interaction & communication. In addition, more studies investigated that neither parent had to face vocational loss, physical and psychological impairment, distorted social life but also had negative impact on siblings and entire family.

Keywords: Autism, Neurodevelopmental, Quality of life, Daily living activities, Restricted, Repetitive.

INTRODUCTION:

The term “autism”, deriving from Greek words “autos” (self) and “ismos”(action), ‘Leo kanner’ was first to introduce “AUTISM” in 1943, was a psychiatrist at John Hopkins University. According to “diagnostic and statistical manual for mental disorders (DSM-5)”, a guide created by “American psychiatric association (APA)” Used to diagnose mental disorder such as: Autism spectrum disorder should have the symptoms relating to: Difficulty with communication and interaction with other people, Restricted interests and repetitive behaviors and Symptoms that hurt the person’s ability to function properly in school, work, and other areas of life. “Hindustan times” reported a study proposed by “All India Institute of Medical Sciences. (AIIMS)”, at least one in 89 children aged between two and nine years have been diagnosed with autism in India. Autism Spectrum Disorder (ASD) affects around 3 million people in the Indian subcontinent, and is being increasingly recognized as an important issue. Recent estimated prevalence of ASD in India ranges from 0.15% to 1.01% in various studies, depending on the screening method used, and the areas surveyed. The “INCLIN” (2011), studied the prevalence of ASD was 1 in 125 in children 3-6 years and 1 in 85 in children 6-9 years of age. The prevalence in rural areas was 0.90%, 0.6% in hilly regions, 1.01% in urban areas, 0.1% in tribal areas and 0.61% in the coastal regions. ‘Rights of Persons with Disabilities (RPWD)’ Act (2016) has included ASD under the category of disabilities. Researcher (Anil Chechen et al. 2019) conducted a systematic review “The World Health Organization” first defined ‘Quality of life’ as multifaceted, consisting of total well- being in social, physical, and mental functioning. Diener, Suh, Lucas, & Smith, (1999), defined QOL in journal “Europe’s Journal of Psychology” that concept of quality of life broadly encompasses how an individual measures the ‘goodness’ of multiple aspects of their life. These evaluations include one’s emotional reactions to life occurrences, disposition, sense of life fulfillment and satisfaction, and satisfaction with work and personal relationships.

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social communication and the presence of restricted interests and repetitive behaviors. Autism is known as a “spectrum” disorder because there is wide variation in the type and severity of symptoms people experience (DSM-5, National Institute of Mental Health, 2018).

WHO defines QOL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standard and concerns”. (Retrieved 22 may 2020). Standard indicators of QOL include wealth, employment, environment, physical and mental health, education, leisure time, social belonging, religious belief, safety, security and freedom. (Barcaccia, Barbara, 4 Sep. 2013, “Quality of life: everyone wants it but what is it?” *Forbes/Education*, Retrieved 10 May 2016).

RESEARCH METHODOLOGY**Selection of Studies**

A Meta-analysis was conducted on Studies to examining the “Effect on Quality of life of Parents with Autism Children”. Studies retrieved from Google scholar, PubMed Journals, Research papers & Research Articles. Only last 20 years of studies are driven for Meta-analysis. Approximately 100 Articles were investigated and despite that 75 Studies were rejected because these studies were not associated with Quality of Life. Finally 25 Studies were included in this study relating to the topic and all Studies published in English language only. Most of the Studies belong to Abroad and few Studies are taken from Indian Authors which include different scenario of descriptors on Quality of life of parents with Autistic Children.

Inclusion criteria & Exclusion criteria

Features	Inclusion	Exclusion
Type of publication	Research paper, Journals, webpage, Google scholar, Pub med	Magazines, webinar/seminar & conference abstract
Language of publication	English	Other language

**A meta-analysis
Studies regarding autism**

	Journal name	Paper title	Author name	Date of publication	Sample technique	Data collection method	Conclusion
1	<i>American Journal of Mental Retardation</i>	Psychological well-being and coping in mothers of youths with autism, down syndrome, or fragile X syndrome	L. Abbeduto, M. M. Seltzer, P. Shattuck et al.,	vol. 109, no. 3, pp. 237–254, 2004	Sample was taken from Demographic area consists of mothers of Adolescents and Young Adults with Fragile-X Syndrome, Autism & Down Syndrome.	“Autism Behavior Checklist” was administered on Adolescents and Young Adults to assess Behavior of 3 groups. “Depression scale” (Radloff, 1977) was administered on Mothers to assess Depression level of Mothers of 3 groups of Young Adults and Adolescents. “Questionnaire on Resources and Stress” (QRS:F; Friedrich, Greenberg & Crnic, 1983) is a scale to assess Pessimism that is administered on Mothers to find out level of Pessimism about the present situation. Mother and Child relationship was measured with the help of “Positive Affect Index” Coping of Mothers were evaluated with the help of “Multi-dimensional Inventory” (Carver, Scheier,	Result investigated Mothers of Down Syndrome were less pessimistic than Mother of Autism & Fragile-X Syndrome. Further Mothers of Down Syndrome reported closeness with their Disabled Children despite that Mothers of Autism have less intimate relationship & Mothers of fragile-X Syndrome reported mild level of intimate relationship. Higher ‘Depression’ was found in Mothers of Autism Children. Mothers with Down Syndrome & Fragile-X Syndrome showed less ‘Depressive Symptoms’. All 3 groups of Mothers showed good Coping style.

						Weintraub, 1989)	
2	<i>Journal of Intellectual Disability Research</i>	Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being	A.Eisenhower, B. L. Baker, and J. Blacher A.	vol. 49, no. 9, pp. 657–671, 2005	Nature of the research is Exploratory and Sample consists of 215 preschool children of age 3.	“Bayley Scales of Infant Development- II” (Bayle, 1993) “Stanford-Binet Intelligence Scale IV” (Delaney & Hopkins, 1987) was administered on children to categorize them in 5 groups. Children Behavior Checklist (Achenbach, 2000) was completed by the Mothers to measure Behavior and Developmental problem of Children. “The Family Impact Questionnaire” (Donenberg & Baker, 1993) was used to measure Mothers perception for rearing of their Child. “The Centre for Epidemiological Studies Depression Scale” (CES-D; Radloff, 1977) was used to assess ‘Depression’.	Consequently Children with Autism & Cerebral palsy showed highly impaired behavior. Children with Down Syndrome & Typically developing showed less behavior problems. A result found Negative impact on Mothers with ‘High Depression’ as passing of time mothers reported more ‘stress’ and ‘Depression’ with Autism Children. so, whole research investigated that Autism Children obtained higher scores on Behavior & Developmental problems compared to other Disabled Children and have great impact on Mother’s Physical & Psychological well-being.
3	<i>Autism</i>	Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay	A. Estes, J. Munson, G. Dawson, E. Koehler, X.-H. Zhou, and R. Abbott	vol. 13, no. 4, pp. 375–387, 2009	The study consists of 74 Mothers of children with Autism and Developmental Delayed Children without Autism.	“ADI-R” (Rutter et al., 2003) is Parents Interview & “ADOS-G” (Lord et al., 2003) is Semi structured play observation were used to measure Autism in Children. “Mullen Scales of Early Learning Visual Reception and Fine Motor scale (Mullen, 1997)” was used to measure Developmental Delay. “Questionnaire on Resources and Stress (Konstantareas et al. 1992)” is a self-report questionnaire & contains 78 items administered on	Finally result of the research showed that Mothers of Children with Autism & Mothers of Children with Developing Delayed are completely different. Autism Children showed more Behavior Problems and Mal adaptive behavior on the Domain of ‘Daily Activity’ Thus, Mothers of Autism Children showed High level of ‘Distress’ compared to mothers of Developing Delayed children.

						<p>mothers to measure stress and burden of care in families of Children with Autism. . “Brief Symptom Inventory (Derogatis & Melisaratos, 1983)” is a self-report questionnaire administered on mothers to measure psychological distress. “Aberrant Behavior Checklist (ABC; Aman & Singh, 1986)” is a 58-item questionnaire administered on Children to measure Behavior problems. . “Vineland Adaptive Behavior Scales Interview Edition’ (Sparrow, Balla, & Cicchetti, 1984) is a standardized interview was used to measure Adaptive behavior of Children.</p>	
4	<i>Health and Quality of Life Outcomes</i>	Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder	D. Mugno, L. Ruta, V. G. D'Arrigo, and L. Mazzone	vol. 5, article 22, 2007	160 Children and adolescents were recruited from clinical settings affected by PDDs, CP, MR. an additional group as control group was taken from clinical settings & consists of 65 children (typically developing)	WHOQOL-BREF 100 test was administered on parents.	Parents with PDDs showed impaired Quality of life compared to other group of children. Mothers reported lower Quality of life than Father. Mothers reported more stressed & burdened than other diagnosed children. parents reported high depression level.
5	<i>Journal of the</i>	Psychiatric Disorders in	Simonof f E,	2008-08-01, Volume	A subgroup	Psychiatric assessment was	Result showed autism spectrum disorder has

	<i>American Academy of Child & Adolescent Psychiatry</i>	Children With Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample	Pickles A, Charman T, Chandler S, Loucas T, et al.	47, Issue 8, Pages 921-929,	of 112 children was selected from cohort. 10-14yrs. Old children	done.	more chance of comorbid features.
6	<i>Clinical Child and Family Psychology</i>	Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis.	van Steensel, F. J., Bogels, S. M., & Perrin, S.	7 July 2011, 14(3), Pp: 302-317 https://doi.org/10.1007/s10567-011-0097-0	A systematic review was done and studies taken from PsyInfo, Pubmed, Web of Science, ERIC. The research consists of 31 studies. Parents were recruited.	To assess anxiety some studies administered Semi-structured interview, some studies used Questionnaires & a few studies used Instruments.	40% children were affected with Anxiety or other Anxiety disorder & it is clinically proven. Most of the studies found a significant relationship between Autism and comorbidity. Mostly Autism children have other psychotic features due to their impaired quality of life.
7	<i>Clinical Psychology Review</i>	Anxiety in children and adolescents with autism spectrum disorders.	White, S. W., Oswald, D., Ollendick, T., & Sachdev, L.	April 2009 29(3), Pp: 216-229. https://doi.org/10.1016/j.cpr.2009.01.003	Meta-analysis consists of 40 studies recruited from Psych-Info & Medline. Pre-school children and Adolescents were recruited for the research purpose.		Results are not understood in this research between Anxiety and Autism.
8	<i>Brain sciences</i>	Mothers' Experiences and Challenges Raising a Child with Autism Spectrum Disorder: A Qualitative Study	Dimitrios Papadopoulos	2021 Mar; 11(3): 309. Published online 2021 Mar 2. doi: 10.3390/brainsci11030309 PMID: 34117012	9 Mothers were recruited from Metropolitan area of Athens with their Autism Children. Qualitative	Data was collected by using face-to-face interview, semi-structured interview & in-depth qualitative interview. Mothers took at least 45 minute to complete	Consequently, One study reveals mother was in depression & distressed when she knew that his son is diagnosed as Autistic child. Another study showed mother felt Distress and Emotional fatigue. Few mothers

				PMID: 33801233	e research design is used.	interview.	reported guilt. Few mothers showed frustrated & helpless. Mothers reported family burden and their father lose his job, mothers also resigned from their work for rearing their child. Mothers reported social pressure and not allow for outing with their child. So Autism has negative impact on mothers Emotion, Family & society.
9	<i>Autism research and treatment</i>	Lived experiences of Mothers raising children with Autism in Chitwan district, Nepal	Acharya Sabitri, Sharma Kalpana	nov.2021 ArticleID6614490 https://doi.org/10.1155/2021/6614490	Purposive sampling was done. Qualitative research design is used and nature of the research is exploratory. 9 Mothers with Autism Children were taken as sample from urban area.	In-depth interview – guidelines is an open ended questionnaire was prepared by researcher administered on Mothers.	Mothers encountered many problems while rearing their child. Mothers reported difficulty with finance, their future, imbalanced physic and psychological stress. On other hand mothers also use various techniques to cope up with situation.
10	<i>Developmental Psychology</i>	Trajectories of emotional well-being in mothers of adolescents and adults with autism	Barker, E. T., Hartley, S. L., Seltzer, M. M., Floyd, F. J., Greenberg, J. S., & Orsmond, G.I.	2011 V 47, I(2) Pp:551-561 https://doi.org/10.1037/a0021268	Nature of the research is longitudinal. And cross sectional research design is used. 379 Mothers were recruited with their Autistic children. objective of the research is to measure Emotional well-being of Younger Mothers compared to Older Mothers.	Autism Children were diagnosed on the basis of “ADI-R” (Lord et al. 1994) is a parent’s interview. “Scales of Independent Behaviors – Revised” (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996) was completed by Mothers to measure Behavior problems of Children. “Center for Epidemiologic Studies-Depression Scale” (CES-D; Radloff, 1977) was used to assess Mothers depression level. “Profile of Mood States”	Result investigated that Younger mothers showed higher level of negative emotion. Younger mother has high level of Depression & Anxiety compared to Older mothers. Further result showed Social support and coping techniques are helpful to improve Emotional well-being of mothers with Autism children.

						(POMS; McNair, Lorr, & Droppleman, 1981) was used to assess maternal Anxiety. "Parenting Stress Index" (Abidin, 1986) was used to measure the number of stressful events experiences.	
1 1	<i>Indian J Psychol</i>	Stress and Coping Styles in Mothers of Children with Autism Spectrum Disorder	Selvaku mar N, Panicker AS	Apr. 25,2020 V: 43, I(3), Pp: 225-232 doi: 10.4103/IJPSYM.IJP SYM_333_19.	Consecuti ve sampling was done. 30 Mothers were recruited with Autistic children age range from 3 to 15 years old.	"Childhood Autism Rating Scale" was employed to assess Autism. Social-functioning of Children were assess through 'Vineland Social Maturity Scale'. "Depression, Anxiety, Stress Scale 21(Lovibond SH, Lovibond PF et al.1995)" is a questionnaire administered on Mothers to measure negative emotional states. 'WHOQOL-BREF'(WHO-QOL Group,1995) is a measure to' investigate Quality of life of Mothers. 'COPE'(Carvee CS et al. 1989)inventory is a multidimensional coping inventory and administered on mothers to measure coping skills.	Mothers showed severe negative state on DASS-21 scale. Mothers showed low Quality of life on all domains which is associated with Depression, anxiety and stress. On other hand result showed mothers used coping strategies to handle the situation.
1 2	<i>Journal of education and practice</i>	The coping strategies used by parents of children with autism in Saudi Arabia	Reem Balubaid reem, Sahab lama	2017 V:8, No:35	Purposive sampling was done. 8 parents recruited & age range from 30 to 60.	Data was collected through Semi-structured Interview.	Study investigated that parents feel physical and psychological stress while taking care of their child and challenging situations in social life. Some of the participants reported about religious thoughts, family support, spouse understanding & use of different strategies to cope up with the situation.
1 3	<i>American academy of child &</i>	Post high school daily living skills	BA.Elaine B.Clarke	18 novmber 2020,	This is a longitudin al study	The Vineland Adaptive Behavior Scales	Daily living skills decrease after leaving school of children with

	<i>adolescent psychiatry</i>	in Autism Spectrum Disorder.	, McCauley James B, Lord Catherine	V 60, I(8), Pp: 978-985, DOI: https://doi.org/10.1016/j.jaac.2020.11.008	and consists of 98 adults from demographic area.	were administered 8 times from ages 2 to 26.	Autism.
14	<i>Transcultural psychiatry: sage journal</i>	The discovery of autism: Indian parents' experiences of caring of their child with an autism spectrum disorder	Desai Miraj, Divan Gauri, et al.	July 2012, V:49 I (3-4), Pp: 613-637. DOI: 10.1177/1363461512447139	Qualitative research design is used. 12 parents were recruited from clinical settings. 1 father, 7 mothers, and 2 set of parents of 10 children with "Autism Spectrum Disorder".	Data was collected through in-depth interview.	result revealed that every parents has to face unexpected and unfamiliar changes in life and caring of their Child, full fill child's requirements, to discover how to socially connect, how to educate, how to be independent, how to secure their future.
15	IOSR Journal of Humanities And Social Science (IOSR-JHSS)	Parental attitude & expectations in raising a child with Autism Spectrum Disorder in India	Srikanth Gita, Narayan Swati	August 2020 V:25, I: 8 Pp:50-56 E-ISSN: 2279-0837, p-ISSN: 2279-0845. www.iosrjournals.org	28 Parents of autistic children were taken from urban area. Children were at the age between 1.5 -17 years old.	"Children Autism Rating scale" & "Autism Diagnostic Observation Schedule-2" administered on children to diagnose 'Autism'. "Survey Questionnaire" was employed on parents.	All participants reported that their children must qualified mainstream & 10 th or 12 th board exam.

RESULTS AND DISCUSSION

The current Research investigated that parents with Autism Children has a great impact of caregiving and rearing practices on 'Quality of life'. Parents feel Mal-adjustment in Society and in Environment. Especially mothers have to face various behavior problems and Developmental problems with Autism children. Numerous Authors tend to explain their studies on different aspects.

A study suggests that Mothers with Autism Children were more pessimistic. In addition Mothers of young Adults and Adolescents reported high level of Depression and detached relationship with their children compare to Children with other Developmental disorder. (L. Abbeduto et al., 2004). Mothers reported high level of Depression and Stress and it lasts as children grow older (A.S. Eisenhower et al., 2005). Mothers with Autism children showed higher psychological distress due to impaired behavior of their children. Further in this research Autism children showed Mal adjustment in Daily living activities and schooling. Further researcher found a strong correlation between Parental stress and Behavior problems of Autism Children. (Annette Estes et al., 2009). Another study examined a comparison between younger mothers and older mothers. Older mothers showed less Depression and Anxiety at the beginning of the study compared to younger mothers (Erin T. Barker et al. 2011). A study showed Mothers had Mild to Moderate Depression and severe Anxiety with Autism Children. Mothers reported impaired Quality of life, lower psychological well-being and severe stress (Nivedhitha Silvakumar et al., 2020). Parents feel physical and psychological stress while taking care of Autism Children. Parents face many challenges in society and they have to face a number of challenges in public and reduce visiting with Autism children (Reem Balubaid et al., 2017). Mothers reported Behavior and Developmental issues with Autism children. Mothers reported sleep disturbance, Depression and Anxious about their child's future. Further mothers reported negative emotions come into her mind. Again mothers expressed detachment and ignorance of the society. In addition Mothers have to face financial crises and lose of vocation (Sabitri acharya et al., 2021). Despite all some studies suggests that Mothers have emotion focus coping skills therefore, the coping techniques are polishing tool to overcome from current situation for Mothers (L. Abbeduto et al., 2004.). In addition, Mothers showed, social support and coping skills can improve maternal well-being (Erin T. Barker et al. 2011). Mothers reported use of active coping to overcome from psychological distress. Some of them use positive reframing and planning. Few mothers apply acceptance

and religious coping techniques to get rid of Depression, Anxiety and Stress (Nivedhitha Silvakumar et al., 2020). Mothers reported a support group with the help of this other mothers gets help, support and knowledge from parents and professionals. Some parents report support of Family members, neighbors and relatives helped them to cope up with the situation (Reem Balubaid et al., 2017). Most of the mothers use different coping styles such as: respite care, religious beliefs, positive coping and problem focused strategies (Sabitri acharya et al.2021). One study reveals mother was in depression & distressed when she knew that his son is diagnosed as 'Autism'. Mothers showed Distress and Emotional fatigue. Few mothers reported guilt and shame. Few mothers showed frustrated & helpless due to daily activities of children and their future. Mothers expressed neglected and disturbed relationship with spouse. Autism children have a negative effect on siblings because not giving enough time to them by mothers. Mothers reported family burden and their father lose his job, mothers also resigned from their work for rearing their child. Mothers reported social pressure and not allow for outing with their child. So Autism has negative impact on mothers Emotion, Family & society (Dimitrios Papadopoulos, 2021).

Parents of Autism showed less self-care and low score on physical health dimension. Mothers showed more burdened and care compared to father with Autism children. Single parent reported 'Depression' due to unable to handle their child behavior (Atsurou Yamada et al., 2012). In another study parents showed psychological difficulties with Autism children and expressed poor Quality of life on all domains (Valsamma eapen et al., 2014). Autism children showed poor social Quality of life, poor emotional Quality of life and poor school quality of life than typically developing children (Marieke de Vries et al., 2015). A study examined that parents with Autism children face difficulty in daily life, disturbed physical health, mental health and feel pain/ discomfort. Same problems have to face primary caregivers also. Parents reported less financial problem with 'Autism Children'. Co-morbidity has a great negative impact on health related quality of life of Autistic children and their primary caregivers. Few mothers reported job loss because of rearing their children which is a huge responsibility. Scores on care related Quality of life showed Anxiety and Depression (Leontine w. ten hoopen et al., 2019). (Nancy Grace Robert Renford et al, 2020) examined an average level on physical, social, psychological and environmental domain. In contrast some parents reported good Quality of life on all domains due to support. A study introduced that mostly mothers suffer from psychological distress due to involve in care task with Autism children. In this study mothers reported higher level of Depression & stress with teenage Autism girls. Further separation, divorce, moving home and suicide is examined in family of Autism children. Therefore, Autism Children have totally negative impact on Sibling's life as: marital life, vocation and family planning too. Autism effects on financial income of parents due to expensive medication and intervention. Autism children are highly affected by social impact. They face difficulty in school environment, in society, in vocation and so on (Rabia Begum et al.2019). In a study mother and father both have high level of stress and depression with Autism toddlers. Further result revealed that Mothers were affected by children's self-regulation skills (e.g., eating, sleeping, and emotion regulation). Fathers reported affected with external behavior done by Autism children in public which impact negative (Naomi Ornstein Davis et al., 2008). In contrast, few parents report Positive thinking, spiritual belief & self-esteem create a good psychological well-being and enhances coping skills (Nancy Grace Robert Renford et al, 2020). A study investigates that Social support and spousal support is must to cope up with psychological distress. Grandparents support is also helpful to lead a good and stress free life and for good 'Quality of life' with Autism children (Atsurou Yamada et al., 2012).

Conclusion

Various past researches proved that Autism is a lifelong disorder which remains entire life and trace a great negative impact on caregivers or parents and whole family. Purpose of the current research is to examine Quality of life of parents and researcher tried to prove that Autism impacts upon father, mother, vocation, siblings and family members. Parent with Autism children suffers from high level of Depression, Anxiety and Stress. Most of the studies proved that Autism effects especially on mothers compared to father. Parents feel guilt, socially detached, embarrassed in public due to abnormal behavior of Autism children. Parent face financial loss & work decay due to expensive medical interventions. In contrast parent tries to cope up and adapt different coping techniques or skills to deal with Autism children and psychological distress.

Suggestion

In addition social support, family support and spouse support can also help parent to reduce psychological distress. Thus, intervention programs should be organized to train parent to overcome from the developmental and behavioral issues of autism children. Training centers should be established near by the city. Counseling program should be provided to every parent. Therapy based intervention program should be introduced to parent to deal with impaired executive functioning of Autistic children.

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